



# Unplanned Pregnancy and Abortion Care (UnPAC) Study

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The views expressed in this report are those of the authors and do not necessarily reflect the views or policies of the HSE.

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#### List of Abbreviations

BPAS British Pregnancy Advisory Service

CAF Clinical Advisory Forum
COVID-19 SARS-CoV-2 virus

CPC Crisis Pregnancy Counselling
CVS Chorionic Villus Sampling

DPIA Data Protection Impact Assessment

D&C Dilation and Curettage DPO **Data Protection Officer** Early Medical Abortion **EMA EPU** Early Pregnancy Unit EU **European Union FFA** Fatal Foetal Anomaly **FMM** Foetal Medicine Midwife **FMS** Foetal Medicine Specialist

GA Gestational Age

GDPR General Data Protection Regulation

GP General Practitioner
GT Grounded Theory

hCG Human chorionic gonadotropin

HSE Health Service Executive

ICGP Irish College of General Practitioners
IFPA Irish Family Planning Association

IHREC Irish Human Rights and Equality Commission IOG Institute of Obstetricians and Gynaecologists

IUD Intrauterine DeviceIVF In Vitro FertilisationLLC Life Limiting Condition

MRI Magnetic Resonance Imaging
MVA Manual Vacuum Aspiration
NIPS Non-Invasive Prenatal Screening
NMH National Maternity Hospital

NWIHP National Women and Infants Health Programme

OT Occupational Therapy
PI Principal Investigator

PPS Personal Public Service (Number)

SHCPP Sexual Health and Crisis Pregnancy Programme SPSS Statistical Package for the Social Sciences

START Southern Task-Force on Abortion and Reproductive Topics

TCD Trinity College Dublin

The 2018 Act The Health (Regulation of Termination of Pregnancy) Act 2018

TOP Termination of Pregnancy

UnPAC Unplanned Pregnancy and Abortion Care

WHC Women's Health Clinic
WHO World Health Organization

#### Introduction

We are pleased to introduce this qualitative research study on the experiences of pregnant women who have accessed unplanned pregnancy support and abortion services since the enactment of the Health (Regulation of Termination of Pregnancy) Act 2018 on 1 January 2019. This research was commissioned by the Health Service Executive's (HSE) Sexual Health and Crisis Pregnancy Programme (SHCPP), Health and Wellbeing, Research and Strategy. This study was commissioned within the remit of the National Sexual Health Strategy (2015 – 2020) and with the support of HSE National Women and Infant's Health Programme (NWIHP) and HSE Primary Care Strategy and Planning (PCSP).

Written into the 2018 Act was the provision for a review of the operation of the legislation. A public consultation and review of the experiences of service providers like GPs, medical practitioners, and medical colleges will form part of the review. The review's third and final strand will comprise the findings from the Unplanned Pregnancy and Abortion Care (UnPAC) study, signifying the importance and relevance of these findings and the need to listen and better understand service users' experiences within this arena. This report will make a significant contribution to the legislative review process and potential future change, a testament to the study authors and participants.

A core tenet of the HSE is the development of high-quality research and the translation of research findings into evidence-based practice. The HSE acknowledges the importance of listening to service users and understanding lived experience when designing and implementing quality health services. The HSE's 'Action Plan for Health Research' (2019-2029) highlights how healthcare systems that value research have better organisational performance, lower mortality rates, reduced staff turnover, improved service user satisfaction and greater organisational efficiency.

The UnPAC study is an example of high-quality research which has applied a rigorous methodology. The study sampled service users from multiple healthcare settings in rural and urban regions, recruiting women with a diverse set of healthcare experiences. Significant preliminary work, prior to participant recruitment, involved the completion of stakeholder focus groups and interviews, and a literature review, grounding the authors in pertinent policy and practice from the outset. The study's novel findings are descriptive, but they provide significant insight into service users' perspectives and the meanings they attach to their experiences.

We would like to end by thanking the authors, Drs Catherine Conlon, Kate Antosik-Parsons and Éadaoin Butler from the School of Social Work and Social Policy at Trinity College Dublin, as well as the contributions from Jo Green, Wenyu Li and Kathryn Ammon. Thank you to our SHCPP colleagues including Janice Donlon, Owen Brennan, Anita Ghafoor Butt, Kate Tierney and Dr Nicola O'Connell. Thank you to the UnPAC Steering Committee who provided support for this project throughout and the many service providers who facilitated the recruitment process. We would like to express our thanks for contributions throughout the course of the study from Dr Aoife Mullally, HSE Clinical Lead, Termination of Pregnancy, Kilian McGrane, Director of NWIHP and Geraldine Crowley, Assistant National Director, PCSP.

Finally, we wish to extend a sincere thank you to the participants of this study whose valuable contribution and insights in discussing their experiences will inform the review of the operation of the legislation as well as future practice and research.

Helen Deely, AND Health & Wellbeing, Strategy & Research, HSE Maeve O'Brien, Interim Programme Lead, SHCPP Strategy & Research, HSE

#### Foreword

As the Clinical Lead for Termination of Pregnancy Services I welcome this report which represents a very significant collection of people's experience of the early years of the abortion care service in Ireland. The Repeal of the 8th Amendment and the commencement of this service represents a huge cultural change within women's healthcare. The difficulties associated with implementing and providing this service have been widely reported but one of the most valuable metrics of its success is the experiences of the women who have accessed the service since it began. It is encouraging that women mainly report positive experiences and compassionate care.

As providers of abortion care, we are obliged to practice within the confines of the Health (Regulation of Termination of Pregnancy) Act 2018 and this is not without its challenges. Currently the service is dependent on a small number of committed providers who are responsible for service provision, drafting of guidelines and care pathways, training and education. Our enduring aim is to ensure that woman and girls in Ireland have access to safe, high-quality, person-centred care that is sustainable for future generations.

#### **Dr Aoife Mullally**

Clinical Lead, Termination of Pregnancy Services, National Women and Infants Health Programme.

# About the Sexual Health and Crisis Pregnancy Programme

The Health Service Executive (HSE) Sexual Health and Crisis Pregnancy Programme (SHCPP) is a national policy priority programme situated within Health and Wellbeing, HSE Strategy and Research. The SHCPP is responsible for implementing the National Sexual Health Strategy 2015–2020. The aims of the strategy are to improve sexual health and wellbeing and to reduce negative sexual health outcomes. A key recommendation in the strategy is to build on the existing evidence base to understand emerging trends related to crisis pregnancy and sexual health, and to undertake new research initiatives to address knowledge gaps (Department of Health, 2015). The Programme also funds the My Options helpline, a crisis pregnancy and pregnancy counselling service, providing information and support on all options related to unplanned pregnancy, including information on continued pregnancy supports and abortion services.

To read the strategy, click here.

#### About the Authors

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Dr Catherine Conlon is Assistant Professor at the School of Social Work and Social Policy, Trinity College Dublin (TCD). Her research focuses on the social politics of reproduction and sexuality. An expert in qualitative research methods, she has published widely on abortion and crisis pregnancy, sexual socialisation, and inter-generational relations. She completed research with Irish women attending abortion services in England in 1994-1996 and again in 2004-2006 and on topics including parents' accounts of talking with their children about sexuality, the body and growing up. She co-authored, with Evelyn Mahon and Lucy Dillon, *Women and Crisis Pregnancy* published by Government Publications in 1998. She publishes in high-impact, peer-reviewed academic journals including *Qualitative Research*, *Qualitative Health Research* and *Gender & Society*. Dr Conlon teaches across undergraduate and postgraduate programmes, supervises Masters and PhD students, and is Co-Director of TCD's Social Policy Joint Honours programme.

#### **Dr Kate Antosik-Parsons**

Dr Kate Antosik-Parsons is a post-doctoral Research Fellow in Social Studies at the School of Social Work and Social Policy, TCD. Her research focuses on the cultural and social histories of gender and sexuality in Ireland. She has published on topics such as embodiment, gender and sexuality in Irish art and visual culture, and on pedagogy and leadership in feminist activism. In 2019, she was the L'Internationale Researcher for the National College of Art and Design (NCAD). She conducted archival research and collected oral histories about performance art during the 1990s for NCAD's contribution to 'Our Many Europes', a project co-funded by the Creative Europe Programme of the European Union for the L'Internationale transnational museum confederation. She has taught courses in Art History, Gender Studies, Global Studies and Irish Studies at universities in Ireland and the United States including University College Dublin and San José State University. She is a member of College Art Association, the International Association for Study of Irish Literatures, and Visual Artists Ireland.

#### **Dr Éadaoin Butler**

Dr Éadaoin Butler is a Research Fellow at the School of Nursing and Midwifery, TCD, having been previously employed in the School of Social Work and Social Policy, TCD. She is particularly interested in the views and experiences of various health care service users and has expertise in quantitative and qualitative data analysis. Dr Butler earned a PhD in Health Science from the University of Auckland in 2021, where her thesis was awarded a place on the Dean of Graduate Studies List. Prior to this, she received a Masters of Science (MSc) in Health Psychology from National University of Ireland, Galway and a Bachelor of Arts (BA) (Hons) in Psychology from University College Dublin (UCD).

#### Jo Greene

Jo Greene holds an MSc in Applied Social Research (Distinction) and a first class honours BA in Sociology and Social Policy from TCD. Her mixed methods MSc dissertation explored preferences for self-managed telemedicine services after legalisation of abortion services in Ireland, and was published in BMJ Sexual & Reproductive Health. Jo is researching the initiation of technology dependence in children with complex and integrated care needs for a European Research Council funded project. Jo is an Associate Lecturer teaching social policy to undergraduates at the Institute of Public Administration.

#### Wenyu Li

Wenyu Li is a PhD candidate in the School of Social Work and Social Policy, TCD, supervised by Dr Catherine Conlon. Wenyu completed an MSc in Applied Social Research in TCD 2020-2021 during which she undertook a work placement internship on the UnPAC study. She completed her dissertation on the experience of Chinese students as international students in Irish universities during the COVID-19 public health emergency.

#### **Kathryn Ammon**

Kathryn Grey Ammon is a PhD candidate in the School of Social Work and Social Policy, TCD, supervised by Dr Catherine Conlon. Funded by a TCD Provost's PhD Award, her dissertation focuses on secondary analysis of a unique legacy data set composed of interviews with Irish women seeking abortion care over a 30-year period. Her research interests include abortion access, gender, and nationalisms. Kathryn holds an MSc in Equality Studies from UCD as a 2020 Mitchell Scholar, and a BA in Political Science, History, and Women's Studies from the University of Kansas.

#### Research Team's Acknowledgements

This study was commissioned by the HSE Sexual Health and Crisis Pregnancy Programme (SHCPP), Health and Wellbeing. The research team would like to thank SHCPP team members Maeve O'Brien, Janice Donlon, Owen Brennan, Kate Tierney, Anita Ghafoor Butt and Dr Nicola O'Connell for their support throughout the course of this research study. We would like to acknowledge Helen Deely, Assistant National Director, Health and Wellbeing, Dr Aoife Mullally, HSE Clinical Lead for termination of pregnancy, Kilian McGrane, Director, National Women and Infants Health Programme and Geraldine Crowley, Assistant National Director, Enhanced Community Care Programme & Primary Care Contracts.

The research team would like to acknowledge the expert guidance of the Project Steering Committee who provided invaluable insights and support throughout the duration of the project (in alphabetical order):

- Maeve O'Brien, (Chair), SHCPP, HSE Health and Wellbeing
- Owen Brennan, SHCPP, HSE Health and Wellbeing
- Anne Burke, Well Woman Centre
- Sarah Devilly, One Family
- Janice Donlon, SHCPP, HSE Health and Wellbeing
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- Aisling Heffernan, Primary Care Strategy and Planning, HSE
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- Maeve Taylor, IFPA

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- My Options
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- Donagh Stenson and colleagues at the British Pregnancy Advisory Service
- Amy Walsh, Terminations for Medical Reasons
- Well Woman Centre

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The research team wish to thank the many healthcare and administrative staff working in services providing abortion care who supported the recruitment of participants to this study, everyone undertook this demanding work generously in the context of very busy services which we will not name individually in interests of confidentiality.

The research team want to thank each woman who took part in this research, generously sharing with us their experiences and emotions about a private, personal event in their lives. We were privileged to talk with you, we hope you feel we have done justice to your experiences, and we thank you deeply for the insights and understandings you provided. Women contributed to this study to inform the development of abortion care services for others in the future and all of us share a responsibility to respond to that in considering the findings of this report.

#### **Executive Summary**

#### Introduction

The Sexual Health and Crisis Pregnancy Programme (SHCPP), HSE Health and Wellbeing, with the support of the HSE National Women and Infant Health Programme (NWIHP) and HSE Primary Care Strategy and Planning, commissioned a research study to develop an in-depth understanding of the experiences of pregnant women who accessed unplanned pregnancy support and abortion services since the enactment of the 2018 Health (Regulation of Termination of Pregnancy) Act.

In 2015, Ireland launched its first National Sexual Health Strategy (2015–2020). The Strategy sets out the need for "robust and high quality sexual health information" to underpin policy, practice, service planning and strategic monitoring. The SHCPP is responsible for the strategy's implementation. A key SHCPP objective is the development of high-quality evidence to better understand emergent crisis pregnancy and sexual health trends in Ireland, and to address knowledge gaps.

The 2018 Act came into effect on 1 January 2019. The new law permits termination of pregnancy under certain circumstances, including where there is a risk to life of the pregnant person, in emergency situations, where the pregnancy is likely to lead to the death of the foetus within 28 days of birth, and without restriction up to 12 weeks of pregnancy.

A review of the operation of the 2018 Act was set out under Section 7 of the 2018 Act which states that, "The Minister shall, not later than three years after the commencement of this section, carry out a review of the operation of this Act". The review clause was included in the 2018 Act to facilitate monitoring of the operation of the legislation in practice, as well as of the delivery of services in the area.

The review comprises of two main phases and is being led by an independent Chair. As part of the first phase of the review, information, and evidence on the operation of the 2018 Act is being collected from women who use the service, from health professionals that provide the service, and from the public, via a public consultation. The second phase of the review is led by an independent Chair who will analyse the findings of the three strands of information to assess the extent to which the objectives of the 2018 Act have been achieved. The UnPAC study will inform the service user strand of the review of the operation of the 2018 Act and will be considered alongside the other two strands of evidence.

The study objectives were to gather in-depth information from women who have availed of unplanned pregnancy support services and clinical abortion services in Ireland; to provide a comprehensive description of the experiences of women who have availed of these services in Ireland, taking account of differing backgrounds, ages and locations; and to provide a comprehensive description of the trajectories of women who have accessed abortion care in Ireland, including use of unplanned pregnancy support and other health care services.

#### Methodology

The study comprised four work packages.

Work package one was a policy case study of the implementation of the 2018 Act. The research team compiled and reviewed legislative documents and instruments, policy documents, and clinical guidelines

generated from the 2018 Act and its implementation, and conducted 24 interviews and three focus groups with key stakeholders. A situational framework analysis was applied to analyse findings.

Work package two comprised a literature review, which collated evidence on abortion provision within the Irish context since implementation of abortion services in January 2019. The review sought to assess how Irish providers adopted the new legalisation, and to collate existing evidence on availability, accessibility, acceptability and quality of unplanned pregnancy support and abortion care services.

Work package three was a large, in-depth qualitative study of service users' (n=58) experiences of unplanned pregnancy support services and abortion care. Semi-structured in-depth interviews were completed with participants. Ethical approval was received from the Trinity College Dublin School of Social Work and Social Policy Research Ethics Committee. This research study collected data between December 2019 and August 2021, so it captured the service in the early stages of implementation.

Participants were recruited if they were aged over 18 and had capacity to consent. Eligible participants were those attending unplanned pregnancy counselling services; those under 12 weeks' gestation and seeking abortion care in community or primary care settings; or those under 12 weeks' gestation and referred to hospital settings for abortion care or for management of post-abortion symptoms. Participants were recruited if over 12 weeks' gestation and seeking or qualifying for abortion under the 2018 Act. Participants were recruited if they were accessing abortion care outside Ireland since implementation of the 2018 Act.

Settings where recruitment took place were general practice (GP) clinics, women's health clinics (WHCs), hospitals, the British Pregnancy Advisory Service and pregnancy counselling services. Participants could self-refer to the study. Interviews were transcribed and uploaded to NVivo. A grounded theory methodology was applied to data analysis.

Work package four was a quantitative and qualitative analysis of data from Women on Web (WoW), an online telemedicine abortion care provider, providing services to regions with limited access.

Data was generated from email correspondence between WoW and women from Ireland requesting the service between 1 January 2019 and 31 December 2020. Thematic analysis was applied to analyse data. Quantitative data comprised analysis of self-reported sociodemographic characteristics, pregnancy history, and reasons for contact of women consulting the service.

The SHCPP provided project oversight and funding for the study. A Project Steering Committee provided expertise to the research team through the duration of the study.

#### **Results**

The overall experience of many service users was frequently described positively, with service users describing how abortions were attained following contact with My Options and referral to GPs, hospitals and other settings.

My Options signposts to services, including abortion-providing GPs, and provides post-abortion support. Women described My Options as a responsive, caring and continuous element of the care pathway. Under the current model of care, My Options is the sole source of information on GP abortion providers, creating a scenario where there is no onus on those working in wider services to be knowledgeable about, willing to discuss, or refer women seeking abortion into the care pathway. People who contacted hospital or GP services described experiencing stress related to seeking access to abortion services but not being

referred. Some saw My Options as an additional unnecessary step to access legally regulated services, and actively avoided the service for that reason.

People were satisfied with the care they received from primary care and WHC providers, many encountering non-judgemental and empathetic providers. Regarding GP-led care, although people were generally positive about their experience, many described a major challenge in accessing providers as appointments are not universally or transparently provided by GPs. Not all participants were aware of the role of My Options, some assuming that they could access abortion from their own GP. If their GP was not a provider, this left them vulnerable to delay. Access was a particular issue for women in rural areas, with some required to travel long distances, a particular barrier for those without access to their own vehicle.

Participants described hospital-based care providers in administrative and clinical roles as non-judgemental, professional and maintaining good communication. However, the location of services within maternity settings was considered problematic by some due to the chance of encountering pregnant women and babies, and staff not connected with the service, who may not have been sensitive or committed providers. The absence of separate waiting areas for scanning and assessment, and separate inpatient beds from maternity care facilities, were also queried.

To access abortion under Section 12 of the 2018 Act, three full days must elapse following certification of the pregnancy as under 12 weeks' gestation by a medical practitioner. Some viewed the wait period simply as a legal requirement to be overcome, while others viewed it as a deterrent to care. For some, the three-day wait was a time of heightened anxiety and distress. Few considered it to be of any personal benefit to them in their decision-making process.

Overall, those who chose to access counselling described it as giving reassurance, affirmation, validation, information, and an opportunity to discuss decisions. The importance of counselling remaining free was highlighted. It was also the case that for some, counselling was required to support them due to fall-out of a difficult care pathway. Many did not, however, see counselling as relevant to their abortion care pathway where it was considered unnecessary or they had sufficient existing supports. Many viewed the role of pre-abortion counselling as assistance with abortion decision-making, suggesting a potential mismatch between participants' understandings and those of service providers.

In this study, 12 people sought or accessed abortion care over 12 weeks' gestation. In each case the person had received a foetal anomaly diagnosis on a wanted pregnancy that had prompted them to consider termination. Referral for assessment was prompt, but assessments were protracted, taking a heavy toll. People portrayed finding themselves hoping for a "fatal enough" diagnosis rather than being denied care and faced with travelling outside the jurisdiction. Legislation, and particularly the associated criminal penalties, had a distinct chilling effect on interactions and openness between clinicians and women during the assessment process. Where diagnoses were inconclusive and/or did not satisfy the criteria to qualify for care under Irish law, participants noted reticence among clinicians to engage in open and detailed discussion on quality-of-life prospects for the foetus. Not qualifying for care in Ireland signified the denial of care, and travelling to access termination abroad was associated with shame, stigma and judgement.

Analysis of contacts by people from Ireland to WoW in 2019 and 2020 showed that after a person received an automated response from the website highlighting local availability of abortion in Ireland, most did not progress their request. Those who did go on to receive abortion pills from WoW cited initial abortion access issues, such as a lack of providers in their area, lack of choice in where to access care, and fear of stigma. A relatively high proportion of people contacting WoW demonstrated a preference for the perceived privacy and comfort afforded by telemedicine services.

#### **Conclusions**

The conclusions drawn directly from service users' experiences of navigating often complex care pathways raise issues for consideration as part of the review of the operation of the 2018 Act. This research study collected data between December 2019 and August 2021, so it captured the service in the early stages of implementation. Abortion care in Ireland involves a number of different providers, each playing differing roles, and experiences of accessing abortions were affected by a degree of service provision fragmentation.

The issues highlighted should be considered in conjunction with data emerging from the service provider review project and the public consultation, which will provide an additional perspective on provision of terminations in Ireland. As regards implementation, some issues raised are conceptual and require further scoping, in conjunction with data emerging from the service provider review, with consideration for feasibility, acceptability, infrastructure and cost.

The issues raised relate to programmes within the HSE as well as wider policy issues; however, there are practice and cultural change implications for other health care professionals and organisations. Issues highlighted for consideration are addressed to key stakeholders as follows:

#### **The Sexual Health and Crisis Pregnancy Programme:**

- The place of counselling in the abortion services model of care should be reviewed with a view to identifying opportunities and pathways to support women in need across the range of services.
- The data indicated interest by service users in a peer support initiative for people seeking abortion care services. We recommend the SHCPP explore if such an initiative could be implemented as part of the crisis pregnancy counselling and support services.

### Primary Care services and the National Women and Infants Health Programme (relating to Section 12 of the 2018 Act):

- Duty of care of health providers in primary and maternity care settings to provide information and referral
  for people seeking abortion services to settings where they can access care.
- Regional coverage of GP and WHC providers of the service.
- Infrastructure for new and infrequent GP providers to be supported by more experienced providers through peer support and formalisation of mentoring programmes to support new providers.
- Integration of the service in all maternity hospitals or unit sites having regard to capacity, resource and values impediments to provision.
- Self-managing community-provided early medical abortion requires a person to have a safe, private
  place where they can care for themselves while administering the medication. This will not be the case
  for everyone, particularly if the person is homelessness. Inpatient day-care facilities in community/
  primary care settings should be developed to address this need.
- Co-locating the termination of pregnancy service with gynaecology units or early pregnancy units.
- Availability of surgical methods of abortion, including manual vacuum aspiration, in Irish hospital settings
  is currently limited. This should be reviewed with a view to expanding provision to achieve choice of
  method in all hospital settings.

#### The National Women and Infants Health Programme (relating to Section 11 of the 2018 Act):

NWIHP should consider undertaking an exercise with physicians, midwives, and all professionals caring
for people during the assessment process under Section 11 of the 2018 Act, to review guidelines and
practices regarding certain aspects of care.

#### Issues to Consider as Part of the Review of the Operation of the 2018 Act

- Remote consultations being retained in the model of care on a permanent basis to make for an optimally accessible, responsive service.
- The effect of mandatory three-day wait on access to care.
- Provision for repeat termination after 12 weeks' gestation, if clinically appropriate.
- · The effect of criminalisation provisions on accessibility and quality of care
- The criteria for qualification in relation to foetal anomaly.

#### **Institute of Obstetricians and Gynaecologists**

 The Institute should consider the role of hospital multidisciplinary team involvement at the tertiary site in the certification of fatal foetal anomalies, so that assessment and certification is confined to two physicians as required by the law under s.11 of the 2018 Act, so as to ensure a timelier and more contained decision-making process.



#### Introduction

#### 1.1 Background to the Study

The HSE Sexual Health and Crisis Pregnancy Programme (SHCPP), with the support of the HSE National Women and Infant Health Programme (NWIHP) and Primary Care Strategy and Planning, commissioned this study pursuant to the programme's remit to build on the existing evidence base to understand emerging trends relating to crisis pregnancy and sexual health, and to undertake new research initiatives to address knowledge gaps relevant to sexual health and wellbeing and crisis pregnancy in Ireland.

The Health (Regulation of Termination of Pregnancy) Act 2018 came into effect on 1 January 2019, permitting termination of pregnancy where there is a risk to the life, or of serious harm to the health, of the pregnant woman (Section 9), including in an emergency situation (Section 10); where the pregnancy is likely to lead to the death of the foetus either before or within 28 days of birth because of a problem with its development (Section 11); and without restriction up to 12 weeks of pregnancy (Section 12)¹. Under the Health (Regulation of Termination of Pregnancy) Act 2018, abortion services can be provided by way of medical abortion by general practitioners (GPs) or by medical doctors in women's health clinics (WHCs) up to nine completed weeks' gestation. Between 10 and 12 weeks' gestation, GPs and WHCs should refer patients to hospital settings to access abortion services. Pregnant women and people can also be referred to hospital settings to access abortion services if clinically indicated at any stage up to 12 weeks' gestation. Medical or surgical abortions can take place in hospital settings up to 12 weeks' gestation. Abortion services beyond 12 weeks' gestation are restricted to those circumstances specified in Sections 9–11 of the Act, and can only be provided in hospital settings. Pregnant women and people seeking abortion services are required to attend a GP, WHC or maternity setting for two separate appointments, with a three-day wait required between the first and the second appointment before the abortion can be provided.

The HSE, through the SHCPP, funds external statutory and non-statutory services to deliver unplanned pregnancy and post-abortion counselling. The services are intended to support people through an unplanned pregnancy. The services provide the opportunity to talk to a trained counsellor about the pregnancy and how it affects their personal circumstances; and to access factual information on available services and supports, including continued pregnancy supports and abortion services. The HSE-funded support services include face-to-face crisis pregnancy counselling services and telephone counselling and support. Face-to-face counselling is available in over 20 locations across the country and is free of charge to pregnant women and people, their partners or a family member. Telephone counselling via My Options provides free and confidential information and counselling to support people six days a week, and originally ran from 9am to 9pm Monday to Friday and 10am to 2pm Saturday, though from April 2020 these hours were amended to 9am to 8pm Monday to Friday and 10am to 2pm Saturday. A 24/7 nurse advice line is also available for those who are going through or have gone through an abortion procedure. Both the face-to-face and telephone counselling support services are legally entitled to provide information to women and pregnant people about GPs and WHCs who will provide abortion services in Ireland<sup>2</sup>.

<sup>1 &</sup>lt;a href="http://www.irishstatutebook.ie/eli/2018/act/31/section/11/enacted/en/html">http://www.irishstatutebook.ie/eli/2018/act/31/section/11/enacted/en/html</a>

<sup>2</sup> More information on unplanned pregnancy support services can be found here: <a href="https://www.hse.ie/eng/services/news/newsfeatures/unplanned-pregnancy-support-and-abortion-care-study/">https://www.hse.ie/eng/services/news/newsfeatures/unplanned-pregnancy-support-and-abortion-care-study/</a>

When commissioning this study, the aim set out by the HSE SHCPP for the research study was to develop an in-depth understanding of the experiences of pregnant women who have accessed unplanned pregnancy support services and abortion services since the enactment of the legislation on 1 January 2019. The study objectives were:

- 1. To gather in-depth information from women who have availed of unplanned pregnancy support services and clinical abortion services in Ireland;
- 2. To provide a comprehensive description of the experiences of women who have availed of these services in Ireland, taking account of differing backgrounds, ages and locations;
- 3. To provide a comprehensive description of the trajectories of women who have accessed abortion care in Ireland, including linking with unplanned pregnancy support services and health care services.

A review of the operation of the 2018 Act was set out under Section 7 of the 2018 Act which states that "The Minister shall, not later than three years after the commencement of this section, carry out a review of the operation of this Act". The review clause was included in the 2018 Act to facilitate monitoring of the operation of the legislation in practice, as well as of the delivery of services in the area. The review of the operation of the Act aims to assess the effectiveness of the operation of the legislation.

The review comprises of two main phases and is being led by an independent Chair. As part of the first phase of the review, information, and evidence on the operation of the 2018 Act is being collected from women who use the service, from health professionals that provide the service and from the public, via a public consultation. The public consultation was opened on 8 December 2021 and closed on 1 April 2022 and a review with health professionals was initiated in May 2022 and is due to be completed in November 2022. The second phase of the review is led by an independent Chair who will assess the extent to which the objectives of the Act have been achieved, analysing in that regard the findings of the three strands of information.

On 11th March 2021, the Department of Health wrote to the SHCPP to inform them that as the UnPAC study would inform the service user strand of the review of the operation of the 2018 Act and that the study's findings on women's experiences will feed into the review of the operation of the 2018 Act.

This research on women's experiences of accessing unplanned pregnancy support and abortion services in Ireland will inform the service user strand of the review of the operation of 2018 Act, with the independent Chair considering the study's findings on women's experiences arising from the research, as part of the review.

The project began in December 2019 and is reporting in July 2022.

#### 1.2 Abortion Statistics 2019-2020

During 2019, the first year of implementation of abortion care in Ireland, 6,666 terminations were notified by Irish care providers and in 2020, 6,577 terminations were notified. A breakdown of the grounds in the legislation under which terminations were provided during both years is shown in Table 1.1.

Table 1.1. Notification of terminations of pregnancy between 1 January 2019 and 31 December 2020

Section of the Act	2019	2020
9 – Risk to life or health	21	20
10 - Risk to life or health in an emergency	3	5
11 - Condition likely to lead to death of foetus	100	97
12 - Early pregnancy	6,542	6,455
Total	6,666	6,577

Statistics from England and Wales for those years show that people from Ireland continued to access abortion care there since the implementation of the 2018 Act on 1 January 2019. Table 1.2 below displays the number of people resident in the Republic of Ireland who accessed abortion services in England and Wales in 2019 and 2020.

**Table 1.2.** Abortions provided to residents of the Republic of Ireland in England and Wales, 2019 and 2020

Ground of UK Act	2019	2020
Ground C <sup>3</sup>	311	131
Ground E (alone or with A, B, C or D) <sup>4</sup>	64	63
Total	375	194

The unplanned pregnancy and abortion care support services provided by the HSE SHCPP relate to all people seeking termination of pregnancy, both within and outside the jurisdiction.

#### 1.3 Structure of the Report

The report begins with a description of the legislation and model of care relating to abortion services in Ireland in Chapter 2, followed by an account of the research methodology employed in Chapter 3. A review of pertinent literature is provided to give context in Chapter 4. Chapters 5 through 12 present analysis of original empirical data generated during the study with people seeking or accessing unplanned pregnancy supports or termination of pregnancy in Ireland between December 2019 and April 2021. Chapter 13 presents analysis of Women on Web (WoW) data from 2019 and 2020. Chapter 14 presents a summary of key findings of the analysis, while Chapter 15 presents the PI's reflections on completion of the study and considerations arising from the research.

<sup>3</sup> Ground C: That the pregnancy has NOT exceeded its 24th week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman.

<sup>4</sup> Ground E: That there is substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.

Ground A: risk to the life of the pregnant woman or person

Ground B: to prevent grave permanent injury to the physical or mental health of the pregnant woman or person Ground D: risk of injury to the physical or mental health of any existing children in the family of the pregnant woman or person (up to 24 weeks in the pregnancy)

#### 1.4 Gender-Inclusive Language Statement

It is important to note at the outset of this report the language contained within. The researchers recognise that people may need to access abortion care services. In the data analysis section of the report we have used the term "women" to describe the study participants, as no person took part in the study who identified themselves as trans or non-binary to the researchers - and we acknowledge this as a limitation of our data set. We also recognise that transgender and non-binary people face barriers in accessing health care services and, as Likis (2021) suggests, employing gender-inclusive language can convey the active inclusion of people across the gender spectrum. The recent Gender Inclusive Language in Perinatal Services policy (Greene & Riddington, 2020) by Brighton and Sussex University Hospitals, drafted in collaboration with service users and partner organisations, produced guidance for documents, protocols and communications that acknowledge gender identity can be a source of oppression and health inequality, and advocates for a "gender additive" approach. This means that gender-neutral language is used alongside the language of womanhood to ensure the representation and inclusion of people who need to access perinatal services. The Health (Regulation of Termination of Pregnancy) Act 2018 specifies "woman" and "pregnant woman" while the HSE model of care (see Section 2.3) uses the term "person". According to de Londras (2020b: 138), using language like "pregnant women and people" in the text of the legislation not only recognises that the "burdens of the 8th Amendment fell almost entirely on women and girls in Ireland" but also creates transinclusivity for those who are entitled to access care under the law. We employ the terms "pregnant women and people" throughout the report with the intention of being as inclusive and sensitive as possible.



# Legislation and Model of Care Relating to Termination of Pregnancy in Ireland Since 2019

#### 2.1 Introduction

This chapter provides a brief account of the legal situation governing termination of pregnancy in Ireland during the timeframe of the study, 2019-2021, and its background. The model of care in place for implementing these legal regulations is also outlined. The purpose of the chapter is to set out the care pathways relating to unplanned pregnancy supports and abortion care services navigated by any person using these services. The chapter is intended to act as a point of reference for readers of the report as they read the detailed analysis of data collected with service users.

This chapter outlines findings from a policy case study, informed in part by a series of interviews with service providers and policy stakeholders (see Appendix 1a for a full list of stakeholder interviews and focus groups). The study also involved the compilation and review of legislative documents and instruments, policy documents, clinical guidelines, and service implementation documents that were generated from the 2018 Act and its subsequent implementation. Examples of the literature reviewed in this policy study include the legislation itself, all relevant clinical guidelines, the HSE's Model of Care for Termination of Pregnancy (Health Service Executive, 2018), the My Options website<sup>5</sup>, the HSE information leaflets for service users, the Department of Health's 'Annual Report' (Department of Health, 2018), 'Notifications in Accordance with Section 20 of the Health (Regulation of Termination of Pregnancy) Act 2018, Annual Report 2019' (Department of Health 2019) and 2020 (Department of Health 2020), relevant data on number of abortions given to people from the Republic of Ireland published by the Office for National Statistics UK (Department of Health & Social Care, 2018) and the available annual reports of providing hospitals where the service implementation process of the 2018 Act was outlined and activity statistics were reviewed and published.

#### 2.2 Legislation Relating to Termination of Pregnancy in Ireland

Until 2018, the Protection of Life During Pregnancy Act 2013 regulated access to lawful termination of pregnancy in Ireland. Under that legislation, a termination of pregnancy could only be carried out to avert a real and substantial risk to the life of the pregnant woman. Amending the legal position on abortion required a change to Article 40.3.3 of the constitution. Until 2018, Article 40.3.3 provided that: "The State acknowledges the right to life of the unborn and with due regard to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right. This subsection shall not limit freedom to travel between the State and another state. This subsection shall not limit freedom to obtain or make available, in the State, subject to such conditions as may be laid down by law, information relating to services lawfully available in another state."

<sup>5</sup> My Options website: https://www2.hse.ie/services/unplanned-pregnancy-support-services/my-options-freephone-line. html?gclid=EAlalQobChMlhL-Usujv9QIVh7PtCh3hsQoKEAAYASAAEgJJO\_D\_BwE&gclsrc=aw.ds

On 25 May 2018, the Referendum on the 36<sup>th</sup> Amendment of the Constitution Bill (concerning regulation of termination of pregnancy) was held. The referendum passed, with 66.4% in favour and 33.6% against. Following the amendment to the constitution, Article 40.3.3 now reads: "*Provision may be made by law for the regulation of termination of pregnancy*."

The Health (Regulation of Termination of Pregnancy) Act 2018 ("the 2018 Act") was passed by the Houses of the Oireachtas on 13 December 2018 and signed into law by the President on 20 December 2018. The new Act repealed the Protection of Life During Pregnancy Act 2013 and the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act 1995.

The main purpose of the Act of 2018 is to set out the law governing access to termination of pregnancy in Ireland. It permits termination to be carried out in cases where there is a risk to the life, or of serious harm to the health, of the pregnant woman, including in an emergency; where there is a condition present which is likely to lead to the death of the foetus either before or within 28 days of birth; and without restriction up to 12 weeks of pregnancy. The expanded service for termination of pregnancy under the Act of 2018 was introduced on 1 January 2019.

The Act allows for conscientious objection to facilitate health care professionals opting out of providing the service. It also specifies a mandatory three-day wait for service users between a first consultation with a registered medical practitioner, seeking the service, and a second consultation providing the service.

# 2.3 Implementation of Health (Regulation of Termination of Pregnancy) Act 2018

The Health (Regulation of Termination of Pregnancy) Act 2018 came into effect on 1 January 2019. Termination of pregnancy services are provided by registered medical practitioners for the HSE, in primary care settings by general practitioners (GPs) or doctors in women's health clinics (WHCs), and in maternity units and hospitals. The service is provided under the clinical guidance of the HSE NWIHP, which issued a draft model of care for the service in December 2018 (Health Service Executive, 2018).

A Clinical Lead for Termination of Pregnancy Services was appointed in December 2019. Interim Clinical Guidance on Termination of Pregnancy under 12 Weeks, December 2018 (Institute of Obstetricians and Gynaecologists, 2018), Pathway for Management of Fatal Fetal Anomalies and/or Life-limiting Conditions Diagnosed during Pregnancy: Termination of Pregnancy, January 2019 (Institute of Obstetricians and Gynaecologists, 2019a) and Risk to Life or Health of a Pregnant Woman in relation to Termination of Pregnancy, May 2019 (Institute of Obstetricians and Gynaecologists, 2019b), were issued by the Institute of Obstetricians and Gynaecologists (IOG) in relation to termination of pregnancy. Unplanned pregnancy supports and counselling and termination of pregnancy services are provided free of charge.

The NWIHP Programme under the governance of the Chief Clinical Officer, provides strategic direction and leadership for termination of pregnancy (TOP) services and appointed the aforementioned Clinical Lead for Termination of Pregnancy Services. The Clinical Lead established a Clinical Advisory Forum (CAF) comprising service providers across the acute and community networks, as well as other key stakeholders and special interest groups, including, the National Women's Council of Ireland, My Options and the IOG. The CAF includes representatives of other HSE programmes whose activities contribute to the implementation of services to give effect to the 2018 Act including HSE Primary Care Division, Acute Division and Sexual Health and Crisis Pregnancy Programme.

## 2.3.i Community Care Pathway for Medical Termination of Pregnancy Under s.12 of 2018 Act

Within primary care, registered medical practitioners operating as GPs or doctors in as GPs or doctors in WHCs who wish to provide the service enter into a Termination of Pregnancy Contract<sup>6</sup> with the HSE. As of December 2021, 404 GPs and doctors had entered into the contract to provide the service. To place this in context, according to the HSE, there are approximately 2,500 GPs working in practices, group practices, primary care centres and health centres in Ireland<sup>7</sup>. The HSE provides the medical practitioner with the medicinal products and relevant literature for use in the provision of the service, will facilitate training by funding approved training courses through the Irish College of General Practitioners (ICGP), and compiles a list of all providers who consent to allow their name to be publicly communicated as providers through a HSE-provided helpline for service users.

Under the model of care, GPs and doctors in WHCs can provide early medical abortion (EMA, abortion induced by medication) up to nine weeks' gestation. People may be referred into maternity units or hospitals if clinically indicated, but otherwise their full care pathway can be completed in the community. The original model of care (as implemented on 1 January 2019) envisages two face-to-face consults, separated by the mandatory three-day waiting period. The first consult is so that the pregnancy can be dated. If the pregnancy cannot be accurately dated, the person is referred for an ultrasound at a hospital or HSE-contracted scanning clinic. If the pregnancy is confirmed as less than nine weeks' gestation, they attend for a second consult and can consent to medical termination and receive detailed guidance on selfmanagement of the abortion along with accompanying literature. The first medication (mifepristone) is taken in the presence of the doctor. The second medication (misoprostol) is taken at home, approximately 24-48 hours later. People may be provided with an additional dose of misoprostol to take in the event that the first dose has been insufficient. When this additional dose has been unused they are generally advised to return it to their care provider, although the additional dose is half the original dosage and is insufficient to induce abortion alone. People are provided with a low-sensitivity pregnancy test to self-administer two weeks after the medical termination, to determine if the termination has completed. The model of care also includes an optional third consultation for follow-up care two weeks post-abortion and referral to additional services, e.g. family planning (free for people with a General Medical Scheme card) or counselling (free of charge). If a person does not attend the third consultation, the doctor contacts them to confirm they are no longer pregnant. Early data indicates that community-based EMA has been safe and effective in Ireland. Among 420 people who proceeded to EMA at 27 providing GP practices in 2019, almost all (98%) completed the process without surgical intervention (Horgan et al., 2021).

The model of care highlights that practice nurses and midwives play in important role in caring for pregnant women and people seeking termination of pregnancy services.

To support the community care pathway the HSE implemented a telephone helpline, My Options, staffed by specialist pregnancy counsellors and available from 9am to 9pm Monday to Friday and 10am to 2pm Saturday (though from April 2020 these hours were amended to 9am to 8pm Monday to Friday and 10am to 2pm Saturday). This is an optional component of the community care pathway people opt into by phoning the helpline. My Options also operates a webchat function available since May 2019 to provide information and support, though no GP information is given on the webchat. The key functions of My Options are:

i) To provide pregnant women and people seeking care with names and contact details of doctors providing termination of pregnancy;

<sup>6</sup> Termination of Pregnancy Contract - HSE.ie. Accessed 7.02.2022 <a href="https://www.hse.ie/eng/about/who/gmscontracts/termination-of-pregnancy-draft-contract/termination-of-pregnancy-service-contract-nov-2019.pdf">https://www.hse.ie/eng/about/who/gmscontracts/termination-of-pregnancy-draft-contract/termination-of-pregnancy-service-contract-nov-2019.pdf</a>

<sup>&#</sup>x27;General Practitioners or Family Doctors'. Accessed 21/01/2022: <a href="https://www.hse.ie/eng/services/list/2/gp/gp.html#:~:text=There%20are%20about%202%2C500%20General,seeks%20when%20they%20feel%20unwell.">https://www.hse.ie/eng/services/list/2/gp/gp.html#:~:text=There%20are%20about%202%2C500%20General,seeks%20when%20they%20feel%20unwell.</a>

- ii) To provide them with information about all options regarding pregnancy including termination of pregnancy, adoption and parenting;
- iii) To offer telephone counselling if requested and/or details of community-based pregnancy counselling services; and
- iv) To offer listening support to callers in exploring their pregnancy options.

In relation to providing information on doctors providing the abortion service, only names and details of doctors who have consented to being included on an "open list" are shared by My Options. Some providing doctors do not consent to their names being given to people calling the line, for reasons including fear of targeting by protestors or concerns about capacity of their service to treat patients not registered to their surgery. Providing GPs not on the "open list" usually only provide care to people who are already on their surgery list requesting abortion care, and My Options does not have access to information on providers on the "closed list". While there has been discussion about implementing legislation to provide for safe-access zones around providing doctors' surgeries and hospitals, this has not been acted on. As of December 2021, 248 doctors have opted to be on the 'open list'.

The My Options helpline also incorporates a HSE-funded 24/7 nurse helpline to answer clinical queries or questions of concern while self-managing medical termination in the community, or in relation to any symptoms they are concerned about following the medical termination.

The guidelines from the ICGP regarding provision of abortion in primary care settings state that not every service user needs an ultrasound. A referral to ultrasound is only necessary in cases where the person is unsure of their dates and close to nine weeks; has an irregular cycle; has one risk factor for ectopic pregnancy without signs or symptoms; or requests it. Scanning provision for this service is principally provided by Affidea, a private service contracted to the HSE with facilities in a number of different locations around the country. If a scan is required and there is not a locally contracted scanning clinic nearby, scanning services in the nearest maternity hospital are made available to the service.

Where a pregnant woman or person is assessed to be over nine weeks' gestation or has a clinical indication querying suitability for community-based medical termination, they will be referred to a maternity hospital or unit for abortion care. Plate 2.1 below depicts the Medical Termination of Pregnancy (Less than 9 Weeks) Care Pathway as set out by the HSE in its draft model of care issued in December 2018.

#### **Visit 1: Community Care**

- Consultation/Examination
- · Urine pregnancy test
- · FBC/rhesus testing
- Provide verbal & written information/contact number for 'My Options'
- Advise on contraception
- · Provide an STI risk assessment, as appropriate
- Refer for ultrasound if clinically indicated but dating pregnancy based on LMP in most cases accurate
- Certify that the pregnancy is not exceeding 12 weeks
- Refer to hospital if person is between 9-12 weeks, or if clinically indicated or according to patient preference

#### 3 days from certification

#### **Visit 2: Community Care**

- Re-certify person is not exceeding 12 weeks if a different doctor is seeing the person at visit 2
- Explain the termination of pregnancy procedure
- · Obtain informed consent
- · Administer first medication mifepristone
- · Supply second medication & instructions misoprostol
- Advise & provide written information on what to expect/possible complications
- · Provide prescription for pain relief, as appropriate
- · Provide information on contraception and provide a prescription for contraception, as appropriate
- · Provide the person with low sensitivity pregnancy test with instructions
- · Provide information/contact number for 'My Options'
- Refer for anti-D, with the person's consent, between 7-9 weeks when there is a rhesus negative blood group
- Notification of record (28 days to submit)

#### 1-2 days

· Person takes second medication at home, as instructed

#### 2 weeks

· Low sensitivity pregnancy test taken at home, as instructed



#### Visit 3 (optional): Community Care

- Aftercare consultation
- · Refer to hospital for complications or for ongoing pregnancy, where indicated
- · Refer to other services e.g. counselling, as required
- · Provide prescription for contraception, as appropriate
- · Provide report to the person's primary doctor, if the person consents to it
- If the person does not book an aftercare consultation, they should be contacted to confirm the low sensitivity pregnancy test has been taken and that they are no longer pregnant

J

Person referred to hospital, where indicated

**Plate 2.1.** Medical Termination of Pregnancy (Less than Nine Weeks) Care Pathway, source: HSE Final Draft Termination of Pregnancy Model of Care 18.12.18 (Health Service Executive, 2018)

#### 2.3.ii Implementation of Remote Model of Care Following Onset of COVID-19

On 6 April 2020 the Department of Health issued COVID-19 Public Health Emergency Termination of Pregnancy – Temporary Provisions for Early Pregnancy Model of Care in response to the COVID-19 pandemic (Spillane et al., 2021). This revised model of care acknowledged the unprecedented challenges of the COVID-19 outbreak for patients and clinicians alike.

The remote model of care allows for the first and second consultations in the community setting to be fully remote by telephone or video conference. The revised remote model of care advises that face-to-face consultations may be held if clinically necessary, but such consultations should be kept to a minimum and that duration should be kept to a minimum to reduce the risk to all parties. The justification for this new remote model was to help reduce the risk to the health of the medical practitioner, the patient involved, and other patients and staff, and reduce the burden on medical practitioners. In the first wave of the COVID-19 pandemic, people were restricted from travelling more than 2km from their homes, though this has been relaxed at different stages to 5km; up to 20km; and at its most lax allowing for intercounty travel. While necessary medical visits were exempt from these travel restrictions, Garda (police) checkpoints meant that pregnant women and people travelling for abortion care could be stopped and asked about the nature of their travel beyond restricted limits, and may have needed to provide evidence of a medical appointment.

Spillane et al. (2021) explain how the delivery of early abortion care by remote consultation (phone or video conferencing) is commonly referred to as telemedicine abortion, and that in implementing telemedicine abortion provision in the Irish context, policymakers determined that telemedicine abortion could be introduced without amending the abortion law (p.379). Community providers have implemented the remote model in diverse ways with some, particularly WHCs, delivering both consultations remotely while in general practice individual GPs offered either fully remote care or a blended model comprising the first consultation remotely with the second in-person. Spillane et al. (2021) set out how the Irish Family Planning Association (IFPA) implemented a fully remote model comprising an interdisciplinary care pathway whereby patients had two phone consultations with a doctor before arranging for collection of their Home Care Pack from the clinic, which contained the abortion medications, pain killers, a step-by-step guide leaflet, and a pregnancy test. Spillane et al. (2021) describe how, to mitigate concerns that quality of care would be compromised by the inability to see patients in-person, a range of additional supports were built into the care pathway. This included the development of a step-by-step guide to using the Home Care Pack and a series of videos explaining how the new abortion care pathway works, developed collaboratively by IFPA clinical, counselling and communications staff. A translation function was also added to the IFPA website to enable patients to read the information in their own language.

#### 2.3.iii Hospital Care Pathway for Termination of Pregnancy under s.12 of 2018 Act

Some people seeking termination of pregnancy under s.12 of the 2018 Act are referred from doctors in the community to maternity hospitals or units providing termination of pregnancy services. Maternity hospitals or units opt in to provide this care. As of July 2022, 11 of the 19 hospitals or units were providing elective abortion services, with a view to increasing to 14 by end of 2022. All 19 units provide care for people with complications of early pregnancy abortion and where there is a risk to the health of the pregnant person. The HSE 2018 model of care (Health Service Executive, 2018) states that NWIHP is responsible for ensuring an accessible service for people in all geographic regions of Ireland. There is a mutual dependency between community-based providers of abortion care and secondary or tertiary providers. In areas where maternity hospitals or units do not provide termination of pregnancy services, this may deter community and primary care providers from signing up to the service, diminishing accessibility to services in these areas.

The service is provided in secondary or tertiary hospital settings also under NWIHP. Within most settings where the service is provided there is a local clinical lead for termination of pregnancy care. In the hospital setting abortion care is provided by consultant and trainee obstetrician-gynaecologists in conjunction with midwifery and nursing staff, allied health professionals (e.g. social workers and counsellors) and, in cases of surgical terminations, anaesthesiology consultants and trainees. Interim clinical guidance specifies that all clinical staff involved in providing abortion care in hospital settings should receive evidence-based training to ensure they have the relevant knowledge, skills and competencies to provide termination care in line with clinical guidelines, which includes values clarification training.

The model of care envisages methods of termination in secondary care under s.12 of the 2018 Act to include medical termination of pregnancy where the person is administered the first medication (mifepristone) as an outpatient and is then admitted to hospital have the second medication (misoprostol) regime completed under supervision. Surgical methods are also envisaged in the model of care, comprising manual vacuum aspiration (MVA) without general anaesthetic, or electric vacuum aspiration usually under general anaesthetic. Surgical methods may require the resources of a theatre facility, though MVA can be performed in ambulatory settings as general anaesthetic is not required.

Where a post-termination pregnancy test is positive and/or a person is symptomatic following a medical termination in the community or a medical or surgical termination in hospital, this is managed in either community or hospital settings as clinically determined. The interim clinical guidelines recommend that the decision to evacuate the uterus following incomplete termination of pregnancy should be based on clinical signs and symptoms and not on ultrasound (Institute of Obstetricians and Gynaecologists, 2018).

There is no flexibility regarding the 12-week limit to access abortion care under s.12. Even where a person begins abortion care under 12 weeks but does not successfully complete the process before the 12-week limit, they are precluded from accessing care after that point.

# 2.4 Termination of Pregnancy After 12 Weeks' Gestation: s.9, s.10 and s.11 of 2018 Act

# 2.4.i Sections 9 and 10: Termination of Pregnancy Where There is Risk to Life or Health Including in Emergency

Sections 9 and 10 of the 2018 Act allow for termination of pregnancy where there is risk to life or health including in emergency, as follows:

#### Risk to life or health

- 9. (1) A termination of pregnancy may be carried out in accordance with this section where two medical practitioners, having examined the pregnant woman, are of the reasonable opinion formed in good faith that—
  - (a) there is a risk to the life, or of serious harm to the health, of the pregnant woman,
  - (b) the foetus has not reached viability, and
  - (c) it is appropriate to carry out the termination of pregnancy in order to avert the risk referred to in paragraph (a).
- (2) Of the 2 medical practitioners referred to in subsection (1)—
  - (a) one shall be an obstetrician, and
  - (b) the other shall be an appropriate medical practitioner.

- (3) A termination of pregnancy shall not be carried out under this section unless each of the medical practitioners referred to in subsection (1) has certified his or her opinion as to the matters referred to in that subsection.
- (4) The termination of pregnancy to which the certification referred to in subsection (3) relates shall be carried out—
  - (a) by the obstetrician referred to in subsection (2)(a), or
  - (b) where the medical practitioner referred to in subsection (2)(b) is also an obstetrician, by that obstetrician or the obstetrician referred to in subsection (2).

#### Risk to life or health in emergency

- 10. (1) Notwithstanding the generality of section 9, or any determination made or pending pursuant to section 16 of an application under section 13(2), a termination of pregnancy may be carried out in accordance with this section by a medical practitioner where, having examined the pregnant woman, he or she is of the reasonable opinion formed in good faith that—
  - (a) there is an immediate risk to the life, or of serious harm to the health, of the pregnant woman, and
  - (b) it is immediately necessary to carry out the termination of pregnancy in order to avert that risk.
- (2) Where a medical practitioner proposes to carry out a termination of pregnancy under this section, he or she shall certify his or her opinion as to the matters referred to in subsection (1)—
  - (a) before carrying out the termination of pregnancy concerned, or
  - (b) where it is not practicable to do so before carrying out the termination of pregnancy, as soon as may be but, in any event, not later than three days after the carrying out of the termination of pregnancy concerned.

# 2.4.ii Section 11: Termination of Pregnancy Where There is a Condition Likely to Lead to Death of Foetus

Section 11 of the Health (Regulation of Termination of Pregnancy) Act 2018 deals with termination of pregnancy where there is a condition likely to lead to the death of the foetus. According to Section 11 of the Act:

- 11 (1) A termination of pregnancy may be carried out in accordance with this section where two medical practitioners, having examined the pregnant woman, are of the reasonable opinion formed in good faith that there is present a condition affecting the foetus that is likely to lead to the death of the foetus either before, or within 28 days of, birth.
- (2) Of the two medical practitioners referred to in subsection (1)—
  - (a) one shall be an obstetrician, and
  - (b) the other shall be a medical practitioner of a relevant specialty.
- (3) A termination of pregnancy shall not be carried out under this section unless each of the medical practitioners referred to in subsection (1) has certified his or her opinion as to the matters referred to in that subsection.
- (4) The termination of pregnancy to which the certification referred to in subsection (3) relates shall be carried out
  - (a) by the obstetrician referred to in subsection (2)(a), or
  - (b) where the medical practitioner referred to in subsection (2)(b) is also an obstetrician, by that obstetrician or the obstetrician referred to in subsection (2)(a).

Both medical practitioners must certify their own opinions. The termination of pregnancy is to be carried out by an obstetrician who certified the termination.

The IOG prepared Interim Clinical Guidance – Pathway for Management of Fatal Fetal Anomalies and/ or Life-Limiting Conditions Diagnosed During Pregnancy (Institute of Obstetricians and Gynaecologists, 2019a) for health care providers regarding Section 11 of the 2018 Act. The guidance states that a perinatal palliative care approach is appropriate after antenatal diagnosis of fatal foetal anomalies and/or life-limiting conditions, both for parents who opt for termination of pregnancy and those who continue.

The guidelines specify the following care pathway (p.11): "Prompt referral to a fetal medicine specialist ideally within 24 to 72 hours is the standard of care where a major fetal anomaly is suspected, followed by provision of written information resources and support. While awaiting referral the Parents should be given direct contact details of a support person in the referring hospital."

The guidelines set out different pathways around antenatal diagnosis/initial care as follows (p.11):

- "Antenatal diagnosis of a major structural fetal anomaly may be made at the 11-13-week scan or second trimester anomaly scan at 20-22 weeks and is ordinarily confirmed by either the local Obstetrician and/ or fetal medicine specialist in the tertiary centre (or by a fetal medicine specialist from the tertiary centre who has a sessional commitment in another unit).
- Where termination of pregnancy is being considered, a fetal medicine specialist should be involved in the antenatal diagnosis and subsequent care of the pregnancy. It is further recommended that a fetal medicine specialist be one of the signatories on the certification documents.
- The majority of pregnant women and people in this situation will be referred to the tertiary hospital in their area (or to the fetal medicine team in the tertiary hospital) for review and assessment by fetal medicine specialists. This may include additional investigations (e.g. invasive testing for genetic diagnosis or fetal MRI where ultrasound has limitations for full evaluation), and referral to specialist fetal echocardiography for cardiac anomalies. These cases are subsequently discussed by the multidisciplinary team at the tertiary site to reach a consensus about the diagnosis and prognosis, and to consider the option of termination of pregnancy being discussed with the Parents, as well as any implications for maternal health where the pregnancy is on-going.
- Some fetal conditions for which there are simple definitive diagnostic tests and an unequivocal prognosis (e.g. anencephaly), may be diagnosed and managed at local hospital level, where fetal medicine expertise exists, or where a fetal medicine specialist from the tertiary centre has a sessional commitment. Invasive testing may occur at the tertiary centre, but results are communicated to local units and ongoing care is managed with the local Obstetricians and Neonatologists/Paediatricians, supported as needed by the tertiary site." (Institute of Obstetricians and Gynaecologists, 2019a: p.10-11).

In summary, the pathway set out in the Interim Clinical Guidance recommends referral to a foetal medicine specialist within a 24-72-hour window of suspecting an anomaly. The foetal medicine specialist is expected to be involved in the full care pathway for a person considering termination of pregnancy. It anticipates the majority of people will be referred to a tertiary hospital for review, specialist assessment and possibly investigative testing. A multidisciplinary team at the tertiary site will discuss the case to reach a consensus about diagnosis and prognosis, and to consider the option of termination of pregnancy being discussed with the parents. Results will be communicated to local units and ongoing care is managed with local obstetricians and neonatologists/paediatricians, supported as needed by the tertiary site.

# 2.4.iii Conscientious Objection in Provision of Termination of Pregnancy Services

Section 22(1) of the 2018 Act provides that no medical practitioner, nurse or midwife shall be obliged to carry out, or to participate in carrying out, a termination of pregnancy in accordance with section 9 (risk to life or health), section 11 (condition likely to lead to death of foetus) or section 12 (early pregnancy) to which he or she has a conscientious objection.

However, this is qualified by section 22(2) of the Act which states that section 22(1) shall not be construed to affect any duty to participate in a termination of pregnancy in accordance with section 10, i.e. where there is an immediate risk to the life, or of serious harm to the health, of the pregnant woman and it is immediately necessary to carry out the termination in order to avert that risk. This is reflected in the Irish Medical Council's Guide to Professional Conduct and Ethics for Registered Medical Professionals (Irish Medical Council, 2019), which states that members may "refuse to provide, or to participate in carrying out, a procedure, lawful treatment or form of care which conflicts with your sincerely held ethical or moral values" (p.35), dependent on the below stipulations:

- 49.2 If you have a conscientious objection to a treatment or form of care, you should inform patients, colleagues, and, where relevant, your employer as soon as possible.
- 49.3 If you hold a conscientious objection to a treatment, you must:
  - · inform the patient that they have a right to seek treatment from another doctor; and
  - give the patient enough information to enable them to transfer to another doctor to get the treatment they want.
- When you refer a patient and/or facilitate their transfer of care, you should make sure that this is done in a safe, effective and timely manner. You should help make it as easy as possible for the patient. When discussing the referring and/or transferring of a patient's care to another health professional, you should be sensitive and respectful so as to minimise any distress your decision may cause. You should make sure that patients' care is not interrupted and their access to care is not impeded.
- 49.5 You should not provide false or misleading information, or wilfully obstruct a patient's access to treatment based on your conscientious objection.
- 49.6 If the patient cannot arrange their own transfer of care, you should make these arrangements on their behalf.
- 49.7 In an emergency situation, you must provide as a matter of priority the care and treatment your patient needs (Irish Medical Council, 2019: p. 35).

Therefore, in emergency situations a medical practitioner, nurse or midwife must provide treatment to the pregnant person, irrespective of any conscientious objection that the medical practitioner, nurse or midwife may have.

## 2.4.iv Unplanned Pregnancy Supports

The HSE SHCPP delivers a programme of funded initiatives including crisis pregnancy counselling services, My Options helpline and a series of masterclasses in conjunction with Maynooth University for professionals who encounter unplanned pregnancy in the course of their professional life including teachers, doctors, nurses, social workers, therapists, chaplains, all pastoral care workers and youth workers.

My Options provides information, listening and support on all options relating to unplanned pregnancy, including continued pregnancy supports and abortion services, through both telephone and webchat services. The webchat service provides information and support but not GP details. The helpline offers counselling over the phone and/or provides information on free face-to-face counselling. My Options signposts to services, including GPs providing abortion care, and community services and supports related to continuing a pregnancy. The helpline also provides post-abortion support. My Options provides a 24/7 nursing team for medical support and reassurance to people who are in the process of having, or who have recently had, an abortion. The nursing team provides medical advice for anyone experiencing clinical symptoms following an abortion, for example bleeding or pain, and also advises people on when to go to a doctor.

The SHCPP also funds counselling agencies to provide unplanned pregnancy and post-abortion counselling. These agencies provide face-to-face pregnancy counselling free of charge to women and pregnant people, their partners or a family member. All services provide non-directive, non-judgemental counselling. Funded unplanned pregnancy counselling is provided through a range of organisations including WHCs (e.g. Irish Family Planning Association and Well Woman), dedicated services (e.g. West Cork Crisis Pregnancy Counselling Services, One Family), HSE and hospital providers (e.g. Ballinasloe Crisis Pregnancy Support Service and Midlands Crisis Pregnancy Counselling Services)<sup>8</sup>.

# 2.5 Chapter Overview

This chapter set out the key components of the model of care relating to unplanned pregnancy and abortion care, encompassing unplanned pregnancy and abortion information and counselling services as well as post-abortion care, and the legislation, governance and models of care relating to termination of pregnancy in community and hospital settings.

<sup>8</sup> A full list of funded agencies is available at: <a href="https://www2.hse.ie/services/unplanned-pregnancy-support-services/find-a-face-to-face-unplanned-pregnancy-counselling-service.html">https://www2.hse.ie/services/unplanned-pregnancy-support-services/find-a-face-to-face-unplanned-pregnancy-counselling-service.html</a>.



# Research Methodology

## 3.1 Introduction

This study comprised four work packages:

- i) Work package one: A policy case study of the implementation of the Act (Chapters 1 & 2);
- ii) **Work package two**: A literature review which collated evidence on abortion provision in the Irish context since the implementation of abortion services in Ireland in January 2018 (Chapter 4);
- iii) **Work package three**: An in-depth qualitative study of service users' experiences of unplanned pregnancy support services and abortion care (Chapters 5-12); and
- iv) **Work package four**: A quantitative and qualitative analysis of Women on Web (WoW) data, an online telemedicine abortion care provider to regions with limited access (Chapter 13).

This chapter describes the methodological approach adopted in each work package. Section 3.2 describes the policy case study approach. Section 3.3 gives an overview of the literature review methodology. Sections 3.4 describes the methodological approach taken for work package three, the large qualitative study with service users, while Section 3.5 of this report outlines the WoW study methods.

All four work packages were undertaken by the same project team and ran in parallel to each other.

# 3.2 Work Package One: Policy Case Study Approach

In order to inform the development of the study and the study materials, the study team sought to provide a comprehensive description of the trajectories of women and people who had accessed abortions in Ireland. To contextualise and better understand the provision of abortions in Ireland and the policy landscape, a policy case study approach was adopted.

Over the course of this project, a review of all relevant policy documents and clinical guidelines pertaining to the 2018 Act was undertaken. The research team compiled and reviewed legislative documents and instruments, policy documents, clinical guidelines, and service implementation documents that were generated from the 2018 Act and its subsequent implementation. The literature reviewed included the HSE's Model of Care for Termination of Pregnancy (Health Service Executive, 2018), the My Options website<sup>9</sup>, the HSE information leaflets for service users, the Department of Health's Annual Report (Department of Health, 2018), Notifications in Accordance with Section 20 of the Health (Regulation of Termination of Pregnancy) Act 2018, Annual Report 2019 (Department of Health 2019) and 2020 (Department of Health 2020), relevant data on number of abortions given to people from the Republic of Ireland published by the Office for National Statistics UK (Department of Health & Social Care, 2018) and the available annual reports

<sup>9</sup> My Options website: <a href="https://www2.hse.ie/services/unplanned-pregnancy-support-services/my-options-freephone-line.html?gclid=EAlalQobChMlhL-Usujv9QIVh7PtCh3hsQoKEAAYASAAEgJJO\_D\_BwE&gclsrc=aw.ds">httml?gclid=EAlalQobChMlhL-Usujv9QIVh7PtCh3hsQoKEAAYASAAEgJJO\_D\_BwE&gclsrc=aw.ds</a>

of providing hospitals where the service implementation process of the 2018 Act was outlined and activity statistics were reviewed and published.

In addition to the review of the existing literature, 24 interviews with key stakeholders were undertaken, along with three focus groups (see Appendix 1a for the number and type of stakeholders interviewed). These interviews and focus groups were transcribed and a situational analysis framework to data analysis was applied (Clarke et al., 2018).

This work package was undertaken to help the research team better understand the contextual field. Findings from the compilation and review of the policy, clinical and legislative documents and from the indepth interviews and focus groups with stakeholders are outlined in Chapters 1 and 2 of this report.

# 3.3 Work Package Two: Literature Review Approach

A literature review is a narrative review which adopts strands of a systematic approach to eliminate bias and ensure transparency and replicability during the literature search process. In the context of the UnPAC study, a full systematic review was not feasible, however, a systematic review methodology underpinned how the search strategy was formulated and applied. The key objective was to comprehensively review the literature on abortion legalisation and implementation in Ireland since 2018.

A two-step search strategy was utilised to identify and capture the most recent peer-reviewed evidence available alongside relevant policy and service provider documents. An initial exploratory search in the Trinity College Library and Google Scholar provided the foundation for formulating the search criteria. Using an iterative process, keywords were extracted and used to build a comprehensive list of terms which were applied to the development and implementation of the search strategy.

A systematic online search was conducted following broadly the Campbell Methods Guide (Kugley et al., 2016). A complementary search of journals using BrowZine was carried out in publications such as *Contraception, Journal of Reproductive Health and Medicine*, and *BMJ Sexual and Reproductive Health*. A systematic online search was conducted using PubMed, Web of Science, Cochrane Central Register of Controlled Trials, Scopus, MEDLINE and Jstor. An alert was created on Google Scholar and Mendeley for any new publications on "abortion Ireland". In addition, the reference lists of included publications were manually reviewed to identify and include relevant sources.

To search effectively and strategically, the Patient Intervention Comparison Outcome framework was utilised to break down the research question into constituent parts and the literature was searched with Boolean operators using the following criteria:

- Population search terms: (Patient) ""women" OR "woman" OR "female" OR "pregnant" OR "pregnancy" OR "maternal"; "Ireland" and "abortion" OR "abortion legalisation" OR "abortion implementation"
- Issue/Intervention search terms: (Intervention) "abortion" OR "medical abortion" OR "termination" OR "induced" OR "misoprostol" OR "misoprostol" OR "abortion pill" OR "reproductive healthcare" OR "telemedicine abortion"
- Comparison search terms: (or main alternative intervention) "self-management" OR "self-managed" OR
   "self-manage" OR "self-administered" OR "self-administer" OR "self-induced" OR "self-medication" OR
   "home use" OR "at home";
- Outcome search terms: "access" OR "preference" OR "travel" OR "covid" OR "covid-19" OR "pandemic" OR "choice" OR "autonomy" OR "restricted" OR "fear" OR "stigma" OR "safety"

Potential sources identified were scrutinised for relevant search terms and keywords. These were subjected to a pre-selection process whereby abstracts were read to ensure compliance with the inclusion criteria and relevance to the topic under research in this study rather than all articles available on medical termination of pregnancy.

In addition to the above search terms and keywords, the documents were only included if published between January 2019 and October 2021. The resultant documents were then selected for the literature review and compiled into the bibliography included for this study.

The literature review findings are outlined in Chapter Four.

# 3.4 Work Package Three: Qualitative Interview Research Approach

The research approach taken in work package three, the qualitative study of service users' experiences, was premised on the constructivist grounded theory (Charmaz, 2014) method and data generated following principles of purposive and theoretical sampling (Conlon et al., 2020). This section sets out the ethical and data management procedures followed in the study, the methodology informing the research design and the research methods followed to generate, analyse and report on the empirical data.

A qualitative research approach following the grounded theory (GT) method (Flick, 2018; Timonen et al., 2018), and specifically the constructivist iteration of GT (Charmaz, 2014; Conlon, 2020), was employed in this study. The method is designed to generate understandings and meanings grounded in data generated through empirical observation and in-depth engagement with the phenomenon of interest. As the study was concerned with a novel process and context from the perspective of key actors – women using abortion services – the GT approach facilitated insights coming through from this novel context. GT was a good fit for a study inquiring into an area of health provision, namely unplanned pregnancy and abortion care services that have been in place in this and other contexts for some time. The method also allowed for specific insights into how this area of health provision is being engaged with and experienced by service users given the particular socio-political/cultural context, regulatory framework and implementation model.

The research design for this GT study had regard to the focus on people's experiences of unplanned pregnancy supports and abortion care services in the context of a radical change in abortion care at legislative, policy and service delivery level. While the method privileges empirical data over existing theories or frameworks, within this study the constructivist method was chosen and adapted. The constructivist iteration of GT acknowledges pre-existing knowledge and frameworks and facilitates their application. This is best aligned with research carried out for applied policy purposes, where some specified parameters (e.g. pre-existing model of care and care pathways), as well as frameworks such as the Availability, Accessibility, Acceptability and Quality (AAAQ) Framework adopted by the World Health Organization (WHO), are of interest to those charged with policy implementation.

A first issue when developing a GT study design is to attend to what place existing knowledge on women's experiences of abortion care services would have. While classical versions of grounded theory method proposed that the inquiry begins without the researcher establishing the existing state of knowledge in the area to optimise "grounded" discovery, more recent versions recognise that pragmatically this is not feasible (Flick, 2018; Timonen et al., 2018). Researchers are rarely completely new to an area and research funders expect researchers will build on existing knowledge to optimise learning. This project design followed pragmatic application of the grounded theory method (Timonen et al., 2018) that both acknowledges and anticipates the researchers will begin with some pre-existing knowledge in the area, will consult the state-of-the art literature, and will operate within some models and frameworks.

The principles of GT primarily employed within the project research design therefore emphasised two key principles of:

- A maximally open approach to generating empirical data; and
- Privileging the empirical data in constructing an analytical framework over existing theories or frameworks.

While a synthesis of literature and key existing frameworks was referred to, an emphasis on openness in the design of data generation and analysis facilitated new, context-specific insights emerging.

The requirement of the method to be maximally open meant collecting data early on using lightly structured data generation methods, e.g. interview guides. Critically, it meant starting analysis as soon as data was available, to identify concepts and processes emerging early from the data as empirically observed. Emergent insights informed generation of further data following theoretical sampling principles (Conlon et al., 2020) designed to deepen and test these insights, and regarding the processes, conditions and contexts relating to the phenomenon of interest on the ground. Theoretical sampling also allows diverse or multiple conditions and contexts to be attended to, as the researcher notes not just patterns suggestive of emergent explanations but also gaps and anomalies, and seeks out data to fill gaps and illuminate anomalies. A key focus involves seeking out anomalous and contrasting contexts and perspectives, to check all the time if the accounts and explanations emerging from analysis are rigorous and a good fit.

Simultaneous data collection and analysis, then, is the core feature of GT studies. Early analysis of empirical data directs the focus for further data generation to deepen insights and test explanations being proposed in analysis. In this project data analysis and data collection proceeded in tandem with the focus on filling out all dimensions of emergent concepts and relationships identified through analytical procedures until concepts were optimally saturated (Conlon et al., 2020; Foley et al., 2021).

The specific research methods employed to realise the premises of the constructivist GT in this applied research study are set out below.

## 3.4.i Sampling and Recruitment for Qualitative Interviews

Semi-structured, in-depth interviews with people accessing unplanned pregnancy and abortion care services were considered the optimal format of data collection for this project. This interviewing format allows for maximally open and flexible data generation aligned with the grounded and emergent premises driving the study (Timonen et al., 2018). One-to-one interviews were also a format that best acknowledged the sensitivity of the topic and the centrality of pregnant women and people's accounts driving the project.

The target sample population was pregnant women and people using unplanned pregnancy support services and abortion care. Exclusion criteria were:

- 1. Anyone under 18 years of age;
- 2. Anyone deemed by their health care provider to have incapacity to give consent.

The data was collected in a range of settings, and fieldwork sites were selected having regard to the different care pathways available to people accessing unplanned pregnancy and abortion care supports, including the following. Table 3.1 outlines the groups of people recruited to the study.

Table 3.1 Summary of groupings from which participants were recruited

Group	Participant
Group 1	People attending unplanned pregnancy counselling services who may decide to continue the pregnancy or not
Group 2	People under 12 weeks' gestation seeking abortion care whose care pathway was confined completely to community/primary care settings
Group 3	People under 12 weeks' gestation seeking abortion care who were referred to hospital settings for abortion care because of clinical indicators or reaching 9-12 weeks' gestation
Group 4	People under 12 weeks' gestation who had abortion care provided in community/primary or hospital settings who were referred to hospital for care relating to post-abortion symptoms
Group 5	People over 12 weeks' gestation who were seeking and/or qualified for abortion care under the 2018 Act
Group 6	People accessing abortion care outside the jurisdiction since the implementation of the 2018 Act.

### 3.4.i.i Recruiting Participants

Purposive sampling was employed to recruit across each of these categories as set out below. Within each category, theoretical sampling principles were followed to achieve an overall data set compiled with rigorous attention to diversity and depth. Theoretical sampling is a core feature of the grounded theory method, originating in the early work of the founders of the method (Glaser & Strauss, 1967; 2012). It functions in all variants of the method including classical (Glaser, 1978; Glaser & Holton, 2004), Corbin/Strauss (Corbin & Strauss, 2015; Strauss & Corbin, 1998), constructivist (Charmaz, 2014), situational analysis (Clarke et al., 2018), and critical realist (Hodd, 2018; Oliver, 2012) grounded theory. The researcher moves from purposive sampling (or other forms of non-probability sampling) to sampling for concepts that are emergent in the data (Bryant, 2020; Charmaz, 2014; Corbin & Strauss, 2015; Glaser, 1992). The conscious pursuit of key concepts in data generation signals that a researcher has begun to theoretically sample (Charmaz, 2014).

Theoretical sampling is not a discrete stage of sampling in a grounded theory study. It works in parallel with and/or is interspersed among other sampling methods when conceptual categories (more encompassing concepts) emerge at different stages of the study, and where the researcher needs to generate the comparative data to build concepts and categories constitutive of rigorous accounts, patterns, constructs and explanations in the data (Conlon et al., 2020).

The rigour of the method is located not in statistical representativity but rather in attention to thorough interrogation of emergent, grounded theoretical and conceptual dimensions of the phenomenon of interest. The promise of the method beyond statistical representativity is in discovery of phenomena and contextually specific novel insights. Through a knowledge translation process, these insights can be employed in more positivist (statistically representative) research design to allow for a study of how these emergent insights manifest as recurring and systemic features of the phenomenon, e.g. through user satisfaction surveys informed by the findings of the GT study.

The discussion above regarding the use of GT methodology considers issues such as potential for bias and generalisability in how procedures relating to sample selection for participants and generating findings featured in the study.

Recruitment in this study started in December 2019 and continued until August 2021. The recruitment process was iterative and guided by the GT principle of data saturation. This meant that if a theme emerged in later interviews, we continued to sample participants for the purposes of generating new data so as to later explore and confirm the emergent theme in subsequent interviews, as well as revisiting existing data.

The design of the study involved recruiting participants at the point of their presentation for either counselling or abortion care by:

- 1. Care providers (e.g. doctors, nurses/midwives, or counsellors) or an abortion support organisation (e.g. Termination for Medical Reasons) telling people about the study and providing them with an Invitation to Participate (Appendix 1b, 1c, or 1d) and Participant Information Sheet (Appendix 2a, 2b, or 2c);
- 2. Care providers giving people a Consent to be Contacted Form (Appendix 3a) for reading, confidential self-completion and placement in a sealed envelope, or giving people an electronic Consent to be Contacted Form (Appendix 3b);
- 3. Sealed envelopes containing Consent to be Contacted Forms (Appendix 3a) being returned to care providers for delivery to researchers or posted directly to researchers by service users themselves using stamped addressed envelopes, or electronic Consent to be Contacted Forms (Appendix 3b) being returned directly to the research team via a secure web-based platform hosted by Trinity College Dublin (Qualtrics).

While the three recruitment pathways outlined were part of the research design, during the study two people contacted the researchers saying they had read about the study on the HSE website<sup>10</sup>. In these cases, the people were sent the Invitation to Participate (Appendix 1b or 1c), Participant Information Sheet (Appendix 2a or 2b) and Consent to be Contacted Form (Appendix 3a or 3b) directly. Regardless of referral mode (via care provider or self), all self-completed Consent to be Contacted Forms (Appendix 3a and 3b) returned to researchers were reviewed in line with the purposive and theoretical sampling principles outlined above. People satisfying sampling criteria were followed up for interview by researchers using contact details supplied.

People were invited for interview and if they agreed, a time, setting and format of their choice were arranged at which final consent to interview was given. At the outset of the study, most interviews were conducted inperson. However, in light of the need for physical distancing following the onset of the COVID-19 pandemic, all interviews from March 2020 onwards were conducted remotely by telephone or voice or video call (MS Teams or Zoom), as selected by participants. Participants received no payment or remuneration for their participation. We do not have information on the people who chose not to participate in this study.

# 3.4.i.ii Recruiting Participants Attending HSE-funded Unplanned Pregnancy/Post-abortion Counselling

People attending unplanned pregnancy and post-abortion counselling services include:

- People using support and counselling services who may have used or may progress to use abortion care services;
- People attending post-abortion counselling who had an abortion in Ireland since 1 January 2019 under the 2018 Act:
- People attending post-abortion counselling who had an abortion outside of Ireland since 1 January 2019.

Recruitment sites for the study were purposively selected for higher levels of activity, so access was negotiated to a sub-set of HSE SHCPP-funded unplanned pregnancy counselling services. Counsellors in these settings were apprised of the study so that they were fully informed to answer any questions clients raised with them about the study. In particular, the safeguards for confidentiality and ensuring care would not be affected by the decision to take part or not were emphasised with counsellors. Counsellors were provided with Invitations to Participate (Appendix 1b), Participant Information Sheets (Appendix 2a) and Consent to be Contacted Forms (Appendix 3a), which they provided to clients, who completed them and returned them either to the service provider for return to the researchers or directly to the researchers by post. Researchers then contacted respondents to discuss further what taking part in the study involved, and if people consented an arrangement was made to interview them either face to face or remotely by phone, Microsoft Teams or Zoom.

#### 3.4.i.iii Recruitment of Participants from GPs

The HSE National Contracts Office facilitated researchers sending an email to all GPs signed up to provide termination of pregnancy services. The email asked GPs to opt in to be included on a list of potential sampling sites for the research, and allow their contact details to be released to researchers for direct engagement. Thirty-six of the approximately 400 practicing GPs at that time opted in to recruit participants for the study. The research team then purposively sampled a selection of GPs for participation, based on geographical spread to allow for both rural and urban representation. Researchers then contacted the selected GPs to provide them with further information on the study and to ask their consent to participate. Each GP was sent a collection of five recruitment packages, each package of which included an Invitation to Participate (Appendix 1b), a Consent to be Contacted Form (Appendix 3a) and an envelope for TCD.

The study design anticipated that each recruiting GP would recruit a maximum of five people but no minimum was set. In the event, some GPs did have five people present for care, but others had fewer, including some who had no one present, or only one person. This approach was adopted to ensure there was no over-representation of any one setting. As we recognised more rurally located GPs may have fewer presenting service users, we over-sampled rural GP practices.

To recruit people from Groups 2, 3 and 4 (see Table 3.1) into the study, participating GPs told the first five people presenting for abortion care during the recruitment timeframe about the study and provided them with an Invitation to Participate (Appendix 1b) and Participant Information Sheet (Appendix 2a) at the end of Visit 1. When they returned for their second consultation with the GP (Visit 2) they were reminded of the study and given the Consent to be Contacted Form (Appendix 3a). They were asked to return the form to their care provider (completed or not) in a sealed envelope. They were given time to read and complete the form privately, and to decide to opt in or not to be contacted by the research team. People placed the completed form and sealed it in a TCD envelope and returned to their GP provider. After COVID-19 restrictions were imposed, these envelopes were returned by post. This process ensured the GP did not know the status of the person's participation in the study. This was kept securely by the GP and collected by a member of the research team.

Returns to the research team included refusals to take part (which were not followed up by the research team) and consents to be contacted by the researchers. If a potential participant indicated their consent to be contacted, then we followed up by the format the person selected. In all cases it was either telephone or email. Up to three attempts at contact were made after which the researcher had left either a voicemail or an email message inviting the person to respond back to the team after which no further contact was made.

### 3.4.i.iv Recruitment of Participants from Women's Health Clinics

Two WHC providers with clinics in a total of five sites in the greater Dublin area agreed to act as recruitment sites for the study. Each WHC provider was given 10 recruitment packs across their service, on the basis that they could recruit a maximum of 10 women from each site. People attending participating WHCs during the recruitment timeframe were given an Invitation to Participate (Appendix 1b) and Participant Information Sheet (Appendix 2a) at the end of Visit 1. When they returned to the WHC for their second consultation (Visit 2) they were reminded of the study and given the Consent to be Contacted Form (Appendix 3a). They were asked to return the form to their care provider (completed or not) in a sealed envelope. This was kept securely by the care provider and returned to the research team. The recruitment procedure in the WHC was the same as the GP settings.

With the onset of the COVID-19 pandemic WHCs moved to fully remote teleconsultations. To facilitate recruitment of participants during this time the recruitment method was modified so that care providers could send an electronic version of the Invitation to Participate (Appendix 1b), Participant Information Sheet (Appendix 2b) and Consent to be Contacted Form (Appendix 3b). To indicate their consent, potential participants filled out a secure, web-based Consent to be Contacted Form hosted by the Social Sciences Data Survey software Qualtrics, administered securely by Trinity College Dublin.

#### 3.4.i.v Recruitment of Participants from Hospitals (Under 12 Weeks)

Two hospital sites agreed to act as recruitment settings for the study, one urban-based stand-alone tertiary maternity hospital and one maternity unit attached to a regional hospital<sup>11</sup>. Service users attending hospitals for abortion care under 12 weeks' gestation were given an Invitation to Participate (Appendix 1b) and Participant Information Sheet (Appendix 2a) at the end of their first consult at the hospital. When they returned for their second hospital consultation they were reminded of the study and given the Consent to be Contacted Form (Appendix 3a). They were asked to return the form to their care provider (completed or not) in a sealed envelope. This was kept securely by the care provider for return to the research team.

#### 3.4.i.vi Recruitment of Participants Accessing/Seeking Care Over 12 Weeks' Gestation

A range of recruitment points were used to reach people accessing care over 12 weeks' gestation:

- The two hospital sites supporting recruitment for the study provided Invitations to Participate (Appendix 1b), Participant Information Sheets (Appendix 2a) and Consent to be Contacted Forms (Appendix 3a) to people attending for follow-up care after assessment for Fatal Foetal Anomaly (FFA) and/or provision of termination of pregnancy care in that hospital, another Irish hospital, or outside the jurisdiction. The caregivers telling people about the study included consultants, midwives and counsellors.
- UK service provider British Pregnancy Advisory Service (BPAS) sent electronic information about the study to people from the Republic of Ireland who accessed their abortion services within the study timeframe and who had given consent to be contacted by BPAS' marketing department. BPAS' role was simply to introduce prospective participants to the study team; nonetheless, the project was subject to full BPAS governance procedures. The email contained a hyperlink to click on should the receiver want more information about the study (Appendix 1d). This took them to a secure, web-based form with full study information (Appendix 2c) and an electronic Consent to be Contacted Form (Appendix 3b) hosted on the Qualtrics platform administered by Trinity College Dublin. Those who wished to participate submitted the electronic form, which returned it directly to the research team.
- Termination for Medical Reasons is a support organisation for people who terminate a pregnancy for medical reasons. The Invitation to Participate (Appendix 1b), Participant Information Sheet (Appendix

<sup>11</sup> Negotiations were entered into with another hospital regarding acting as a third hospital setting for recruitment. Following the onset of COVID-19 the research team took stock of sampling procedures and capacity, having regard to the added processes introduced by COVID-19. It was determined that theoretical sampling procedures could be fully achieved within existing settings and the decision was taken not to proceed with the third site on pragmatic grounds.

2a) and Consent to be Contacted Form (Appendix 3a) were distributed to members of the organisation, asking for anyone who had accessed care in Ireland since implementation of the 2018 Act to consider taking part in the study.

## 3.4.i.vii Recruitment of Self-Referred Participants

Three participants encountered the UnPAC study outside of an interaction with a care provider or an abortion support organisation and expressed their interest in participation directly to the research team. These self-referred participants were provided with the Invitation to Participate (Appendix 1b or 1c), Participant Information Sheet (Appendix 2a or 2b) and Consent to be Contacted Form (Appendix 3a or 3b) and given time to consider participation. A member of the research team then contacted them to seek informed consent and arrange an interview.

# 3.4.ii Qualitative Study Data Set

A total of 58 participants were interviewed for the study from across the sites described above. Table 3.2 demonstrates the recruitment sites of participants, the vast majority of which were recruited via a care provider (n=55, 94.82%). One was recruited through support group Termination for Medical Reasons and three people contacted the researchers having heard about the study through the HSE website and wanting to contribute. Researchers included these three participants as their care took place within the study timeframe.

**Table 3.2.** Initial recruitment sites of study participants (n=58)

Recruitment site	n (%)
GP	21 (36.2)
Women's health clinic	11 (19.0)
Hospital	13 (22.5)
Pregnancy counselling	7 (12.1)
Self	3 (5.2)
British Pregnancy Advisory Service	2 (3.4)
Termination for Medical Reasons	1 (1.7)
Total	58

Approximately two-thirds (n=39, 67.2%) received their initial abortion care (i.e. first round of EMA pills/initial surgical procedure) in a community setting under 12 weeks' gestation (Table 3.3).

**Table 3.3.** Summary of study participants' gestational dates and sites abortion care was initially received (n=58)

Gestational date	Site where abortion care was initially received	n (%)
≤ 12 weeks	GP	25 (43.1)
	Women's health clinic	14 (24.1)
	Hospital	7 (12.1)
> 12 weeks	Hospital (Ireland) <sup>a</sup>	5 (8.6)
	Hospital/clinic (UK)	7 (12.1)

<sup>&</sup>lt;sup>a</sup> Includes one participant who qualified for care in Ireland but chose to continue the pregnancy.

Thirteen study participants accessed HSE-funded unplanned pregnancy supports (n=10) and/or post-abortion counselling (n=6). Table 3.4 reports the sociodemographic characteristics of the study participants. Most were aged between 20 and 39 years, while there was an even distribution of participants living in urban and rural areas. While the nationality of the majority of participants was Irish, a range of other nationalities were represented in the study including participants from various other parts of Europe and the rest of the world. Most participants had received second-level education.

Table 3.4. Sociodemographic characteristics of study participants (n=58)<sup>a</sup>

Sociodemographic characteristics	Category	n (%)
Age	18-24	10 (19.2)
	25-29	8 (15.4)
	30-34	8 (15.4)
	35-39	19 (36.5)
	40-44	7 (13.5)
Area	Urban	29 (50.9)
	Rural	28 (49.1)
Nationality	Irish	41 (70.7)
	Other European	9 (15.5)
	North American/South American/Irish-South American/European-South American/Asian/ African	8 (13.7)
Education level	Third level <sup>b</sup>	7 (13.5)
	Second level	45 (86.5)

<sup>&</sup>lt;sup>a</sup> Not all participants reported all characteristics. The specific "n" for each category is as follows: age (n=52); area (n=57); nationality (n=58); education level (n=52).

### 3.4.iii Limitations to the Data Set

The following limitations have been identified in relation to inclusivity within the data set achieved for the study:

- As research interviews were conducted verbally through English only, lack of proficiency in English was a
  potential language barrier, though English was a second language for some study participants;
- No Traveller people are represented in the study;
- No undocumented migrants participated in an interview;
- No participant in the study was under the age of 18, reflecting parameters set by Research Ethics Committees;
- No participant in the study was living out of home, including in emergency accommodation;
- No interview participant self-identified as transgender or non-binary;
- No participant in the study accessed care on the grounds of risk to the life or health of the pregnant person.

<sup>&</sup>lt;sup>b</sup> Includes participants currently attending third-level education and those with post-Leaving Certificate qualifications.

## 3.4.iv Qualitative Study Research Interviews

Interviews were conducted face-to-face following a semi-structured format at the outset of the study between December 2019 and March 2020. When the COVID-19 public health emergency set in, fieldwork was initially suspended until June 2020, after which it resumed using remote methods of voice or video calls via MS Teams or Zoom or phone calls, as sanctioned by the Research Ethics Committee of Trinity College Dublin.

Both face-to-face (n=9) and remote (n=49) interviews lasted in the region of one hour with some shorter and some longer in duration, according to the preference of participants. All interviews across all formats were recorded and transcribed for data analysis. Specific ethic of care issues featured in the research interviews in particular, and these are detailed below. Quotes are presented verbatim and pseudonyms are used throughout this report.

## 3.4.v Qualitative Data Handling and Analysis

Interviews were recorded using digital voice recorders with participants' consent. A professional transcription service with experience in health research was used to transcribe interviews. A confidentiality agreement was in place with the transcription service. Audio recordings were uploaded to a secure dropbox, which were deleted following confirmation of download by the transcription service. Once transcribed, the digital recordings used by the transcription service were destroyed. The transcription service then uploaded the transcribed interviews to the drop-box for download by the research team, after which they were deleted from the drop-box. The research team confirmed receipt with the transcription service, after which time the transcription service deleted their stored version of the transcribed interview. Transcribed interviews were stored on password-protected computers configured to Trinity College Information Systems and in compliance with General Data Protection Regulations (GDPR). To protect their identity, each participant was assigned a pseudonym. Care was taken not to assign pseudonyms that were the real names of any participants. Interview data was anonymised as appropriate under the Data Protection Act 2018 (Section 36(2)) (Health Research) Regulations 2018. Anonymisation was performed by a member of the research team following the protocol set out by the Irish Qualitative Data Archive<sup>12</sup>, whereby identifying information (e.g. place names, names of family members) was modified or redacted based on its potential to be anonymised and/or necessity for the research.

As set out above, GT methods were employed for the study, which privilege empirical data in constructing an analytical framework over existing theories or frameworks. While a synthesis of literature and key existing frameworks were referred to, an emphasis on openness in the design of data generation and analysis facilitated new context-specific insights emerging. The method is designed to facilitate understandings and meanings emerging from empirical data generated in the study, and a central feature of the method is simultaneous data collection and analysis.

Interviewing began early in the research process and analysis began with the first interview. GT anticipates that the researcher will engage in a process of "memoing" after each source of data is collected, whereby they write down their initial reflections and observations on the data and its meaning as well as identifying future direction for data collection. These memos can also be consulted in later stages of analysis, for example to check coding against earlier observations. In this study, memoing was performed as a collaborative oral process. This entailed interviewers debriefing with at least one other member of the research team after each interview. Electronic records were kept of these oral memoing sessions. There were some benefits to this stage being undertaken in a collaborative oral manner rather than in a lone written one. Firstly, it facilitated the interviewer to discuss their initial observations and reflections with

another member of the research team and seek their input and feedback. Secondly, and of particular importance in this study, it enabled the interviewer to debrief regarding their emotional response to what was occasionally distressing data, as well as consult with another team member regarding the appropriateness of their response to disclosures of concern (e.g. domestic violence).

Anonymised transcripts were uploaded to NVivo qualitative software. Data was coded for analysis using NVivo following the analysis procedures set out by Charmaz (2014). Specifically, transcripts were read after each interview and open line coding was undertaken with early-stage interviews, involving the researcher capturing emerging themes at a fine level early in data generation. Collaborative coding occurred throughout, with the research team meeting regularly to discuss and cross-check themes as they emerged and developed. Data collection proceeded informed by early-stage analysis and new data was compared with data assigned to existing codes to identify similarities and differences as well as to check for new insights emerging as data generation progressed. As noted above, some themes emerged from the data as new insights pursuant to the GT procedures, while other themes related to pre-existing frameworks and models that were purposively pursued in research interviews, reflecting the applied nature of the study.

As data analysis progressed and codes became more established and filled out, the codes were synthesised, compared and contrasted to develop abstract categories that elevated codes to explanatory processes. Relationships between categories were considered, explicated out and assessed. NVivo's analysis tools were used to assist with this process, with cross-tabulations performed to assess potential relationships between categories, and parent and child codes established as hierarchical relationships became evident. Categories were conceptually developed and integrated through continually checking them against the empirical data generated in the study to validate and refine interpretation to the point where understanding was saturated, indicated by reaching the point where no new insights were emerging. Notably, at a later stage of analysis a member of the research team who had not been involved in data collection or analysis reviewed and synthesised the memo records and presented this synthesis to the members of the research team responsible for data analysis. This process gave the research team an opportunity to reflect on their analysis in light of their previous observations generated during data collection, and consider where categories may have needed further review. The integration of categories was directed towards revealing causes, conditions and consequences of the process under study. This method of data analysis leads to conceptual saturation when no new categories are generated from interrogation of the data, which signals the conclusion to the project is reached.

# 3.5 Work Package Four: A quantitative and qualitative analysis of Women on Web (WoW) data

Once the research team began this study, it became clear from official data (Department of Health, 2019, 2020) that since implementation of the 2018 Act in Ireland, most people receive abortions in Ireland however, there continues to be a proportion of people accessing abortion care outside Ireland. In order to be fully comprehensive in this study, the research team made the decision to conduct further research in this area in order to fully incorporate the experiences of people accessing abortion outside the jurisdiction. This section outlines work package four, a study which set out to examine experiences of service users accessing telemedicine abortion care outside the jurisdiction of Ireland, since the enactment of the 2018 Act.

Within the overall UnPAC study, the team undertook this parallel work package focusing on continued requests from Ireland to online telemedicine abortion provider, WoW following enactment of the legalisation. The aim of this work package was to conduct a descriptive study of the number of women and people accessing telemedicine abortion care from outside the jurisdiction and to account for their experiences.

WoW is a non-profit organisation providing safe online telemedicine abortion care to regions with limited access. People contact WoW by filling out an online consultation form. If clinical criteria are met, a physician, outside the Irish jurisdiction, prescribes according to the WHO recommended regimen for EMA up to 13 completed weeks' gestation. WoW provides guidance on taking medication, monitoring the process, possible adverse effects, and how to respond if these occur. A trained help desk team provide help throughout the abortion process (Women on Web, 2021).

In this work package we examined patterns of WoW consultations by people from Ireland using data for the full years of 2019 and 2020. As the data set included March to December 2020, examination of the impact of COVID-19 on consultation patterns was possible.

We received ethical approval for this study from Trinity College Dublin School of Social Work and Social Policy Research Ethics Committee, approved on 05/11/2019. Informed consent for analysis of service-related data was provided by service users at the time of submitting the form. The Data Protection Impact Assessment (DPIA) process described below in Section 3.9 also relates to the collection and storage of data in this study. All data was collected and stored in line with GDPR guidelines.

WoW set out on their website the information they collect on service users. We applied data on all contacts from Ireland between 1 January 2019 and 31 December 2020.

WoW provided irrevocably anonymised quantitative and qualitative data relating to contacts from Ireland to their service between 1 January 2019 and 31 December 2020. The quantitative data set comprised responses to WoW's online consultation form where users self-report sociodemographic characteristics, pregnancy history, and reasons for contact. This data was provided in MS Excel and exported into Statistical Package for the Social Sciences (SPSS) v26 for analysis. The data was cleaned to ensure people not resident in Ireland and duplicate contacts were removed. We knew that some contacts from Ireland provide delivery addresses in Northern Ireland or Britain to avoid detection by Irish customs, but these were identified as Irish residents as they had selected "Ireland" as their home country prior to inputting the delivery address.

Frequency of completed requests was compared between 2020 and 2019. To determine if there was any change during the COVID-19 restrictions period, differences from March to June 2020 (when restrictions applied) and March to June 2019 (when they did not) were assessed. During this time, the Irish remote model of care was implemented on 6 April 2020. Comparison of completed requests between October and December 2020 and the equivalent months in 2019 assessed if the frequency of completed requests had changed in the latter part of 2020, when the remote model of care had been in operation for a longer period of time. To compare periods in which COVID-19 was not of concern in Ireland, a further analysis of differences between January and February 2020 and January and February 2019 was also performed. Service user characteristics were compared between 2020 and 2019. Differences in reasons for contact were compared across all time periods. In addition, reasons for contact by women who received abortion pills from WoW in 2019 and 2020 were compared to those who did not. Chi-square tests were performed on categorical variables. All tests were two-tailed, with significance set at *p*<0.05.

The qualitative data set was generated from email correspondence between WoW and women from Ireland requesting their service between 1 January 2019 and 31 December 2020. After the change in Irish legalisation, emails received by WoW from Ireland were responded to with an automated email with information on how to contact My Options. People still seeking online provision were invited to explain why they needed this, given the local availability of abortion. Email correspondence was anonymised and

compiled by WoW into MS Excel and shared with the research team. An inductively generated codebook (Appendix 6) was created, and thematic analysis applied to the data (Clarke & Braun, 2013). Thematic analysis was used for this component of the study as the most appropriate method, having regard to the nature of the data and how it was generated.

# 3.6 Overall Research Ethics and Data Management Procedures

The qualitative interview and WoW studies (work packages three and four) were granted ethical approval on 05/11/2019 by the Trinity College Dublin School of Social Work and Social Policy Research Ethics Committee, which is overseen and governed by the Research Ethics Policy Group of Trinity College Dublin. Revised ethics approval was granted by the Research Ethics Committee on 08/05/2020 and 21/04/2021 when modifications responding to COVID-19 restrictions were introduced, including use of electronic format information sheets and consent forms as well as remote interviewing methods.

Ethical approval was also secured from two hospitals sites as well as from BPAS, all settings where data collection was carried out with local Research Ethics Committees in place.

The study underwent a full Data Protection Impact Assessment (DPIA; Appendix 5) in Trinity College Dublin under the Trinity College Dublin's Data Protection Office, to ensure compliance with GDPR obligations. The DPIA also served to determine if the concept of "privacy by design" was adequately embedded into the project procedures, to assess all the risks involved in the processing of participant data and to consider whether the processing envisaged by the project was necessary and proportionate. As part of this process, the requirements of 'Policy on Good Research Practice' (Trinity College Dublin, 2014) and the Data Protection Act 2018 (Section 36(2)) (Health Research) Regulations 2018<sup>13</sup> were adhered to for implementing controls in relation to the use of personal and sensitive personal data. All researchers working on this project participated in Trinity College Dublin's GDPR online training in advance of beginning work on the project.

Specific ethical issues arising in this research related to consent, sensitivity of the topic, and provision of support resources to participants if a need was identified within the study. Detailed consideration of issues relating to consent (to ensure GDPR compliance) was facilitated through consultation with the Trinity College Dublin Explicit Consent Checklist, against which researchers can check their research consent form. All participants were fully informed of how their data would be handled and stored; specifically, that their audio-recording would be transcribed and then deleted, and their transcription anonymised and uploaded to password-protected computers accessible only by the research team in line with GDPR requirements. Participants were advised that in accordance with GDPR they were entitled to access their data and withdraw from the study at any stage without prejudice. Participants were advised that their interview data would be retained by Trinity College Dublin for five years, after which time it would be deposited in secure data repositories, like the Irish Qualitative Data Archive, hosted by Maynooth University, to be available for future research related to this topic, under strict access controls.

Access to interview transcripts following upload to data repositories outside Trinity College Dublin required consideration from both data protection and ethical perspectives. Access will only be permissible by request to the study's Principal Investigator (PI), and is subject to their satisfaction that the confidentiality of participants is safeguarded in adherence with the ethical approval governing this project.

Ethical issues raised during the recruitment stage related to providing guarantees of confidentiality and anonymity (attended to with reference to GDPR regulations), assuring participants that their decision

regarding participation would not in any way affect their access to care services, allowing participants adequate time to consider participation before giving (or declining) consent to interview, ensuring consent procedures created both a figurative and literal distance between the care service and the research, and ensuring participants were fully apprised of their right to withdraw from the study at any time. Importantly, the consent process for this study was designed to ensure health practitioners would not know whether a person had agreed to participate in the study or not. This was achieved with a two-stage consent process. In the first stage, the health practitioner provided the potential participant with information about the study and asked if they would consent to the researcher contacting them to fully inform them of the study. The second stage of the consent process entailed the researcher contacting the participant, reiterating the full Participant Information Sheet, completing the explicit consent process and asking the participant to sign the Study Consent Form (Appendix 4). For remote interviews participants received the Study Consent Form (Appendix 4) electronically and their consent was obtained and recorded verbally prior to the commencement of the interview. Thus, the care provider was unaware of the person's decision regarding participation.

Age was an ethical factor in this research. Abortion services are available to people between the ages of 16 and 18 without the involvement of a parent or relevant adult, if the doctor is confident they understand the information and can give valid consent. Those aged 15 years and under who choose not to involve a parent or relevant adult can be offered an abortion by a doctor if there are exceptional circumstances following assessment. For research purposes people under 18 are considered a vulnerable group in relation to consent, and therefore the study only recruited participants over the age of 18.

Ethical obligations relating to consent are raised by child protection legislation regarding data protection. A variety of issues, such as the need to report child welfare concerns to appropriate authorities, may compromise a person's rights to confidentiality and privacy. For this reason, a person can never be promised absolute confidentiality where a retrospective disclosure is made by an adult. However, confidential information should only be shared with others on a "need-to-know" basis and only in circumstances that are completely justifiable. Such circumstances may arise if there are reasonable grounds for believing that:

- There is a risk of harm to a child;
- There is a risk of harm to other children or persons;
- It is mandated by law or a court order to so disclose;
- It is in the public interest to so disclose.

Researchers drew on supports provided through the HSE My Options to collate a set of resources to inform people about, and refer them to, medical and counselling services within the unplanned pregnancy and abortion care services infrastructure. These were made available as appropriate if participants indicated a need for information, supports or resources during interviews or in any follow-up contacts.

Within the study there were disclosures of intimate partner violence (n=1) and sexual assault (n=1). In both cases the person was over 18 years of age when the harm occurred. In both instances the researcher took time during the interview to listen sensitively to and acknowledge the harm the person making the disclosure had endured. The researcher offered resources they had assembled for such an eventuality, comprising advice regarding reporting and contact details for dedicated support services in the area of sexual violence. In both instances the researcher established that the people reporting the harm were already linked in with services and did not feel the need for the researcher to link them with anything further. On both occasions the researcher conducting the interview debriefed with their colleague to re-assess if

their decision that the person was being supported was sound, which was confirmed.

During interviews an ethic of care was demonstrated towards participants having regard to the sensitivity of the topic. Participants were reassured that the interview was not in any way exploring or asking them to defend the decision they made to have an abortion, but was focused on their experiences of the services and supports they sought, encountered and felt the absence of as they availed of abortion care and unplanned pregnancy support services. Participants were reassured that all reasons, thoughts and feelings were valid to express. Venues, times and format for the interview were selected with reference to participants' needs and preferences.

# 3.7 Overview of Methodology

There are four work packages in this study, each comprising a different methodology. The purpose of the policy case study was to contextualise the topic of abortion in Ireland within the policy and legislative literature that had arisen since implementation of the 2018 Act. The literature review sought to contextualise the topic of abortion in Ireland more broadly, and to present and discuss the most recent literature on the topic in Ireland. Both work packages helped inform the development of the study design of work package three, the large qualitative study comprising interviews with service users.

The data for work package three's study primarily comprised semi-structured, qualitative interview data generated through either in-person, face-to-face interaction, or remote interaction using video platforms of MS Teams or Zoom, or voice-only interaction using telephone, according to the preference of participants. Recruitment of participants took place in a range of community, primary care and hospital or tertiary care settings, reflecting the service delivery settings relevant to the focus of interest for the study. The final work package sought to compile evidence on the accessing of telemedicine abortions by women and people in Ireland from a provider outside the jurisdiction.

A research ethics review was undertaken by committees at Trinity College Dublin, an urban and rural maternity hospital and BPAS UK, with approval secured from each for the original design and for modifications implemented in response to COVID-19 public health restrictions. Data management procedures were attended to through a rigorous DPIA procedure overseen by the Data Protection Office at Trinity College Dublin and by a maternity hospital site (name removed to protect anonymity), in line with the Data Protection Act 2018 (Section 36(2)) (Health Research) Regulations.

Data analysis of the qualitative interview study followed GT principles, which privileges empirical data in constructing an analytical framework over existing theories or frameworks. This study employed constructivist GT methodologies designed to optimise opportunities for novel insights emergent in closely observed empirical data. While a synthesis of literature and key existing frameworks were referred to, an emphasis on openness in the design of data generation and analysis facilitated new, context-specific insights emerging. The method is designed to facilitate understandings and meanings emerging from empirical data generated in the study, and a central feature of the method is simultaneous data collection and analysis.

Chapter 4 presents the findings from the literature review work package. Findings in Chapters 5 to 12 include some novel insights achieved through pursuing the GT procedures, as well as findings relating to pre-existing frameworks and models purposively pursued in research interviews, reflecting the applied nature of the study. Findings in Chapter 13 present findings on the WoW work package which involved examination of quantitative and qualitative data collected by an online provider of early medical abortion

pills, providing insight into the continued use of such services by people in Ireland since the implementation of the 2018 Act.

On completion of the study, the researchers presented preliminary findings to the HSE National Contracts' Office, HSE Primary Care Services, NWIHP, the Department of Health's Bioethics Unit and Maternity and Gynaecology Policy Unit, the Irish College of General Practitioners, Southern Task-Force On Abortion & Reproductive Topics (START) GPs, the hospitals who had facilitated study fieldwork, WHCs (the Irish Family Planning Association and Well Woman), the My Options service and the National Women's Council of Ireland. The purpose of these presentations was to disseminate early emerging findings to key stakeholder groups who had facilitated the research study and acted in an advisory capacity. The format of presentations was to inform stakeholders, but did not entail involvement of stakeholders in any process of analysis and or the drawing of conclusions.



# Literature Review

This literature review is concerned primarily with referencing literature on abortion provision, focusing particularly on the Irish context since the implementation of abortion services in Ireland in January 2019. The reviewed literature details Irish providers adapting to legalisation, as well as documenting what issues have been highlighted in relation to availability, accessibility, acceptability or quality regarding unplanned pregnancy and abortion care services.

# 4.1 Issues Highlighted with Current Unplanned Pregnancy and Abortion Care Provision in Ireland

On 20 December 2018, following the decision via referendum to revoke the Eighth Amendment of the Irish Constitution, the Irish government signed into law The Health (Regulation of Termination of Pregnancy) Act (2018) which permitted less restricted access to abortion in the Republic of Ireland from 1 January 2019 than prior to this (IFPA, 2020a; Government of Ireland, 2018). This law allows abortions up to 12 weeks' gestation on request, and later abortion is lawful in the case of fatal foetal abnormality or if continuing the pregnancy would cause serious harm or death. This is accomplished through several "pathways" of abortion access: early medical abortion through GPs and WHCs in the community up to nine weeks, referral to hospital for abortions from 9-12 weeks, and abortions after 12 weeks in limited circumstances, also in hospital. Abortion remains criminalised outside the grounds of this Act (IFPA, 2020a). As this literature review will demonstrate, research on the effects of the 2018 legislation has identified some issues in relation to availability, accessibility and acceptability, namely waiting periods, gestational limits, uneven geographical distribution, and the effects of conscientious objection on providers and patients.

Recent literature has also demonstrated issues providers have raised including stigma, and that lack of appropriate training is impacting on their ability to practice, as well as their own wellbeing (O'Shaughnessy et al., 2021a; 2021b; Dempsey et al., 2021). Notably, in the first year proceeding legislative change, only 10% of staff at a tertiary hospital providing terminations noted they had received any training on abortion provision, though almost all survey participants "expressed a wish for training" (O'Shaughnessy et al., 2021b). With regard to methods of provision, a study details a clinical research trial on manual vacuum aspiration (MVA) for completion of miscarriage as well as first trimester abortions at the Rotunda hospital in Dublin (Hayes-Ryan et al., 2021). This innovation shows that MVA is feasible and rated highly by those who chose the procedure over other methods, and the study has implications for the expansion of MVA services across Ireland as an alternative to medication abortion (Hayes-Ryan et al., 2021). The inclusion of MVA services offers more choice to women and pregnant people seeking abortion care, and shows potential for the normalisation of abortion services more broadly, as more types of services and choice are being offered.

In relation to s.11 of the 2018 Act, foetal medicine specialists report fear and uncertainty over deciding when a foetal anomaly is fatal and when it is severe, or when specifically it will cause death – as women and pregnant people with a severe non-fatal diagnosis will face no recourse beyond travel to the UK for a

termination (Power et al., 2021). This need to travel is noted as resulting in an "immobility" or "stuckness" for those who cannot travel, causing the Irish abortion law to magnify existing marginalisation such as migrant status, and urban/rural divide (Side, 2020).

### 4.1.i Waiting Periods

A legal requirement of the 2018 Act is that while the gestational age is certified at the first doctor appointment, a pregnant person must return three days after certification to proceed with the termination. This mandatory waiting period was recently described as "presumptive and patronising", as it suggests pregnant people are not certain of their decision (Mullally et al., 2020). In support of this position, international evidence shows those who have made the decision to seek a termination rarely change their opinion. In the US, 85% of people requesting abortion at two centres reported they were certain of their decision and did not require pre-abortion counselling (Baron et al., 2015). To access an abortion two visits to a doctor are required, potentially invoking a barrier as this is an added requirement of time, childcare and access. The enforced waiting periods also create uncertainty for doctors as this can lead patients to exceed the 12-week threshold for abortion and being unable to access abortion in Ireland (O'Shaughnessy, 2021a). The Irish legislative system does not have any provision for individuals who exceed the 12-week limit due to waiting periods, possible mis-certification of doctors, or limited appointment days and times due to a lack of providers.

#### 4.1.ii Gestational Limits

When a patient exceeds the 12-week limit on abortion care in Ireland, barring fatal foetal anomaly or serious risks to life or health of the pregnant person, there is no way to access abortion in Ireland. This 12week gestational age (GA) limit presents several problems for those seeking access to abortion services. A mixed-methods, five-year study in the UK, The Netherlands and Spain showed that early access to abortion is not always sufficient to meet people's reproductive health needs. In fact, the primary reason people travelled abroad for abortion care was because they had exceeded GA limits in their own country (79% of respondents). There were many reasons why GA limits were exceeded including irregular periods, lack of clear signs of pregnancy, lack of information about abortion care, or miscalculation of GA by health professionals. The authors concluded that GA limits restrict access to abortion care, especially for those who encounter other barriers in the termination process, and therefore their reproductive needs were not met (De Zordo et al., 2020b), de Londras (2020a) argues that the 2018 Act is significantly dependent on medical judgements to establish if a person qualifies for lawful abortion care, for instance the accurate certification of GA by the GP. Certification can be delayed if an ultrasound is requested to confirm GA, and this combined with the mandatory three-day waiting period could exceed the 12-week limit (de Londras, 2020a). As discussed, because GPs must refer patients between nine and 12 weeks' GA to a hospital setting, this is a further limitation on abortion care as there are only 10 hospital units nationally currently providing this service - still requiring travel for many people.

### 4.1.iii Uneven Geographical Distribution

Following the legalisation of abortion services in January 2019, 373 GPs and 10 maternity units in Ireland registered with the HSE to provide abortion services. Roughly 400 GPs (as of December 2021) now provide the service, but concerns remain that this represents only 16% of the 2,500 GPs in Ireland. Furthermore, just 11 of the 19 maternity units are providing full abortion care in eight of the 26 counties<sup>14</sup>. There are areas throughout the country where services are limited; for example, services are particularly sparse in the northwest and until recently there were no doctors registered to provide services in Sligo (Kennedy, 2021). The lack of abortion services in all maternity hospitals is considered to place an unfair burden on providing hospitals (Boylan, 2019).

These infrastructural shortcomings risk abortion services not being available in practice because they are inadequately geographically distributed. The Irish Human Rights and Equality Commission (IHREC) recommends that regional gaps in services must be identified and remedied, otherwise it risks disproportionally impacting on particular groups of women in the state (IHREC, 2018). In addition to uneven geographic distribution of care, a review of abortion services at a tertiary hospital in the first year of provision concluded that only a small proportion of eligible hospital consultants participated, "with two providing care for half the cohort...a service run by such a small number of physicians is unsustainable" (O'Shaughnessy et al., 2021a). The reasons for the sparse provision of services are complex.

# 4.2 Conscientious Objection

Conscientious objection refers to the refusal to participate in abortion services because of religious, moral, philosophical, or ethical beliefs. This mechanism is built into Irish abortion law through the 2018 Act. A study conducted following implementation of the service showed one in four (24%) members of the Irish Society of Obstetric Anaesthesiologists reported they would conscientiously object to providing anaesthesia for an elective termination of pregnancy (MacDonncha et al., 2020). Elsewhere, Irish foetal medicine specialists (FMSs) who perform abortions post-12 weeks due to fatal foetal anomaly "acknowledged a right to conscientious objection [but] were frustrated with what they called 'conscientious obstruction'" affecting their ability to provide timely care for their patients (Power et al., 2021, p.681). While conscientious objection affects the number and geographic dispersal of providers, stigma among colleagues affects this as well – furthering abortion stigma and serving as an added obstacle to normalising abortion services across Ireland (Dempsey et al., 2021). As abortion is not fully decriminalised for doctors, the fear of incorrectly diagnosing a fatal foetal anomaly and facing criminal repercussions is a factor for some FMSs, and may contribute to the low percentage of maternity hospitals providing abortion care (Power et al., 2021).

## 4.3 Abortion Care and COVID-19

Globally, the COVID-19 pandemic has amplified existing health and economic inequalities by threatening access to health services. Abortion is an essential health service that cannot be delayed, but the pandemic has exposed how services may be curtailed. Different regions and countries may be more impacted than others at different times, but at the service-provision level three key issues have been identified: firstly, a reduction of sexual and reproductive health care workers as they may be diverted to other services; secondly, services suspended in an overwhelmed system; and thirdly, shortages of medications are possible due to closed factories disrupting supply chains (Ahmed & Sonfield, 2020). At the individual level, people may have a fear of taking public transport or visiting health centres during a pandemic. Incomes may be negatively impacted if workplaces are closed, and access to childcare may be limited if childcare centres or schools are shut due to the pandemic (Ahmed & Sonfield, 2020). In addition, travel to another jurisdiction to seek care if gestational age limits are exceeded may be impossible if there are restrictions on travel during the pandemic (De Zordo et al., 2020a). Revisions to models of care were necessary to ensure that people continued to have access to abortion services during COVID-19 restrictions.

Uniquely in Europe, De Zordo et al. (2020a) comment that measures taken in Ireland, France, and Britain (excluding Northern Ireland) have led the way by permitting self-managed early medical abortion (EMA). In response to the pandemic, a revised model of care was implemented in Ireland from 6 April 2020, which allowed for remote or telemedicine consultation with a medical practitioner for the duration of the COVID-19 public health emergency. The consultation, certification and aftercare can be performed using a telephone call or video conferencing. At the first consultation the doctor certifies the pregnancy does not exceed 12 weeks, and if gestation is between nine and 12 weeks the person is referred to a hospital.

#### 4.3.i Telemedicine Provision

There is a long history of people in Ireland using telemedicine to self-manage abortions (Spillane et al., 2021). Prior to legalisation of abortion in Ireland, a simple Google search could return information about how to access telemedicine abortion services (Sheldon, 2016). A 2017 study of 1,000 women in Ireland and Northern Ireland who underwent EMA with supports found that outcomes compare favourably to clinical settings, with 94.7% reporting successfully ending their pregnancy without medical intervention (Aiken et al., 2017a). Since legalisation, a 2020 study with telemedicine abortion providers WoW show that half as many women contacted the service in the three months following legalisation as in the same period a year prior. Although the number of women seeking abortion outside the state jurisdiction decreased by half, these patients cited privacy, stigma, and avoiding protestors, as well as abusive relationships and undocumented status as reasons they sought telemedicine abortion care (Bras et al., 2020). Whether to mitigate barriers of accessing abortion care in Ireland, or because patients preferred the ease of telemedicine care, accessing abortion through telemedicine continued post-legalisation, before the beginning of the COVID-19 pandemic.

With the onset of the COVID-19 pandemic, Ireland adjusted the model of care for people seeking abortion services - telemedicine was introduced to reduce face-to-face contacts with providers, and facilitate people to stay home and not make unnecessary journeys. Spillane et al.'s (2021) article detailing the shift into telemedicine service notes in great detail the IFPA's role in engaging with the government to allow abortions to continue through telemedicine. This did not require amendment of the original 2018 Act, suggesting that abortion care is seen as essential health care, a potential step towards the normalisation of abortion care. Under these steps, the IFPA shifted to providing the two consultations through phone, and then arranging collection of the home care pack from the provider - while still providing for face-to-face medical consultations or counselling sessions when indicated. The IFPA's efforts to pivot into telemedical services occurred alongside similar efforts made by the Irish health service's Clinical Lead in Termination of Pregnancy. In addition to mitigating COVID-19 concerns, respondents also found the telemedicine abortion route was effective for a wide variety of reasons, including increasing privacy, reducing/eliminating transport or childcare costs, and facilitating earlier access to the service (Spillane et al., 2021). While more research is needed to best articulate the long-term benefits or trade-offs with telemedicine provision in Ireland, this work is promising and shows a potential new path for abortion services in Ireland in light of the upcoming legislative review of the operation of the 2018 Act.

# 4.4 Chapter Overview

This chapter reviewed literature on abortion provision in the Irish context since the implementation of abortion services in Ireland in January 2019. The reviewed literature details providers adapting to legalisation, issues in relation to availability, accessibility and acceptability, and innovations in the Irish model of care during COVID-19 when a remote model of care was introduced.



# Role of My Options in the Abortion Care Pathway

# 5.1 Role of My Options in Unplanned Pregnancy and Abortion Care Pathway

This chapter presents the findings of the analysis of data relating to women accessing care under s.12 of the 2018 Act, that is women seeking abortion care up to 12 weeks' gestation, which is permitted without restriction. Within the data set, 46 of the 58 participants took part in in-depth interviews who had accessed abortion care under the 2018 Act between its enactment on 1 January 2019 and the close of data collection in August 2021. Of the 46 participants, 25 received care in GP settings, 14 accessed care in women's health clinics while seven accessed care in hospital settings. Analysis of this care pathway is presented over chapters 5 to 10, beginning with presentation in this chapter of findings relating to the My Options information and counselling helpline.

The key functions of My Options within the unplanned pregnancy and abortion care pathways are to provide people seeking care with names and contact details of doctors providing termination of pregnancy; to provide them with information about all options regarding pregnancy including termination of pregnancy, adoption and/or parenthood; to provide listening support; and to offer telephone counselling if requested and/or details of community-based pregnancy counselling services.

The My Options service is provided by accredited professional counsellors, with a minimum of three years of counselling experience post-graduation. All counsellors have a professional counselling qualification and most counsellors employed within the service have previous experience of working with services users with unplanned pregnancy and/or post-abortion. Prior to employment as a counsellor within My Options, training is provided on unplanned pregnancy counselling, post-abortion counselling and telephone counselling.

The counselling sessions within My Options are available by appointment only. When counselling is requested a counsellor is allocated to the client and an appointment is offered. Further sessions are scheduled on a weekly basis and in accordance with the person's need.

The service also provides a telephone interpreter service available for information and support in 240 languages. My Options is available to the deaf community via the Irish Remote Interpreter Service and some members of the deaf community have used the Irish Text Relay Service to engage with My Options.

Analysis of how My Options featured in interview data is presented below encompassing people's pathways to the service, assessment of how well the service met their needs and issues identified with how this component of the care pathway operates.

In addition, the care pathway for EMA in community settings includes provision of the My Options 24-hour nurse helpline as a support to providers and service users. According to data collected by the SHCPP in the

period from 1 January 2019 to 31 December 2019, there were 2,793 calls directly to the My Options 24-hour nurse helpline regarding abortion care. In the second year of operation of the service (from 1 January 2020 to 31 December 2020) there were 2,146 calls directly to the My Options 24-hour nurse helpline. The data collected by the service shows calls were made for the following reasons: querying whether an abortion had been completed; advice on pain relief; advice after taking first medication; advice after taking second medication; query on symptoms; and reassurance or query on aftercare. Some callers required an Emergency Department or hospital referral, while some callers were referred to their doctor. Very few calls required immediate referral to 999 (National Ambulance Service)<sup>15</sup>. This chapter also outlines the analysis of data pertaining to participants' experiences of using this element of the My Options service.

# 5.2 Pathway to My Options

People's usual pathway to My Options is through the HSE website, often reached using an internet search engine – 'Google' features ubiquitously. Search engines often return My Options as a top search result and people remarked that seeing HSE as host for the service validates and reassures them about its legitimacy.

I googled abortion Ireland. And My Options was first and it was HSE so I knew.

The HSE website directing people to My Options was described as well laid out, and containing sufficient information to meet people's needs when seeking out information regarding unplanned pregnancy and abortion care.

I actually thought the literature was very well written and very clear.

Maria

The information provided on the website about each stage of the abortion process was considered comprehensive and helpful to have available to continuously refer back to:

But no I thought the information was, I thought it was good, like it literally laid everything out, even like after I took the test, I was like "oh what do I do?" after I took the abortion pills and like had it all there and I was like "ok cool".

**Therese** 

While the general consensus was that My Options was accessible and the website was informative, for Grace the website was unclear. She also found navigating the phone line – initially answered by an automated service asking callers to select an option for either the My Options 24-hour nurse helpline or My Options – off-putting and frustrating, saying she was ready to chuck [her] phone out the window because it was just so painful.

There was a good sense of general awareness of My Options by people who had grown up, or lived for some time, in Ireland. Some recalled discussion of the service during the legal changes, while more generally people were able to recall the service when they needed it, suggesting public information campaigns have brought awareness to the service. As Elaine explained, whether you use the service or not, it was comforting to know it is there for support: It was nice to know that [I] could just ring them up and there was nurses on the phone or therapist if [I] needed them.

Often, My Options is the first point of contact with services.

An hour after I did the test I rang My Options.

**Brie** 

When I first found out, at first I called the agency helpline and I talked to them for a bit and they kind of like, gave me like options, and they also did a bit of like counselling.

Sarah

Many described waiting until they had decided on whether they would proceed with or terminate the pregnancy before phoning My Options, and were not seeking the support of counselling services for their decision-making process.

I went on My Options, the website, you know just to have a look. To be honest I phoned them and then chickened out of phoning them, I dialled it and then I hung up like because I felt at that stage, I suppose I felt I could be easily, I wasn't certain of my own thoughts so I wanted to make sure I was certain of that before anything else.

Serena

Some participants had been in contact with hospitals or doctors before contacting My Options. Pippa had presented at a hospital with bleeding in early pregnancy and explained she wanted to access abortion care. The hospital was not a provider and had only confirmed this to Pippa after two repeat visits for a queried miscarriage. On her third visit she was given the number for My Options:

I explained to the girl on the phone what had happened, briefly. I said "I've just walked out of the hospital to ring you to find out if you can help me because they didn't" and she said "what area do you live in?" She was extremely helpful and so calm and she said "look take a minute, take a breath", she was like "what's happened is awful" and she was like "I'm here to help."

**Pippa** 

Some people presented at GPs without having contacted My Options and GPs encouraged them to contact the helpline following their first consultation for support with their decision. Serena felt hesitant at this suggestion, did so and assessed the response as *nice*, *really supportive*. Another woman described how she first consulted her own GP before contacting My Options, interpreting the advice on the website that *the first thing you should do is go to your doctor to confirm you are pregnant* (Quinn). In another instance, a woman first connected with online telemedicine services outside of Ireland. They sent her a reply email with contact details for My Options, which she then called.

Stigma attaching to abortion for some women encompassed a sense of shame that made them hesitant about calling the helpline:

First it's shame of calling anyway to My Options. ...I think it's within me but there is shame because it's so ideological [a] matter. You know, here to us, you know how you think in [my home country]. And it's still stigma from it, I don't know how it is here because I don't speak with anybody.

**Fiona** 

Fiona further explained how her reluctance to contact the service featured as concern that someone would try to change [her] mind.

# **5.3 Assessment of My Options**

In reflecting on their experience of using the My Options service, women were overwhelmingly positive about the response they received and the service provided. Terms they used about the service were that it was straightforward, caring, sensitive, helpful, understanding, lovely, like talking with a friend, and well-informed. Women reported it as a service that had time to listen, with staff trained to respond to people dealing with an unintended pregnancy and considering or seeking abortion.

I was pleasantly surprised at how straightforward and how caring it was. The people that I spoke to were very sensitive and helpful ... rather than it just being a sort of a call service, a helpline with a standard busy person on the end, it felt like someone who had time to listen and who had training and understanding of who might be calling. Yeah, I don't think I was particularly stressed or agitated but I did notice and appreciate.

Áine

While women overwhelmingly felt the response of My Options and the service was helpful and supportive, a few found the format of engagement over the telephone less satisfactory. Jade felt as though *they're a bit robotic in their response back*, noting uncomfortable silence during her call – *they ask you how you're feeling and then you tell them and then they don't really say much back on the phone.* 

The telephone format as a remote form of communication served to alleviate women's reservations about contacting services and being judged. Women reported the telephone as a safer space to contact services than a face-to-face format might have:

I think I was more, not confident but I was more at ease that it was on the phone. I think it would have been different if it was face to face. ... Again, the fear of being judged is there. Whereas on the phone they don't know who you are, they don't know anything about you. You are only hearing a voice whereas I think if it was somebody face to face and you know trying to analyse what's going on in their mind.

Katherine

Women often felt relief after reaching My Options. Part of that related to reassurance that they were *not* the only one – to get pregnant when they didn't want to, to have a second unintended pregnancy, to need abortion care – and also reassurance that everything would be ok as help is available. This aligns with what women themselves wanted and needed.

I rang My Options because I was ... I was mortified so I just needed reassurance that this happens. And I was so embarrassed, I was really ashamed, like I was. Yeah, I was really upset, really upset about it like. ... But anyway, I rang My Options anyway, I said "I'll just ring them just to see" and they were so reassuring that it happens and especially with COVID, women were meant to get their coil put back in and all different situations. That reassured me then, you know, that I wasn't.

Helen

Like Helen, when Katherine discovered she was pregnant again and decided on abortion she was similarly reluctant to contact the GP provider who had provided abortion care to her on a first unintended pregnancy in the previous year. Katherine looked to My Options to help her consider this and described feeling reassured by them:

The lady at the My Options said that if you had a good experience with him, you know he wouldn't judge you anyway. But if you didn't feel comfortable there's other, you know there's other GPs as well. And her just reassuring me was good.

Katherine

Some described feeling fearful calling the service, being nervous and concerned they would encounter judgement for seeking abortion care. The tone of the response by staff quickly allayed such fears:

It was like when I sat at the kitchen with my friend that I talked to ... I remember that nurse that I called My Options, very nice and it was first because I was scared to call because of the judgement, how she spoke with me it was first, it was ok, "it will be ok, you will be ok."

You were nervous or reticent phoning but the way she spoke.

She showed me that it's not a problem.

**Fiona** 

Embedded in women's talk were portrayals of their feelings and sense of self when making the first effort to seek help or care to resolve the pregnancy. Feelings women portrayed included confusion and being alone.

I am really thankful that like the women I was talking to were non-judgemental and, you know, they understood what I was probably feeling at the time, confused, alone, like I made sure that nobody was at home when I was talking to, you know, I don't want anybody to hear what I was saying. Because my voice was like very, very low.

Katherine

## 5.3.i Counselling Through My Options

While many depicted their engagement with My Options as principally to do with getting information on accessing abortion care and providers, some also said counselling featured. Sarah took up the offer given to her in her first call to My Options to call back and talk through her options and decision. She felt as though *it was exactly the support [she] was looking for.* 

The inclusion of a counselling approach in responding to calls by My Options was welcomed by women. This approach meant women felt they did not have to explain themselves when making the call and concerns they had about encountering judgement or questioning did not materialise. Katherine found that it's not them putting words in your mouth or questioning you, why you're calling them or why you're doing this. It was them asking you how you actually feel. She continued that in this situation, what women need is a detached listener on whom they can "dump" a myriad of issues running through their mind, as well as to ask questions they have about accessing abortion:

You just want somebody to listen to you. And you just want somebody to, you know like, give you information, facts and information only. And I got that from them, you know there wasn't them like being emotionally attached I suppose. You know, like putting their own thoughts or opinions. It was them really just asking you "what do you want to do?".

Katherine

Staff in My Options were described as picking up on cues, such as a woman using a low voice or becoming upset, to explore how they are feeling during the call. This was welcomed by women who were experiencing turmoil and distress, and in some cases not reaching out to usual support networks.

They were just really nice to be honest. It was kind of the first time I got slightly emotional about it, which was a combination of hormones and just being slightly emotional about it. But yeah, she was really, really kind.

Quinn

Similarly, Serena was positive about the service as a neutral space to, you know to discuss [the abortion] like to somebody different, who didn't know me or didn't know really anything about us. So that was nice.

While there were overall positive assessments of My Options as a service, there was a prevailing sense of its role as a provider of contact details for abortion care providers trumping its role as a provider of

counselling and comprehensive information about abortion and other unplanned pregnancy supports. In the below, Ophelia portrays My Options as a conduit directing women to providing doctors rather than as a comprehensive provider of information to satisfy women's needs to understand the procedure. She felt that making an appointment to see a provider equated with taking the decision to proceed with an abortion, rather than engaging in discussion and information-seeking on the procedure.

I suppose I was ringing [My Options] with regards looking for information, I probably felt like I didn't get that from them either. In that they were referring me, they just, they asked where I was, if I wanted to see somebody locally, if I wanted to see somebody locally or slightly further afield. And then they recommended [the GP I attended]. ... I had got, and again both from the poster on the back of the toilet door and from my GP, I was under the impression that I was ringing to discuss options with My Options. And that's not what I got. It was, I got a referral to somebody who could talk to me. But that was, it was definitely a three-step process for me to get the information that I wanted regarding the other side of my options literally.

Ophelia

#### Ophelia's perspective was echoed in Elaine's account:

No, I wasn't offered counselling. I can't really remember to be honest. I think it just went sort of straight into the logistics of finding somewhere and I think that kind of overtook anything else. She did say to call back if I had any more queries, but I don't think, I wasn't really given that much information by them. But that might be in part because I'd already kind of looked stuff up, I'm not sure.

**Elaine** 

Overall, while My Options was viewed positively by many research participants, there were some who recalled their engagement with the service in a minimal or perfunctory way:

I can't remember what it's called now but on the HSE website it just referred me to call a phone number, I think it was for the nurse's line or something like that and they referred me to contact my GP. And then just advised that I was looking to terminate the pregnancy.

. . .

I think it was the My Options service is that it?

Yes, oh that is it, My Options, that's what it was called.

Jill

Accessing contact details for a provider was for many women their key emphasis on the value of My Options:

Ringing My Options, did you know what to expect there or what were you hoping to get from them, was it just information or did you need anything more?

No like that was fine, I just needed to know where.

Where you could get the care?

Yeah.

Zoe

Women could discern the role of My Options in guarding information about providing GPs. While some felt the non-availability of an "open list" of providing GPs impeded accessing care as discussed below, others like Irene accepted this as a consequence of the contestation of the service *having known how ugly the whole [Repeal] campaign was*.

Women remarked on the benefit of getting contact information from My Options quickly and in a straightforward way, comprising contacts for usually three doctors that most reported included both male and female GPs. Women seemed to be happy to attend any GP My Options referred them to. A referral from My Options confirmed the GP was a provider and this was the key criterion women looked for in deciding who to contact.

[I] contacted the helpline then who gave me two contacts. ... [I] was pleasantly surprised at how straightforward and how caring it was. The people that I spoke to were very sensitive and helpful and they gave me the information quickly. ... They gave me two names and one was a female GP and one was male. It didn't actually influence my decision.

Áine

My Options' practice is to ask women where they live and then try to find them the nearest GP provider geographically and/or most accessible based on the woman's transport options. As there are a limited number of providers, women often found they could not be given multiple, or sometimes any, contact details of providers in their immediate area:

But [My Options] knew, the minute I said which county I lived in, they were able to say straight away that there is only one GP who is a provider here.

Helen

Fiona thought this was to do with an error on the part of My Options rather than to do with the lack of geographical spread of GPs:

She asked me for area, where do I live, who would suit me the best, I told her the area I live in, but maybe because I lived there. And she found me somebody in another area, maybe she didn't understand me (laugh), another area [near] the area I live in. But anyway, one is very close to my work. And another GP in [the] city centre.

**Fiona** 

My Options also clarifies with women if they want to access a GP local to where they live or if they want to go to one a distance away:

I do understand why people, why the My Options helpline did ask the question as to whether I wanted to see somebody locally or see somebody slightly further afield.

**Ophelia** 

Many contacted the provider most local to them from among the details given to them by My Options:

[My Options] gave me two different options of people [GPs] to call. And one was a little bit closer than the other so I, you know I thanked her and then went with the one that was, called the doctor that was closest to me.

Polly

Staff at My Options also ask women if they already have a GP and if so, do they want to check if they are a provider. Some discovered their GP was a provider, which came as welcome news:

[My Options] actually were able to check for local GPs that were with the service and it actually included my GP anyway. So they were like "oh you just contact her". So, I contacted her to give me a call back and she was amazing.

Tanya

Women contacting My Options are often keen to be connected with providers quickly. Some reported My Options staff having multiple engagements with them and making specific efforts to connect women with a provider as quickly as possible:

And then My Options rang me back with a number for the GP. ... Like I was quite upset on the phone like that I couldn't get anywhere or that I had to even wait the whole weekend to even know when the appointment was even going to be. And the woman rang me back with a number for the GP, to say that he's open on Saturdays, there was only a number of places that were open on Saturdays and she rang me back with this number.

Brie

Although many women recalled My Options as being primarily a source of provider contact details, speaking with My Options did allow some women to get information about the abortion procedure before attending a GP. For Sarah receiving this information meant she *knew what was actually happening and* [...] wasn't that scared anymore. On the other hand, some information women sought regarding the procedure was not addressed by My Options, such as whether they could opt for their choice of method:

And I think I was ringing to ask as well is it possible before the nine weeks to have a surgical, because that's what I want. And I think they were not able to give me that information, they said "we can't give you any medical information about that over the phone, you'll need to sit and talk to your doctor..."

Irene

## 5.3.ii Patterns of Contacts with My Options

Women may call My Options multiple times, with a first call serving to help clarify their thinking or reassure them abortion access is possible and a second call to get information on providers, and then further calls being related to diverse queries either about the pregnancy or services or aftercare, such as Irene who wanted to know if she could go swimming while on holidays:

[Over] not even a week, it was just probably a few days. But yeah, I think in total my calls to My Options would have been 1. What am I doing? 2. Where is the provider? 3. Can I jump in a pool? Maybe there was one more, I can't remember what it was for, but I think I called them about four times.

Irene

During the period of the study, the helpline operated 9am to 9pm Monday through Friday and from 10am to 2pm Saturday, from January 2019 to April 2020. The current hours of operation are 9am to 8pm Monday through Friday and 10am to 2pm Saturday. Calling outside of these hours means women reach an answering machine or the 24-hour nursing helpline staff who explain to call again when My Options is next available. As Fiona's case shows, this can mean having to make multiple calls to reach a provider:

So I found My Options and it was Saturday, I was so in panic and I just called them on Saturday but then I could speak only with nurse. She took all my details but she told me that I have to contact counsellor, that I should call on Monday again. So, I called on Monday morning.

**Fiona** 

# 5.3.iii My Options Supporting Access to Care

There were a range of ways that My Options staff supported people navigating the care pathway and ensuring they accessed the care they needed. Participants described how My Options staff as a matter of course established their stage of gestation at the outset of the consultation, advising them on the timelines available to them to ensure they could access care before the 12-week gestational limit, and if possible in the community.

I had told her my dates, so she was like you need to call them today. So yeah, very clear.

Tanya

My Options staff also advised women on how to handle calls to GP surgeries or WHCs. Women were advised to say they were calling after being given the number from My Options, and this primed doctors or reception staff to know the woman was calling seeking a consultation for abortion. This served to minimise women using terms "pregnancy", "termination" or "abortion", which many women noted they found difficult.

My Options suggested that I tell [the GP practice] that I'd been referred by them. So yeah, the person I spoke to I think was another GP in the practice and she knew straight away...

Áine

It also served to alleviate anxiety regarding the potential response of the receptionist to an appointment request at a practice that women were not patients of:

You know because I was calling a GP I'd never heard of, you know, just from my own experience of GPs, sometimes the receptionist can be really kind of snappy and they kind of want to know what are you calling for, you're not a patient here. And I was really, you know I suppose I was worried I was going to start blubbering on the phone or tripping over myself with my story or, you know. I found it really comforting that I had this kind of script [from My Options], I wrote it out and I had it in front of me and you know I just, it worked and I felt such relief because again I was getting anxious about making that phone call as well.

Fiadh

The benefit of My Options taking steps to both prepare and advise women to be clear that they were seeking a consultation for abortion care was demonstrated by Irene, who didn't ask for an abortion consultation appointment because she just booked in with that doctor because [she] had rang My Options and they told [her] this doctor was participating in the scheme. Because of the failure to specify the nature of the consultation, Irene needed to return for an additional consult with her GP who usually booked longer appointments for abortion consultations.

### 5.3.iv Questioning Role of My Options in Care Pathway

Some participants questioned the limitations on access to providers' details under the current model of care whereby GP details are only provided through the helpline, with a usual practice of a woman being given details of up to three GPs when they call. One woman felt that she *would have liked to have more choices* and questioned if being given only two names (as she was) was the standard – *are two names normally given out at that first point?* (Áine).

Renée, who had come to live in Ireland a few years ago, recalled difficulty in finding a provider, describing it as being *quite hard* [..] to actually find out which clinic do I go to, you know do I go to the GP, do I go to gynaecologist. She had begun with a Google search which led her to the HSE website. When she did not find contact details for providers on the HSE website she did not call My Options, but instead started calling around GPs without success. Finally, in desperation, she reluctantly asked a friend who was an administrator in a doctor's surgery if she knew how to access the care. This was a last resort for Renée, who explained that if I didn't have to tell her, I wouldn't tell her.

Similarly, rather than use the helpline, Brenda opted to consult directly with a doctor without knowing if they were a provider or not. Brenda's account illustrates a preference for direct contact details of providers even when aware these are provided by the helpline:

I looked on the HSE website and there was, you know obviously it doesn't tell, you know where does it, and I was even looking up the north, in Northern Ireland and I was like "look I'll book a doctor's appointment to see what they say, will they send me somewhere, I don't know."

And did you find the HSE website, was that easy to navigate, was that informative?

Oh totally, yeah. It was easy to use and you know it gave you all the information, like it basically answered any questions I had. The only thing is just the providers, but I know that there's a number there to ring.

**Brenda** 

Some women also questioned why information on abortion care could **only** be provided by a specialist helpline, arguing instead that as abortion is now a legally provided service all *medical professionals* ... would know enough about it to at least be able to point [them] in the right direction (Pippa).

Brie questioned the role of the helpline, commenting that to her *it was completely pointless*. While she acknowledged that she *rang and got through to a lovely lady who was very, you know, soft-spoken and made you feel really calm,* she queried whether the helpline could offer the facility to book appointments on behalf of women:

I kind of asked myself this like, but is that their responsibility, but I don't really know if it's their responsibility or not. Or if it is, that I got myself into that situation, you kind of need to get yourself out. And if that's the case then that call line should just be completely gone. But I just felt like that, if you're ringing a call line for the information that I could have got on my phone, would they not make the appointment for you?

Brie

Similarly, Elaine proposed that the service should have the capacity to make bookings for women. For Elaine, in the absence of that provision, My Options simply being a directory to the list of providers is inadequate. In this context, not being able to autonomously access a list of providers diminishes women's capacity to "self-direct" their pathway through reproductive health services. Here Elaine is querying if My Options is functioning to mediate between women's autonomy in their decision-making and autonomy in managing their own care.

So, something that might work well would be if My Options actually booked you in with somebody rather than you having to then phone, yeah. I don't know how that would work, but you know, to join things up a bit more that you're just going through one place rather than having to sort it all for yourself kind of thing. ... On My Options, and I can sort of understand why it isn't there, but there isn't kind of a list of providers. So, you can't just, even if you are doing it self-directed, you can't really start it yourself, you need to go through somebody to get some information to then go to the next step. The information you need isn't kind of readily available to access by yourself.

**Elaine** 

# 5.4 Role of My Options 24-Hour Nurse Helpline

The My Options 24-hour nurse helpline is a built-in feature of the model of care to provide back-up support to community providers prescribing EMA medications. Several people were made aware of the My Options 24-hour nurse helpline by their care provider and felt confident they would have used it if they needed to. When one participant was informed about the helpline by the GP she attended, he emphasised that the My Options 24-hour nurse helpline was more specialised than general health care helplines as the My Options nurses have specific training and are more alert to the complications that may arise:

And [the doctor] said to me "look you can ring health care line, like you know, out-of-hours doctor, Caredoc or whatever." So he said to me "you know you can ring them if you are looking for advice but I would advise you to ring", he said ring My Options you know instead, because he said they deal with that more and he said "when you ring health care line you don't know who you'll get on the end of the phone whereas My Options are trained for that." So, you know that was really reassuring...

Serena

Within our data set most people who spoke about contacting the My Options 24-hour nurse helpline did so for reassurance that the symptoms they were experiencing after taking the second medication were normal. Most felt these calls were helpful and were happy with the service they received. One such caller, Quinn, was concerned that there had *only been like a tiny blood clot*:

I rang My Options and they put me through to the nurse. ...

And what did they say in terms of like when you said to them "ok, I've passed this amount, but it doesn't look like a lot", what was their response to that?

Well they said that if you've passed any blood clot, no matter how small, how big, It's fine. It's likely you have passed it. Also, she did mention that my age and sort of that I was only six weeks pregnant, she was like you're unlikely to see anything.

Quinn

Quinn found this interaction supportive, particularly when the person she spoke to advised some self-care: "So, don't worry, do you know what I mean, stay in bed, look after yourself, don't sort of go clubbing" but she was like "you're going to be fine basically." ... She was super nice. Fiadh rang the helpline when after taking the second medication she had light bleeding but no cramping or pain. She wasn't convinced the medication was working. She felt grateful to have the helpline to ring and to talk to someone. She was advised to take another dosage of the medication given to her by her GP. Fiadh positively evaluated her experience with the My Options 24-hour nurse helpline, explaining, I got through instantly. I was talking to a very understanding, knowledgeable person and you know it just kind of gave me a bit of relief. Helen called for reassurance, remembering that her GP had communicated to her that she could ring the My Options 24-hour nurse helpline with any concerns:

I had to ring them up like, the HSE, the helpline just to ask them, you know because I didn't have a fever, or I wasn't feeling dizzy, so it was just obviously everything was taking ages to go away, you know. ... Yeah, I can always remember the GP saying it to me, that you can ring them if you have any problems ... So that always stayed in my mind. So, I rang them I think you know just to ask them was everything, you know what do they think, you know so.

[...]

they were fine, like they said if I was worried that I could go down to the hospital.

Helen

Others called the My Options 24-hour nurse helpline in the days and weeks after their abortion. Almost two weeks after her medical abortion, Jill called the nurse helpline about the bleeding she was experiencing, being told, it should be fine it's normal bleeding. She further recalled being advised to keep track of how many pads that [she went] through within an hour and if it's over a certain amount then [she needed] to contact the hospital or go to the hospital. A few days after this call Jill received a follow-up call from her GP. She was still bleeding at that time and the GP prescribed a course of antibiotics.

Similarly, Jade contacted the My Options 24-hour nurse helpline twice after her abortion, first calling after she continued to experience pain a few weeks later, explaining that she could be in quite a bit of pain at night. She was advised that it can be up to eight weeks and this and that and you know yeah you can be

in a little bit of pain. The second time Jade rang the My Options 24-hour nurse helpline was when she was abroad. She was concerned about experiencing further pain and having passed tissue:

And then I was abroad... I had a really bad pain on like a Tuesday night and I passed tissue... And it was a lump, like it wasn't a clot, it was tissue. And I was freaked out a bit, I'm on my own in another country, so I told one of the, there was another girl staying in my hotel. [removed] And she said "you should really," she's had two pregnancies, she's like "you really should go." So, I rang the Irish line again and they told me "you probably should go into a hospital" [in that country].

Jade

Later when Jade returned to Ireland she attended her doctor where it was discovered that she had an infection and it was treated with antibiotics. Irene called 10 days after her surgical abortion when she was still bleeding and had planned on going away on holiday. They were able to reassure her that she was safe to travel and provide her with advice about the activities in which she could partake:

I called My Options and I was in the airport. I'm about to get on a plane and I'm bleeding and it's a little bit heavy, is that ok? Is there any sort of a risk? And I said "look I have a disorder so it's kind of can have a vascular component" and they put a nurse on to me and she was like "look you should be fine." And then I said "oh can I swim, I'm going to a spa ... should I stay out of water", all these questions I hadn't thought about. And I was having a last-minute panic .... I was like ok I'm not going to be ringing anyone from Ireland, I don't know who to call, I rang My Options and they were like "don't go into a pool" ... And I was like ok. And I was wondering, because it hadn't quite stopped, could I use a pool or would that trigger infection.

Irene

Of the service users who mentioned calling the My Options 24-hour nurse helpline the majority were happy with the service, with only one for whom this was not the case. Brie found it necessary to ring the helpline when she felt unwell after taking the second medication at home. She described feeling *thrown back* that the person she spoke to sounded busy and didn't offer her what she considered an adequate response to her concerns about a high temperature. Brie felt the nurse she communicated with had not taken enough time with her.

Give five minutes to that person. ... just tell me, is this normal? ... You go to the doctor, you say "right I'm not feeling well today", okay, they'll ask you a number of questions. How is that any different, do you know what I mean like?

Brie

Not all service users recalled being referred to the My Options 24-hour nurse helpline by their community provider. Some GPs give their own mobile numbers to service users to call if they experience any symptoms that give cause for concern. There were also cases of service users being advised to attend hospital services.

# 5.5 Overview of My Options Service and Nurse Helpline

My Options is serving people well in being a responsive, accessible, caring and continuous element of the care pathway. In particular, being able to readily talk with someone knowledgeable about access to and eligibility for abortion services, questions on confirming pregnancy, what the abortion procedure will involve, getting contact details of providers and reassurance that these are GPs who will readily provide the care, and supporting people in making appointments for abortion care by advising them to say they were referred from My Options when calling a provider. My Options helps people identify if their own GP is or is

not a provider, avoiding women approaching their own GP to find they are not a provider and the shame, embarrassment or judgement they consider that would entail. My Options also offers people the option of sourcing a local GP or one outside their own area if this is their preference for privacy reasons. These are all facets of My Options that are valued by service users. Moreover, they all contribute to My Options operating as a responsive and supportive gateway for people to access care. While My Options was very positively evaluated by many research participants, there were participants who recalled their engagement with the service in a minimal or perfunctory way.

However, the model of care positions My Options as the sole source of information on GP providers. The practical effect of this seems to be to remove any onus or responsibility on actors across wider services to be knowledgeable about, willing to discuss, and willing to refer women seeking abortion into the care pathway for abortion services. Some see My Options as a conduit and an additional step that should not be necessary for them to access legally regulated and provided-for services, and actively avoid the service for that reason. Ultimately they have to contact My Options when efforts to directly access the service themselves are unsuccessful, and this is a source of frustration and delay. The My Options 24-hour nurse helpline was assessed positively by participants in the study for being easily accessible, especially out of hours. In particular the service was reassuring to women given the onus of self-managing abortion care. Staff were assessed as understanding and knowledgeable. The service supported people to determine if they needed to take a second round of the second medication, if symptoms they were experiencing indicated they should present to their doctor or hospital, or simply if symptoms they reported were normal/could be self-managed.



# Assessing Community-Based Abortion Care: GP and WHC Providers

This section documents people's experience of receiving community-based abortion care in the under-12-weeks category. While the experiences of those who attended GPs and WHCs were analysed separately, it was observed that once participants had accessed a provider, be they a GP or WHC doctor, their experiences were largely comparable. Thus, the experiences of people attending either a GP or WHC are integrated in this section, with points of difference (the most notable of which is pathways to the providers) highlighted where they arose. Quotes are distinguished as relating to either a GP or WHC service user.

#### **6.1 Pathway to Provider**

One of the major points of difference between the experiences of those attending GPs and WHCs is the pathway to the provider. Under the current model of care GPs opt in to be providers of EMA, with some providing GPs choosing to be included on an "open" list of providers (accessible only through My Options), some choosing to remain on a "closed" list (accessible only to people who request the service directly from them), and a very small number choosing to publicly advertise their provider stance (via their own website, for example). Conversely, WHCs providing abortion care advertise the service on their website, thus making them easier to identify as providers. Although My Options is intended to mitigate difficulties associated with this guarding of information on GP providers, the data below shows this has not been entirely successful.

Forty-five participants described their pathway to abortion care under s.12 of the Health (Regulation of Termination of Pregnancy) Act 2018. There was one other participant in the study who also accessed abortion care under this section of the Act, but their account of their pathway to their care provider was not detailed enough to permit this analysis and thus they were excluded. Analysis of these participants' accounts demonstrated that 13 diverse pathways to an abortion care provider were experienced (Table 6.1).

Table 6.1. Pathways to abortion care provider experienced by participants

Pathway Number	Pathway Details	n
1	Self-Referral to My Options → Referral to Abortion Care Provider	15
2	Self-Referral to Abortion Care Provider	11
3	Self-Referral to Non-Providing Health Care Professional → Referral to Abortion Care Provider	4
4	Self-Referral to Non-Providing Health Care Professional → Referral to My Options → Referral to Abortion Care Provider	4
5	Self-Referral to Non-Providing Health Care Professional → Self-Referral to Abortion Care Provider	2
6	Self-Referral to Non-Providing Health Care Professional → Self-Referral to My Options → Referral to Abortion Care Provider	2
7	Self-Referral to Non-Providing Health Care Professional → Referral to Abortion Care Provider and Referral to My Options → Referral to Abortion Care Provider	1
8	Self-Referral to Non-Providing Health Care Professional → Referral to My Options → Self-Referral to Abortion Care Provider	1
9	Self-Referral to Non-Providing Health Care Professional → Referral to Non-Providing Health Care Professional → Referral to Abortion Care Provider	1
10	Self-Referral to My Options → Self-Referral to Abortion Care Provider	1
11	Self-Referral to Providing Health Care Professional → Referral to My Options → Referral to Abortion Care Provider	1
12	Self-Referral to Providing Health Care Professional → Referral to Non-Providing Health Care Professional → Referral to My Options	1
13	Self-Referral to Online Telemedicine Provider → Referral to My Options → Referral to Abortion Care Provider	1

#### 6.1.i Difficulty Finding GP Providers Independent of My Options

People who did not initially contact My Options often struggled to find a GP provider. Several spoke of needing to contact several practices to determine if they provided abortion care. Polly had a little bit of trouble ... in the beginning calling GPs because a lot of them around [her] weren't providing the service. Another person estimated they phoned about seven or eight [GPs] (Clíona). These participants were frequently concerned that such a challenge would be too difficult for people without any support:

I was thinking for women who were doing it on their own and if they were unsure about it in any way, maybe after three or four calls they would have just given up.

Clíona (GP)

Responses by receptionists and GPs to these requests could vary in terms of tone, from respectful to judgemental:

I never got any kind of, you know judgemental answer or anything like that, like everyone was very nice.

Polly (GP)

Yes, everyone had a different reaction, like for example I called one of the [GP] clinics and I said that I'm pregnant and I cannot keep the pregnancy and I was asked why not.

Reneé (WHC)

Reasons given as to why the GP could not see the person included that the GP is not taking on new patients, is no longer providing the service, or COVID-19 restrictions:

New patients, they don't take new patients, some said because of the COVID restrictions we can't take new. And most of the phone calls I make, most of them they were trying to blame the COVID like you know.

Ursula (GP)

Clíona described how when she requested an appointment for abortion care the receptionist kept referring to "maternity care":

I remember one GP surgery in particular... they just kept saying "ok let me just do this, put your name down and you can come in and we can talk about your maternity care."

Clíona (GP)

Referral to My Options or a providing GP by non-providing GP practices was not the norm. Many experienced a lack of any guidance, with Renée explaining they didn't actually guide me to any other place really and Ursula noting that nobody told me to go to My Options.

For some, the stigma associated with abortion meant that having to openly state they were seeking abortion care was challenging. A few reported using quiet voices, resulting in the receptionist asking them to repeat themselves:

I phoned that GP surgery and the receptionist there, I had to repeat myself, I was like I'm calling about, I've been referred by...and I'm calling from... and she was like "by who? For what?" I was like "ehh, you know?" And it's a tricky situation anyway, you don't really want to be repeating yourself.

Elaine (GP)

As noted previously, saying they were referred from My Options often alleviated this anxiety for those who had been referred via that service. Conversely, another woman rejected the notion that she should feel

uncomfortable in requesting an appointment, assuming that this wasn't the first time they had this phone call (Polly, GP).

Many participants did already have an established GP they attended, but there was often a hesitancy amongst them to directly approach their own GP to seek abortion care. Finding out from My Options if they were a provider or not was valued. Here Fiona discusses how fear of judgement prevailed over her desire to attend her own GP for continuity of care, prompting her to contact My Options rather contact him directly:

Ok and did you feel you could have asked him directly, did you think about just ringing your GP directly or?

No, no because I don't know his opinion, what is his view. Is he against, I don't know. So, I wanted to know if he is on that list. If he was then I could call him or she because there is three of them, I attend two of them. But I could call them and I could have no problems with doing it with my own GPs, but they were not on the list. So I just didn't contact them.

And do you think would you have liked the GP who looks after all of your care to be the GP you attended for the abortion care?

Yes. I would prefer.

Fiona (GP)

On the other hand, some people (who had not been in contact with My Options) contacted their own GP to ask if they were a provider, such as Therese who explained she *just called because that's the only doctor that [she had] here and they said they were [providers].* While Therese's GP was a provider, Ursula was left feeling frustrated and uninformed by the unhelpful response of her GP's receptionist:

No I explain to them, "I have a problem, I didn't get my period, I find out I'm pregnant and I need help because I don't want to carry on that pregnancy." And she told me "oh your GP is not here" and that was a frustration. They did not help much.

Ursula (GP)

Some participants reported assuming their GP should be their first port of call to access abortion care and made an appointment without any prior knowledge of their provider stance. This was often because they assumed GPs would be equipped to discuss all pregnancy options, while a few were under the impression they needed their GP to confirm the pregnancy. For example, Hazel thought her GP *might have information, you know, as in like maybe a phone number or a contact or be able to organise it for you or something do you know.* 

People who "ran the gauntlet" like this frequently found the doctor was not a provider. One response was to not engage with their request, as Quinn describes:

And she, they don't perform terminations and she also wasn't super nice to me, she wasn't not nice but she just, the only two questions I remember her asking me "are you in a stable relationship" and "these things have a way of working out" and I was like "I don't want to have a baby so..."

Quinn (GP)

These avoidant responses left people feeling alone, unsupported and having the burden of finding a provider placed squarely back on their shoulders. Again, there was concern that people with fewer supports in place would struggle to access care because of such responses. Here Hazel describes how she respected her GP's right not to provide the service, but felt they should have at least been able to refer her on to someone who would:

[I] just felt like where do I go next if I can't find support, you know... You've been to your GP like and then it's kind of like "oh God this is all down to me now," do you know. ... Yeah, you know, like surely

they have connections too that they could have found something somewhere, you know. But like I did pay €40 to be told like "well sorry actually I can't help you but you are pregnant" ... and I was kind of like "well I confirmed that myself you know."

Hazel (GP)

One woman's non-providing GP had her return for three visits before advising her that he did not provide abortion care, in a way that appears from the data to constitute conscientious obstruction. Grace attended her family GP feeling unwell to discover she was pregnant. She disclosed to the GP that her pregnancy was a result of sexual assault. The GP advised her to attend pregnancy counselling and had her return for a further two face-to-face appointments costing €180 in total before telling her he was not a provider and, in the view of the service user, reluctantly giving her a My Options leaflet. Her interactions with the GP left her feeling vulnerable, alone, and taken advantage of.

I came back then a few days later whenever and I said "look," I said "I was thinking about it and I really can't go through with it. It came about in a very unfortunate way, I didn't have, it wasn't like consensual" ... So, I told him this and instead of him kind of being sort of, trying to be understanding about it, I think he was really trying to sway me towards keeping it. Maybe because of his own beliefs or I don't know. But I just didn't feel supported and there was nobody else, like I wasn't talking to anybody else at that time. So, I just kind of felt like, in hindsight I felt then that he could have done more to help. But at the time I was so confused and so feeling like vulnerable that he sent me away again and he gave me like, leaflets of like, how to get the care that you need or counselling or whatever like, prenatal counselling and things like this. And he said "try to, like, think it over and come back to me" and I was like "I've thought it over," you know, so I came back again, the third time. This was another €60 like out of my, you know. ... he gave me like [the My Options leaflet], it was only the third time and he was very hesitant to do it as well, I really think he was.

Grace (WHC)

However, there were some participants who also first attended their own GPs to discuss abortion care and discovered they were a non-provider but received a warmer response and an appropriate referral. A few participants were offered peripheral support, such as emotional support or aftercare by their non-providing GP:

So then when I went back to my GP, or when I went to my GP then, you know she said that that was fine, she confirmed the pregnancy just with like a urine sample. And then she said that she actually doesn't offer the terminations in her clinic but that her colleague did and that she could give me his contact details.

. . .

Yeah so she actually said to me on the day that she didn't provide it, and the reason she didn't provide it, and she said to me that she would provide any aftercare I needed, like you know, she said to me like she would do the bloods no problem and she said any visits I needed, you know emotional support or anything no problem.

Serena (GP)

Notably, the GP's initial response to the pregnancy could determine whether the topic of abortion was even raised with them at all. Assumptions that every pregnancy was welcomed were particularly off-putting.

I was like, this just cannot happen like. But [my GP] was just like, "oh this will be the best thing that will ever happen you." And I was like, "oh my God." So, I didn't even broach the subject [of abortion] with him.

Naomi (WHC)

It was uncommon for participants who attended an appointment with their GP without prior knowledge of their provider stance to discover they were a provider. This was only the case for one person whose GP told her, "look we're actually one of the providers. Not many people", she goes "nobody knows about it, well obviously unless they come in and enquire about it" (Brenda).

Beyond contacting My Options, women sometimes gave examples of "cues" they used to assess whether their GP was likely to be a provider or not. These were often based on their previous interactions with their GP or their practice, such as the demographics of the GP or their other patients, or the GP's general demeanour.

I would be surprised if they did provide it, because from being in there and you're surrounded by all these auld lads around you in the waiting room, you very rarely see any young people in there or people of my age you know.

Helen (GP)

I've been into her plenty of times, I just know she's not the sort of person that would be ok with handing me a packet of tablets to do that.

Pippa (GP)

For another woman, her GP's previous supportiveness of her desire to have tubal ligation suggested to her that she would likely be supportive of other forms of reproductive autonomy. The discovery that she was not a provider of abortion care came as a surprise.

Yeah it was [a surprise] I suppose because I think, you know I suppose I didn't expect it, like I thought, you know I just thought she would. You know just simple as that, I just thought she would.

Serena (GP)

#### 6.1.ii Not Wanting to Attend Own GP

There were women for whom the idea of accessing abortion through their own GP did not appeal, regardless of whether their GP was a provider or not. Fear of judgement by their regular GP was a major concern. Here, Diane juxtaposes her GP's awareness of her living situation as being both the reason he would likely be supportive of her accessing abortion, and as something that would cause him to judge her.

It's like, like it's a small town and like obviously I know [the GP is] not going to go out and tell my business but like I used to live right across the way from the doctor's surgery and the man would see me every day and I'd be giving out to the kids and I'd be running up and down with the buggy and the man just turned around to me one day and he goes "Jesus Christ", he was like "will you give yourself a break", he was like "I don't want to see you coming in here pregnant for a good five years" and like that played, like he didn't mean it in any way shape or form offensive like. And he knew a lot of what was going on with my relationship as well and stuff. So, it was just like I don't want to go in and have him thinking that I'm the sort of crazy person who keeps getting pregnant and having all this like dramatics going on in my life. So yeah, I just went with a different doctor, she had to consult with him in the end to get the number and everything.

Diane (GP)

Similarly, Ruth reported not wanting to attend her own GP because she could not be certain of their views on abortion:

I don't know, if you go to your GP you need to be sure he will be supportive, and here I know it might be hard in some places, well that's what I read, it might be difficult to find a GP that will agree sometimes, depends where you are.

Ruth (WHC)

Rather than fear of judgement influencing choice of GP, one person opted to attend a female GP rather than her own male GP, because she *just felt more comfortable with a woman* (Wendy).

Privacy concerns were frequently cited as a reason not to attend regular GPs. Some preferred to keep their abortion care separate from their other medical records, with Una explaining she didn't want to go to [her] GP and kind of add that to [her] history. Those living in small rural communities sometimes highlighted the fact that their privacy could be breached at their local GP:

...if I had been told my GP was the only GP available, I wouldn't have used that service because ... we're in a small town and an extended family member works in that surgery and if anything would have, you know a little bit of a gossip and if anything would have got back to my elderly family members, like they would have excommunicated us, they're very Catholic, I know she's completely against abortion and I couldn't have taken the risk of alienating them, you know. So, I couldn't have gone with my local GP service, it had to be someone I didn't know but that was close and I was so fortunate that the cards kind of lined up for me in that sense.

Fiadh (GP)

Additionally, some participants expressed a desire to maintain a distance between the place where their family received health care and where they received abortion care, viewing these as incompatible. For Maria it was because her GP's clinic was the place where she sought health care for her children, proclaiming that it wouldn't even enter my head [to access abortion care there].

The anonymity of an unknown GP could also be welcomed after a negative encounter with a regular GP:

that was kind of a relief [to attend an unknown GP], it was like well they don't know me, do you know so. I think after the way I got on with my GP it was like "ah this is somebody that doesn't know".

Hazel (GP)

#### 6.1.iii Pathway to the WHC

Participants reported varying pathways to the WHC they attended for abortion care. It was common for them to have prior knowledge of the organisation. Such familiarity meant people felt confident attending the clinic when they needed abortion care.

I've been there before so I know them and a few of the nurses you know you see them and you're like "oh I've seen your face before." Yeah so, I know the place and I know they were nice people, so it was like I'm comfortable with this one, it's a good location and good people and I just call them. So, it wasn't like I'm just going to call around and see who does it, I call them and was like "do you guys do this."

Laura (WHC)

Some participants had been referred by other sources, including My Options, other health care professionals, or friends. Several attended a WHC because they considered it more accessible or preferable compared to a GP. Challenges encountered in accessing a GP provider meant that Zoe contacted a WHC instead:

...it's just when I called [the GP] and like the appointment would have been so late.

#### And did you ask them could they give you something sooner?

Yeah but they said no because of COVID, because if I had gone to my GP I would have had to like walk in and it would have been like a face-to-face appointment. And then in the women's health care clinic centre it would have, like it was just on the phone. ... I just found it easier.

Zoe (WHC)

For some, the transparency of service provision by WHCs compared to GPs meant they felt more accessible. Grace was left confused by the My Options website and chose instead to contact a WHC because she *knew that they would do [abortion] there*. For Aoife, this transparency was particularly important amid a global pandemic:

But no, there isn't a list anywhere that explicitly says we [are GPs who provide abortion]. And I didn't want to have endless conversations because it was November, case numbers are going up. You don't know when you're going to get to see a doctor. Probably COVID adds to the difficulty I suppose.

Aoife (WHC)

WHCs were also considered more accessible by those, like Victoria, who had previously encountered difficulties in registering with a GP and were under the impression a regular GP was needed to access the service. Victoria noted that the WHC seemed to take walk-ins so that's I guess what you have to go with in Dublin.

There was also a sense expressed by some people of WHCs being *more specialised in women's health* than were GPs (Maria). Similarly, Naomi felt abortion was a *normal process* for a WHC. Another participant attended a WHC for abortion aftercare only. This was after having accessed EMA through a GP. She had been referred to a WHC for post-abortion counselling by My Options and decided she would also attend there for aftercare because she *had gotten on so well in the counselling* (Quinn).

Of note, there were a few people who reported challenges in getting an appointment with a WHC at all, either needing to contact several clinics before they could secure a timely appointment, or in one case not hearing back from clinics after having filled out an online form:

I knew I wanted to try and get to see somebody quite soon. So yeah, I rang the women's health centre and I spoke to a few different centres and then I got an appointment with one which is quite near.

Maria (WHC)

There was a place in town that could fit me in but not like, for another 10 days. ... I filled out a couple of forms and none of them ever got back to me. Like they never rang me. Then on the Saturday morning when the clinic opens and she couldn't fit me in for nearly two weeks so I was like "I'm not taking that."

Brie (GP)

These barriers to access were mentally challenging and could reduce a person's sense of security in access to care:

And do you know what it is as well like, you're in the fear as well like of am I even going to be able to do this? And also, I can't live with this for two weeks.

Brie (GP)

### **6.2 Receiving Community-Based Abortion Care**

#### **6.2.i Scheduling Appointments**

Appointments were scheduled with as much flexibility as possible. Often, a balance needed to be struck between personal/work commitments and the provider's availability:

I contacted them and got an appointment like a few days later. It was just due to my work like that I couldn't go in sooner.

Zoe (GP)

It was fast, it was very quick, I can't say but it was just a few days, I think I had to wait like two days or something. Yeah but it was also like, you know they gave me, it was like Thursday 10am and I'm like "I work, can we do this another day" so we found a suitable time for both of us in only a few days. It wasn't bad.

Laura (WHC)

The response of the receptionist was important, with Fiadh appreciating the warm and friendly tone of the GP receptionist she engaged with:

...there was even kind of nice chitchat while she was on the system, you know looking for an appointment, you know a bit of talk about the weather, you know just to make you feel kind of normal, not like a loon making a call.

Fiadh (GP)

In keeping with most people's desire for their abortion to be completed as soon as possible, a timely appointment was considered very important. Appointments for abortion care appeared to be prioritised by receptionists.

Yeah, they just, they knew what I was calling for and they had like plenty of appointment times which I don't know if that was just because of what I was coming for or just they weren't busy that day. But they seemed to be like really able to accommodate me. And I was, I think that was like maybe 10 o'clock in the morning and I had an appointment at half 12 so I left work early. And like no questions were asked on the phone.

Clíona (GP)

This prioritisation of care challenged any sense of stigma or self-criticism participants had:

You kind of feel like you don't deserve it in a way, you know. ... I suppose it's kind of hard to explain, I didn't feel like I was deserving of help when I had put myself in this situation, this was my fault, you know I should have been more careful, you know and there's so many sick people out there, like genuinely sick people that need help and they could be waiting, you know I expected I'd have to wait longer or that I'd be much less of a priority. You know I assumed that every GP is very busy but obviously they did, you know prioritise and you know so it was nice.

Yeah that made you feel better. That alleviated some of that self-criticism or judgement that you were having of yourself.

Yeah, yeah it did.

Fiadh (GP)

However, one person experienced a two-week delay before their first appointment. This was because during a phone consult, the practice nurse advised her that she was very early and said, "that's fine, you're only five weeks, you know don't panic, I'll book you in for a consultation with the doctor in two weeks" (Polly, GP). Polly felt uneasy about this dating but thought that the nurse's assessment was probably correct as she's a nurse, you know she probably knows better. Unfortunately, Polly's sense of unease was warranted because the nurse had written down the wrong month. This was not discovered until she had her initial consult with the GP two weeks later when the GP became alarmed to discover Polly had been left precariously close to the 12-week cut-off.

Specific to WHCs, under the remote model of care both providers introduced a pre-abortion information session/process call provided by counselling staff into their care pathway. One person commented on the fact that all three appointments were booked at once for them – they just scheduled all at once on the first

initial phone call (Victoria), although another remembered having to request this all at once – I asked her to set up all the rest straight away as well, I didn't want to have the call with psychologist and then calling them again and you know booking first appointment and then calling again and booking the second appointment (Renée). One person who accessed under the remote model of care noted a 10-day time frame to complete the care pathway, which she perceived as protracted and stressful.

My thing was, like I mean the whole process took about 10 days which for me when I heard 10 days, now for me it wasn't psychological, it was actually just I felt like crap. I was tired, I was sick, I felt terrible. So, for me 10 days was like ah you're kidding me, you know that kind of way, could we not just do this tomorrow, wait the three days and you know. But actually 10 days isn't, you know kind of in hindsight, it's not, you know and they're busy and it's COVID and they're resourced to a limit, you know.

Aoife (WHC)

While prioritisation of care was considered important, people were also attuned to what they perceived to be unusual appointment scheduling practices. Here Helen recalls wondering if her providing GP kept specific timeslots for women seeking abortion care and if this would breach her privacy:

And like that, my appointment was at, I think it was 8 o'clock in the morning so you're like will it be open? In you go, like going into the clinic, you know will the girls on the reception know because I'm here at 8 o'clock in the morning, this is the abortion time? You know you have all these things going through your head. That adds to it you know.

Helen (GP)

#### **6.2.ii Confirming Eligibility for Care**

Eligibility for care in the community hinges on gestational dates, of which some participants were uncertain when they first contacted their provider. Across the whole data set, some people were unaware that clinically pregnancies are dated from the first day of the last menstrual period. For example, Pippa learned from her providing GP that she was calculating it different than it should be calculated and she was actually further on pregnant than [she] thought.

There were differences in how providers assessed gestation. Of those who attended GPs, some people were referred for ultrasound at the HSE-contracted scanning provider or a local hospital. GPs made these referrals on their behalf, sometimes using their hospital contacts to arrange these referrals:

She told me that because of the uncertainty of dates and that I hadn't missed a period at any stage, that I would need a dating scan. ... So, she got in touch with her contact and rang me back within half an hour to say that I could go the following day to hospital in southwest for a scan.

Gráinne (GP)

For others, the GP was satisfied with performing their own examination to determine the gestation. Jill had to attend an in-person initial appointment (despite the remote model of care being implemented at the time) because her GP had to determine how far along [she] was. She was not referred for an ultrasound and was determined to be six weeks' pregnant by the GP. A previously described administrative error by a practice nurse at a GP clinic meant that one woman had to be urgently referred for hospital care. When this was discovered, Polly's GP exclaimed, "oh my God you weren't five weeks when you spoke to the nurse, you were nine weeks and now you're 11 weeks."

Participants who were referred by GPs for ultrasound were referred at a range of gestations. One person was referred despite being *fairly certain of when [she] had conceived*. Her pregnancy was so early, it did not even show on the ultrasound. She recalled of the experience:

I found it kind of distressing to have to go for a scan if I'm honest, I kind of, I was hoping she would have kind of taken my word based on the tests I'd been doing.

Fiadh (GP)

Among those study participants who attended a WHC prior to the implementation of the remote model of care, blood or urine tests were relatively common, as were ultrasounds:

Yeah so I spoke to the doctor ... they sent me to a place to do an ultrasound to see also exactly how far it was and if it was a good location that I wouldn't need to go to the hospital. That this could be safely done at home.

Laura (WHC)

Scanning appeared to feature more in the early period of the study prior to the remote model of care, and this data showed a diversity in pattern of referrals for scanning across providers.

One participant wondered why scanning had to be performed off site, explaining that having to travel to a clinic in another area was unnecessary stress that like nobody needs, or even if it has to be different locations and there was nothing you could do about that, if they could all have a centralised system, booking system for abortion care and scanning appointments (Naomi, WHC).

Post-implementation of the remote model of care, those attending WHCs mostly had their eligibility for EMA determined via phone:

I spoke to a doctor who just literally had a tick the box, you know medical background side of things. And to make sure that I suppose I was within the nine weeks because I was just going for the early medical abortion.

Aoife (WHC)

Finally, one person in the study group, Anna, described how due to a medical condition she had to be referred to hospital on clinical grounds. She noted how there had been *great communication* between the WHC and the two hospitals involved in her care, one of which was the maternity hospital that provided the abortion care.

#### 6.2.iii Experience of Scanning in Community-Based Care

The guidelines from the ICGP regarding provision of abortion in primary care settings state that not every service user needs an ultrasound. A referral is only necessary in cases where the person is unsure of their dates and close to nine weeks; has an irregular cycle; has one risk factor for ectopic pregnancy without signs or symptoms; or requests it. Scanning provision for this service was principally provided by a private service contracted to the HSE with facilities in a number of different locations around the country. If a scan is required and there is not a locally contracted scanning clinic nearby, scanning services in the nearest maternity hospital are made available to the service. As described previously, referrals to scanning providers (or hospitals where this was the case) for people who were uncertain of their dates or where there was concern regarding ectopic pregnancy were generally made on behalf of the service user. These services then contacted the person to arrange an appointment, as explained by Dolores:

...the doctor she called [the scanning provider] and she said that I should wait until the confirmation. And I had a confirmation on Thursday morning to go on Friday morning.

Dolores (WHC)

However, waiting for contact from the scanning provider could be anxiety-inducing, especially for participants who were uncertain of their dates. Rather than wait for a call from the scanning provider,

Therese contacted them herself *crying* and [...] like please, like I don't know, because at that point [...] it could have been 10 weeks and ultimately she was provided with the appointment. For most, however, the referral for a scan to confirm gestation did yield an appointment promptly from the service provider.

Many referred for dating scans spoke of the additional burden of having to travel to the service. People who attended WHCs often had to travel a substantial distance to a scanning provider from the WHC they attended – *way out*, as Grace described it. Grace, who had been experiencing severe morning sickness, was *feeling really sick* and trying to hold down the litre of water she had been told to drink while travelling to the clinic on public transport. For another person, the importance of timely access to care meant that while *there [were] closer locations* where she could have accessed a scan, she travelled *45 minutes on the bus* to the clinic she attended, so that she could have *the first appointment possible* (Therese).

There were also some people who attended GPs who reported having to travel substantial distances for dating scans. This was particularly difficult for Fiadh who needed to attend a maternity hospital over an hour from her home. She remembered the pain of having to drag the kids to that hospital and needing to have them wait for me in the car outside with iPads. Having to travel between various locations for care could result in service users feeling as though their care was disjointed. This was particularly expressed by Naomi, who was referred back to where [she] had the [dating] scan and have an internal to make sure there was nothing left in [her] uterus when her hormone levels were not dropping after her EMA. Here she describes the impact of having to travel between the various locations on her care pathway:

I was like oh my God. ...And I just found that very stressful. I was like I know machinery and technology and all that is expensive, but I was like if that could all be in the likes of the women's health clinic where you're comfortable anyway. Because it's such an uncomfortable situation and then you're going into different environments. It was just, that was the only problem I had like.

Naomi (WHC)

Assessment of staff providing scans varied. Several participants described positive encounters with staff when referred for scanning at hospitals:

They were very agreeable to times and they were fitting me in like, it wasn't that they just were going to do it for me and that was it, they knew the situation. And I told them that I'd be down to them for 4 o'clock and that was great, they were you know going to accommodate me.

Gráinne (GP)

And then the nurse manager, no they were very nice in there to me and I explained to them I said, "oh God" I said "I wasn't really expecting an internal scan." I said, I said, "I don't even know if I shaved my legs!" (laughing) and she was very nice, she said, "look it, it's not a beauty contest." She said, "we here to do a job."

Isabel (GP)

On the other hand, other people's accounts detailed mixed or entirely negative experiences with staff. Grace described how at the contracted scanning clinic she attended, one of them was really nice and the other one was really cold. She wondered whether the negative attitude of the second staff member may have been due to them being aware of the reason for her attendance at the clinic:

I'm not sure if they knew anything or if they like, do you know. [...] Because one of them was really stand-offish with me and the other one was really friendly and kind of, you know keeping it going, so I'm not sure. I was in a bit of a state as well, like I was pretty, I think actually they might have gathered from the fact that I didn't want to look at the ultrasound.

Grace (WHC)

Likewise, Dolores sensed a coldness from the staff at the scanning provider she was referred to by the WHC. She compared this to her experience with the scan technician at the hospital she attended where she discovered her pregnancy:

At the hospital like the woman that was doing the ultrasound, she was really calm and she was always talking to me like "oh you're doing great," like "we're almost finishing", you know this stuff. And like with the doctor at the clinic she wasn't talking at all, anything and like when I was closing my legs because of, you know a bit uncomfortable, she would just like push a bit my legs without asking me to open a bit.

Dolores (WHC)

Most participants, whether scanned at the contracted scanning clinic or in hospital, expressed that they did not want to view the screen or engage with the scan in any way, and declined the option when it was presented to them:

I didn't want to look at the ultrasound.

Did they ask you do you want to see it?

Yeah, they asked me if I wanted to, yeah and I said no.

Grace (WHC)

They were very good, they said, "look you don't have to look or whatever" and I said, "that's fine" and you know they weren't showing me the screen or anything...

Gráinne (GP)

However, one person who attended a hospital for a dating scan was not specifically asked if she wanted to view the screen and described *lying on the bed and* [...] *dreading seeing like a sac or a tiny heartbeat or something* (Fiadh). Contrasting with the wishes of most other participants in our data set, there was one person who did ask to view the screen. Overall, the data indicates that sonographers providing screening for this service should be mindful of establishing with people what their preferences are regarding viewing the screen or hearing the sound.

Some service users noted that they had to wait to be told the gestational dates by their providing doctor, with the contracted scanning service refusing to disclose the information. With this wait there is the potential for service users to experience stress at what might be perceived as a disjuncture in their care pathway. Fearful that she had exceeded the 12-week limit, one service user pleaded with the scanning clinic staff to tell her the gestational date:

The one thing that was frustrating to me was when I like couldn't find out how far along, like that was actually, like I was like in tears, I was like "I thought I was going to find this out" but I mean she just said that like a doctor is the one that needs to look at it. And that she was not a doctor, but I was like "can you just tell me, like I bet you know" but obviously like it's policy, I get it but.

But still when you're under the time pressure the waiting, you just really want to know. Yeah like it would have made that day a lot better for me than having to like go through another day of like severe anxiety.

Therese (GP)

Within our data set, a few people from rural areas attended dating scans at hospitals rather than with the contracted scanning provider. Two shared their discomfort at being in an environment typically occupied by *heavily pregnant women* (Fiadh). For both women, being in this space caused them to feel guilt that they did not wish to continue their pregnancy:

I found that even a little bit distressing, it was a bit punishing to be sitting beside [pregnant] people. When I've been heavily pregnant like that myself and I should be delighted and you know and you're there sitting beside them and you're just, you feel like you're an abomination beside them.

Fiadh (GP)

You're sitting there with all the happily expectant mothers who are really hoping everything is going right and you know I nearly felt guilty like, I was saying Jesus here I am now and I just absolutely don't want this.

Gráinne (GP)

While Gráinne acknowledged that there were constraints in terms of what was possible, stating that she wasn't *naïve enough to think that there can be a separate service*, she did wonder if there could be better management of the spaces encountered by women who were there as part of abortion care:

It would be very easy to have a side room off that unit where you don't have to sit and wait with all of the, you know all the general maternity services I guess. Something discrete, it doesn't have to be a new building or anything like it but just you know, just a different area.

Gráinne (GP)

Gráinne touches upon a tension presented in other service users' accounts between wanting the abortion care to be separate from maternity care, but accepting that this is a consequence of limited resources and the grafting of the new abortion care onto existing services.

Having not been offered an appointment at the contracted scanning provider, Fiadh felt that *in an ideal world* an ultrasound could be performed *maybe in a private clinic somewhere, you know.* 

#### 6.2.iv Feeling Supported to Make an Autonomous Decision

Several women commented on their providers' skilled assessment of their certainty regarding abortion, which they felt was conducted without encroaching on their reproductive autonomy. For instance, Diane remarked that her GP wasn't trying to sway [her] otherwise, but rather that she was just making sure that it was something [I] was comfortable with. Diane assessed her GP as having done her job really well around it.

There was an expectation among some people that they would be required to "justify" their need for an abortion. There was a general sense of relief when this did not eventuate:

So I was kind of like trying to think of how I would be explaining myself, but I was sort of pleasantly surprised to find that nobody actually asked me these questions, which is great because I didn't actually want to explain myself, so that's good.

Victoria (WHC)

For Joy, her GP's approach to this served to further enhance her certainty regarding her decision:

I definitely felt more comfort from it, you know that kind of way. And she, yeah really was and reassured my own stand on it too, if you know what I mean. Being able to say it out loud and say it to somebody and say it, you know yeah directly as well and this is the decision that we've made.

Joy (GP)

Lack of judgement on the part of providers and not being required to "justify" the need for abortion care were particularly valued. This increased people's sense of being supported and entitled to access the care:

And even though like I did explain to the GP I said "look", I said, "we have x amount of kids already"

... she said "you don't have to explain anything to me." She said, "that's your choice", she said "I'm not judging you", she was very good, very nice.

And was that important for you, did that make a difference for you to hear that? A huge difference.

That you didn't have to justify yourself?

Yeah, yeah huge difference or even I don't know, just the fact even did they think I was having an affair, or you know?

Isabel (GP)

I would have briefly told her what my situation was but either way she wasn't judging me. She was just very kind. ... I mean you're already beating yourself up about it and you're just worried that you're going to meet someone that's going to beat you up even more about it. Because that's an outcome of every interaction you could have with someone when you tell them this.

Fiadh (GP)

Service users reflected on how a non-judgemental approach might be especially important for other women, perhaps who were younger or had less support. Gráinne noted that she was *very conscious of how others would have felt in [her] situation or how 20-year-old [her] would have dealt with it.* Such lack of judgement came as a pleasant surprise to Jill, who feared that Ireland being *quite a heavily Catholic or religious country* meant she *wasn't sure how [she] would be received.* 

For one participant, the language used by the WHC they attended ("crisis pregnancy") suggested to her that she would need to explain why she wanted an abortion. She did not identify herself as someone with a crisis pregnancy, describing herself as an established person in [her] 30s, [...] not like a teenager or somebody who has been raped or something like that... (Victoria). She later offered alternative phrases she felt would be more representative of her situation and acceptable:

Something like unplanned pregnancy, reproductive choices, like I don't like the "crisis" thing, it just summons up this whole urgent emergency and you should be feeling really upset and turbulent and it kind of seems like prescriptive of how you should feel in that situation.

Yeah, yeah, where for you that wasn't aligning at all with how you were feeling, it was yeah unplanned.

Yeah, I think I would prefer to attend a reproductive choices clinic rather than a crisis pregnancy clinic.

Victoria (WHC)

#### 6.2.v Receiving Information About the Abortion Process

For the most part, people were satisfied with the procedural information they received from their provider about abortion and the medical method, including on what the care pathway entailed, the medication regime for EMA and what was involved in self-managing the process. Discussion of My Options above demonstrated how information on that website was positively assessed by women. Women attending WHCs described how the information provided on clinics' websites was very helpful and informative in advance of attending for a consultation

I was reading on the website of the women's health clinic as well how it works because I didn't know that I am going to have to go through surgery, you know in the hospital to remove it or would that be, will I just be given medication. So, then I just read that up to nine weeks you can have the medical abortion and then if it's over nine weeks you just get, you have to go and have the surgery. So, I basically find out from the website. And then I called them they also explained to me everything when I was talking to them.

Renée (WHC)

When making the appointment, particularly when the remote model of care was in place, reception staff often outlined the care pathway to people.

Then the receptionist she just like you know checking the dates and asking you a few questions, like in very nice and polite manner, I didn't find difficult to talk with her. Just myself I was stressful about the situation. And then you know they explain when you can choose the date, when will be the next call, what you need to be, what they are going to send to you on email to have more information.

Orla (WHC)

First appointments with doctors were often lengthy as doctors explained in detail the care pathway and what self-managing the EMA would involve. Participants and doctors consulted by researchers explained that longer appointment slots were allocated for people attending for abortion care than usually allocated for consultations.

So that was the first half [of the consultation] and then she got into technical things say, you know the procedure and what I'd have to do and the waiting time and kind of generally how it would work when I got to her, do you know.

Hazel (GP)

This information was re-iterated at the second appointment. Clíona found this valuable, having been a mess [at her first appointment] and [...] crying like mad in there. She felt that having the information repeated by her providing GP was helpful because like you know only a little bit of it probably went in each time.

Overall, participants considered the information they received from their provider to be comprehensive, helpful and clear. Providers were described as both explaining the procedure ahead in careful detail and providing helpful printed materials. Joy commended the GP she had as being *brilliant the way she explained* everything out to [her] and everything. For Diane, receiving such detailed information meant that she did not need to call the My Options helpline at any time because the doctor [she] went to, she explained everything to a T and like she gave [her] so much information. Detailed and clear information was also a source of relief and reassurance, enhancing service users' sense of trust in the provider:

Oh yeah it was like a sense of relief, it was like oh this person got me. You know she's helping me, she's explained to me, because you could read it all and do you know and I did over and over and you can read it and you can look at it and it's like oh God but when somebody is talking to you it's much different you know.

**Yeah and she had the skills to be sufficiently reassuring and caring.**Absolutely.

Hazel (GP)

And all the time they were like trying to make me feel like don't worry, you have solution, if you want to continue with this that is no problem, if you need something just come here or go ask, like they care about you. ... You feel confident with them and you are not that scared probably.

Hannah (WHC)

As a non-native English speaker, Ruth felt that the WHC she attended explained everything so well that she resolved to continue to attend the provider for ongoing contraceptive care:

[Receiving contraceptive care is] something I'm going to do with them yeah, absolutely everything, so in the situation I was I couldn't be more comfortable and helped and everything was like they were explaining. It was all very clear for me.

Ruth (WHC)

#### 6.2.vi Timing the EMA

Women usually took the first medication during their second consultation with their doctor. Women described doctors giving a lot of attention to helping them identify the optimum timing for them to take the abortion medication, having regard to their wider commitments and schedules during first appointments and scheduling second appointments to facilitate that. Providers spoke with women to determine the best time for them to take their second pill within the context of various other commitments like work or childcare:

...you know she [the providing GP] was so helpful with that, she was like you have kids, you know pick a day that you think that might be easier, some people do it, take it on the weekend and then they can go back to work a couple of days later, she was so helpful with all of that.

Pippa (GP)

With the second pill they talked me through what I would do during the day, so I took it when my kids went to bed because my, after I had spoken to them I kind of reckoned I would rather have a rough night, you know that way rather than have to deal with it in the day when they're up. I would rather have no sleep and be in some sort of, able to get out of bed the next day rather than during the day feeling dreadful, you know.

Aoife (WHC)

For Helen, these conversations also extended to the timing of her first pill, when she explained to her GP that she was shortly due to go on holidays. The GP told her *you go on [the] holiday and when you come back, we've plenty of time.* This reassured Helen, who felt *ok that's grand, you know. There was no fuss, you know.* Doctors provided women with medical certificates for their workplace if it was necessary to enable them to have some recovery time after having taken the pills as Jill describes:

So, she gave me a doctor's note so I took, because I was scheduled to work the Saturday and Sunday, so I ended up taking the Saturday and Sunday off. And I was already off work on Friday, so I took it in the morning and just had the weekend off.

Jill (GP)

However, some avoided medical certificates out of concern that it might breach their privacy, as was the case for Katherine who *didn't want any questions*, wanting instead *to keep it as hush as possible.* 

#### 6.2.vii Preparedness for Self-Managing EMA

Overall, women felt well prepared by their providers for self-managing their EMA. Printed information to supplement the provider's explanation of the medication/abortion process was considered important because, as Barbara explained, although her GP had verbally gone through all these lists and things and side effects and everything, [it was] a lot of information to take in of a Wednesday morning. She also appreciated her GP having circled things that are probably more common or things like that because they're going to stand out of the book from things that are probably less common. Victoria who attended a WHC outlined the information pack and medication provided to her to support her self-managing and found it very comprehensive:

They sent me off home with the three doses of the second medication. And they gave me a pack which was very well presented, very clear, very good instructions and the instructions on there, said ok take your second medication and take those two pills and bleeding will start within, usually within x amount of time. If it doesn't start within x amount of time take the third dose. So, the bleeding did start within the timeframe that they specified. So, I didn't take the third dosage, because that's what the instructions were very clear about.

Victoria (WHC)

There was also good recall of advice given by providers regarding how to monitor blood loss during the EMA, and providers emphasised that women could either call them, the My Options 24-hour nurse helpline or, in case of WHCs, a hospital if they had any concerns:

... do call if there's, I think if you soak through a pad after two hours or four hours, something like that.

Quinn (GP)

They tell you that it's two pads, like that you actually have a kind of, it's not if you think you're bleeding too much, it's like two pads within an hour you need to ring the hospital. If the medication isn't taking away the pain, you need to ring the hospital. If you get a temperature you need to ring the hospital.

Aoife (WHC)

In terms of the accuracy of the provider's description of blood loss during EMA, women generally felt that their provider's description was quite precise, with Serena explaining *I felt it was in line with what [the doctor] had prepared me for.* Maria noted that her WHC doctor had adequately prepared her for the experiencing by having *really held [her] hand in the surgery the whole, walked [her] through the whole what to expect at what stage, time frames between this and this.* Notably, for Victoria, being *really prepared for there to be a lot of bleeding,* alerted her to the EMA having not worked correctly. She *just got a few, maybe like eight hours of cramping, bleeding, more than a period but like it wasn't what [she] was expecting.* This prompted Victoria to call the WHC she attended the next day for follow-up care.

Meanwhile, although women considered their doctors had done a good job of preparing them for what to expect during the process, they reflected that the process each person experienced was individual to them and a process one could only fully appreciate when experienced:

Yeah it was a lot heavier than my normal period, I was basically haemorrhaging. Yeah there is, you know there's a lot of blood clots coming which was actually quite frightening for me, I wasn't expecting it at all, it did say it in the leaflets, you know and online they were saying you know expect a lot of blood clots. But I'm not very good with blood anyway so that was a bit frightening for me.

Ok and did you need to call, the doctor or call the My Options 24-hour nurse helpline number that they had given you?

No, I didn't because, you know it did say expect it, like the doctor said it to me as well. So, you know I was expecting it but it was just still a little bit of a shock to me.

Brenda (GP)

Obviously [my GP] was very, she was very thorough when she went through everything but you still don't know what's coming for you. Yeah you still don't quite understand what's coming down the tracks until kind of it does hit.

Ophelia (GP)

I think she explained it well and she gave me leaflets and things to look through. I'm not sure that anything would actually prepare you for what happens, it was a bit, yeah just very unpleasant.

Elaine (GP)

Regarding pain, some felt that their provider over-prepared them for pain that did not eventuate. However, there was acknowledgement that this may have been necessary to accommodate a range of experiences:

I think the way she described it I was expecting to be in a bit more pain than I was, so I was kind of glad that I didn't feel that much pain, as much pain as she described. But maybe for other people it might have been a bit more painful.

Jill (GP)

In fact, some women did feel under-prepared for the pain they experienced during the EMA.

Ok and you know had she kind of prepared you for that then, that that's what it would be like? She told me it would be painful, but I didn't know it would be so painful.

Laura (WHC)

Ophelia's GP's use of *really bad period cramps* as a descriptor of the potential pain did not match up with her previous experience of what she considered to be bad period cramps. She explained:

I've been there [with bad period cramps]. I hadn't, I definitely hadn't [appreciated the level of pain to expect]. I was lying on the floor of the bathroom and it was just awful, it was just wave after wave and I took, I had a box of Ibuprofen extra or something that I'd gotten on the way home.

Ophelia (GP)

As noted above, advice given regarding what to do in the event of complications differed by providers. Some GPs told people to contact them at any time if they had concerns during the EMA. This availability was a source of reassurance, even if they did not need to contact the GP:

I knew she was at the end of the phone as well. You know so it was kind of reassuring that way.

Hazel (GP)

In some instances GPs provided people with their private mobile numbers to contact them on if they had any concerns during the EMA:

And who was the somebody that you knew you could contact?

[My doctor], I got her private number.

Ok, that was reassuring?

Yes, yes that if anything will be wrong just call her straight away. And it was her private number, so it looked like any time, she told me any time, just call me. And she won't come to me, but she will tell me what to do.

Fiona (GP)

On the other hand, many GPs and WHCs directed people towards the My Options 24-hour nurse helpline for advice regarding complications:

I didn't even know about [My Options] until I went to the women's health clinic. And they told me all the process. And it was one of the things they said to me, if you have excessive bleeding or any issues, this is where you go to find contact of what you do next.

Naomi (WHC)

While both GPs and WHCs were referring women to the My Options 24-hour nurse helpline, one person who had attended a WHC recalled being given a referral letter to hospital in the information pack received with the abortion medication, in the event that she needed to attend the hospital:

But then what they'd prepared me for in the material they gave me and the discussion with the nurse there was that there will be a lot of bleeding and cramping and here I'll give you a letter for if the bleeding and pain is too much to go to the emergency room.

Victoria (WHC)

Aoife, whose local hospital was a non-providing hospital, recalled being advised by the WHC doctor not to attend there in the event of complications but that they'd be nicer to you in one of the maternity hospitals in Dublin.

#### **6.2.viii Managing Complications**

Some participants reported experiencing complications, usually in the form of a positive pregnancy test result at two weeks post-abortion, or in one case a scan detecting a failed abortion. Women contacted their providers and were asked to return to their provider for further tests.

Yes, and then they wrote on [the test] when I was to do that. So it was at that point that I was like, it was the faintest little line and I rang and I said to them listen on the box it says X, Y and Z and they were like oh no to be sure to be sure come in.

Naomi (WHC)

People reported very timely responses when seeking appointments to discuss a positive pregnancy test:

So, I went into her, it was literally first thing the next morning, 9 o'clock in the morning the Thursday.

Brenda (GP)

However, for one woman, the combination of her GP's availability and her own work schedule meant that this appointment took place several days later:

...he's kind of hard, he only worked certain days so I think I had to wait a day or two and then obviously with my, I had to wait a few days, I think it was later on in that week because my job as well.

Jade (GP)

Pathways differed once the provider had confirmed a positive pregnancy test. Most were referred to hospital, like Una (WHC) who said *Anyway*, so they gave me another test, I repeated that, that was positive again and she said, I'm going to have to refer you to the maternity hospital. However, some people were referred to scanning clinics for assessment of post-abortion complications, although the HSE does not have a contract with a private scanning clinic for post-abortion scanning. Again, these referrals were generally made on behalf of the service user. For example, Brenda received a call from her providing GP about 40 minutes after leaving the clinic to tell her to go down to [the scanning clinic] now and they'll see you straight away. Regardless of the outcome, the time taken to arrange these follow-up appointments and/or referrals could mitigate or increase a person's stress at needing further care:

But sure, look I got seen to, the doctor literally the next day so look the doctors were great, you know they made me a priority. And you know there wasn't that much waiting around or you know it was done.

Brenda (GP)

So that basically, you know made me kind of, it gave me some kind of comfort that I knew that I passed it. That I knew that it worked. And you know there was no, I didn't have to ask them, you know I didn't have to beg them, ah like please can you like check this for me, no they were like happy to do everything really that had to be done.

Renée (WHC)

While the majority of participants described prompt response from their doctors when arranging referrals to hospital for complications, Jade, who returned to her GP after an unsuccessful EMA and was concerned that she was now coming quite close to the 12-week limit, described having to be very proactive to get the GP to send referring information to the hospital in order that she would be seen at the earliest available time there:

But I really needed to get into this clinic ... But ... I only have 12 weeks in Ireland, so there isn't an awful lot of time. ... except [the GP] didn't fill it out there and then, he got in touch with the maternity hospital and then said they would be back in touch with me. ... I rang at 4 and they still hadn't sent

the email. So, I went out and got the actual written forms myself from the practice, I had to drive to the GP's clinic to get them.

Jade (GP)

In a few cases where women had positive pregnancy tests following the termination, they were asked to return to their provider to have their hCG (human chorionic gonadotropin) levels monitored rather than being referred to hospital. One of these women, Therese, returned to her providing GP and noted from Friday to Wednesday that her hCG levels were still like dropping a little bit but still high. One week after her last pregnancy test, she tested positive again and got another set of pills from the GP. These pills did not cause Therese to bleed. The next day, she was advised by an on-call doctor who was covering for her providing GP that she should go to a maternity hospital. Reflecting on her conversation with the on-call doctor, Therese said that it sounded like [the on-call doctor] would have recommended that earlier, and questioned her GP's expertise: I don't know if I went to a different doctor would they have told me to like go to the maternity hospital like much sooner. Approximately four weeks had passed between Therese's first round of pills and her being referred to a maternity hospital. While there are existing clinical guidelines on abortion care, Therese's perception that the locum GP was questioning the management of her care led her to wonder were the standards being adhered to.

Similarly, Naomi was asked to return to the WHC she attended for repeat testing over several days, followed by another scan at a scanning clinic she had already attended for gestational dating. Like Therese, these complications eventually culminated in a hospital referral at close to the 12-week cut-off:

And that's when they identified, "hold on your hormone level obviously isn't dropping." So, then they did another one and I went in for a couple of days, every second day for a couple of days and I had the pregnancy test. And it was getting fainter, but it was still there and so long as it was there, and I was like "oh sweet mother of God" like. ... So then [the doctor said] like "no you can see like it has gone down a little bit but it's still there." And that's at the point that they said "right you're pushing now close to 12 weeks. This isn't a zero at the moment, so we'll do a blood test." And I was like ok and I went down, and I had the bloods. And they were really good, like they rang me and everything, spot on when they said they'd ring me like to go back. And they said to me "listen your bloods aren't coming down, can you come in" and it was great because they were like "oh we're open till like whatever time this evening so just pop in" and things like that, "you don't need to make an appointment, just pop in and we'll work around you." And it was great like. And I did that for a couple of nights, Jesus I don't know how many, I must have gone down about four times, three or four times. And then it was like "no you're going to have to, if it doesn't go down this time, you're going to have to go in."

Naomi (WHC)

Other people experienced complications that were not identified by a positive pregnancy test, often related to concerns that there had been too much or too little bleeding during the EMA. These complications were sometimes assessed and managed over the phone, while other participants returned to their provider for further assessment:

So, I let the kind of weekend roll out and I rang the doctor on Monday and she had me come into the surgery. I still was kind of thinking this hadn't worked but she took a blood sample and she sent it off and she compared it to the blood sample she'd taken the last week and it had come down significantly, the hCG levels. So that was kind of like a comfort that oh it actually has worked.

Fiadh (GP)

And I felt supported, yeah because after the Thursday when I took the second medication I didn't feel like it happened, I didn't feel like, because I didn't feel so much pain, I didn't have so much blood, so I was very, very stressed it didn't work. So, I called the women's health clinic to talk to a doctor and she called me an hour after I think to see how I was going. So even though I couldn't really see the doctor, I felt supported in that way. Because when I called she was calling me back right after.

Yeah and she was able to reassure you.

Ruth (WHC)

Fiadh reflected on how having the My Options 24-hour nurse helpline and the GP so readily available to her was comforting and meant she did not seek less optimal care elsewhere:

Or you know because if that service hadn't been in place and there had been no nurse to talk to or the doctor hadn't been there to take bloods, I probably would have just, you know gone online, ordered pills and taken more and you know until I would have felt cramps or pain or something.

Fiadh (GP)

Grace experienced severe pain and chills a few days after having called the WHC to let them know that her abortion had gone well. Rather than contact the WHC, Grace presented to a hospital where she ended up having a dilation and curettage (D&C) procedure to remove retained tissue.

The response of the provider to the complications was important. Polly needed to return to the GP who initially referred her for a surgical abortion because of severe pain caused by the coil that was inserted during the procedure. The GP became very alarmed by the severity of Polly's presentation, which only served to increase Polly's anxiety: she was shouting. And then shouting at me, this could be wrong with you, this could be wrong with you and I was in a full-blown panic at that point. Polly was sent straight back to hospital by her GP.

#### 6.2.ix Being Prepared for Hormone Changes After Abortion

A few people spoke of experiencing a drop in mood after their abortion, which they attributed to rapid hormone changes. These participants had mostly come to this understanding themselves. Polly (GP) recalled *I had to google it, that's how I figured it out* while Áine (GP) portrayed this as an understanding she came to herself.

Only one participant specifically spoke of receiving this information in advance from their provider. This was a source of reassurance for her when she became emotional a few days after her EMA that the GP had told her to keep in mind that I would have a big shift in hormones and that kind of thing afterwards. And that naturally with regards hormones I'm a mess in general. So, I was kind of expecting to, I was expecting to feel the way I was (Ophelia, GP).

Polly explained that she wished [she] would have been told was the drop in hormones of what that would do to you emotionally afterwards.

#### **6.2.x Attending the Third Appointment**

Oh yeah.

Attendance at a third appointment in the absence of complications was infrequent. A small number of women reported returning to their provider for a face-to-face consult while a few others reported attending a follow-up appointment with their own GP. One woman had a follow-up with a WHC she attended for counselling, rather than the GP who provided her with the EMA medication.

However, some recalled the offer of a third appointment only vaguely or not at all while others gave various reasons as to why they did not attend. For one person, the cost of travelling to the appointment was prohibitive, explaining that *it's crippling*, *like* [several] kids, like no medical card and trying to like afford a car, a home, I live in a rural area (Diane, GP). For another woman, a sense of shame precluded her from attending it:

#### Did you want to [attend the appointment]?

I don't know, I should have but I didn't because I kind of, I'm kind of like, this was like a few weeks ago and I was still kind of ashamed and I just wanted to be like over with and like never talk about it again.

Sarah (WHC)

On the other hand, some people chose not to attend the third appointment simply because they did not feel the need:

Yes I think the GP had mentioned it but I suppose because I didn't have any issues or concerns, I think it was up to me if I wanted to check back in or, yeah it doesn't feel like something I need to avail of necessarily.

Áine (GP)

However, one person queried a lack of follow-up from the GP after having been referred for surgical abortion. She expressed a sense of incomplete care, assuming that there would be more like an emotional health check in two weeks' time to kind of make sure you were ok (Irene, GP). Irene felt that such an appointment should be, not mandatory but [...] it should be a scheduled appointment irrespective because of the nature of your hormonal dump after the whole thing, remarking that you are going to be a bit like yuck, irrespective of how much you may have been comfortable or not with having an abortion in the first place. Expressing similar sentiments, as a woman alone in Ireland, Ruth felt that an appointment before she had taken her pregnancy test would have been beneficial just to check how are you feeling after (Ruth, WHC).

More common than participants attending for a third appointment was for providers to check in with service users by phone to inquire if all was well and if they had administered the pregnancy test and had a negative result as the care pathway sets out. Those who attended GPs sometimes had this communication by text message but phone calls were more common across both provider types. Fiona (GP) had been asked to text the result to her provider, *I text her that it is negative*. The response *ok thank you very much* confirmed the doctor received it. For many the form and format of the post-abortion check-in by their provider was satisfactory, with many such as Clíona (GP) saying, *I didn't need to go back in*. In a similar vein, Hazel explained that she would have travelled to a third appointment if necessary but the telephone format for the follow-up was better for her as it avoided having to travel: *a phone call was even better but if I had to go, I would have, yeah no problem* (Hazel, GP).

There was a general consensus that such communication was an acceptable means of closing out the process of the abortion. Receiving the follow-up communication felt supportive and was considered potentially very important for those without other supports:

And it felt like they cared, you know the way that they called me after two weeks, they asked me if I needed to see someone to talk about it and I was like no, no, I'm good.

Laura (WHC)

Is that something you think is, that you welcome, getting the call from them?

Yeah I think like, like for me it is ok, like I don't mind at all. But I think for like some people, it might be like really good, you know.

Dolores (WHC)

Participants who did not receive such communication often wondered that they should have:

But you wouldn't really hear anything from him afterwards. And I always felt that technically he should phone maybe once or twice after to see how you're doing like you know.

Helen (GP)

Similarly, while Gráinne acknowledged that having to do the test around Christmas had caused her to forget to contact her GP between one thing and another, she also felt there really should have been a follow-up call from one end.

However, others considered such a check-in to be of less urgency and were not concerned to have had no follow-up contact with their provider at the time of being interviewed, but did intend to make contact with their providers, as Aoife (WHC) explained *just to let them know that, so they can basically close it down*. Women who had been referred to other services for their abortion care or following complications after their EMA often wondered why their provider had not been in touch to check the outcome, although the importance placed on such a check-in varied. Victoria attended hospital after communicating with her WHC provider her concerns about low levels of blood loss, and queried whether they might have followed up with her:

I would have thought they would have tried to ring me to see how the hospital went but they didn't, so it doesn't matter.

Victoria (WHC)

For Maria, ongoing support and follow-up from the WHC doctor after her referral to maternity hospital was valuable, explaining that it just meant so much to feel like you know she was there for the journey, not just for the two appointments.

### **6.3 Implementation of Remote Model of Care by Community Providers**

As noted in the introductory chapter, on 6 April 2020 the Department of Health issued *COVID-19 Public Health Emergency Termination of Pregnancy – Temporary Provisions for Early Pregnancy Model of Care* in response to the COVID-19 pandemic. This revised model of care allowed for the first and second consultations in the community setting to be fully remote by telephone or video conference. The model of care advises that face-to-face consultations may be held if clinically necessary but such consultations should be kept to a minimum, and that duration should be kept to a minimum to reduce the risk to all parties. The service user is still required to collect the medical abortion medication from the clinic or arrangements can be made for the collection of medications, low-sensitivity pregnancy test, prescriptions and written information by a nominated individual or courier if the service user was unable to travel. Across the data there were different implementations of the remote model in GP and WHC settings.

Engagement with GPs typically involved the first consultation taking place remotely and the second visit in person. Remote consultations usually took place by telephone as opposed to video conferencing, though some GPs appeared to offer the option of both. Not all GPs implemented remote consultations during the remote model of care period. Some participants who received the service during the time of the remote model of care noted how they attended in-person consultations for visit one. For Barbara, it was relatively straightforward to attend this consult as she was local to the area where the GP was located. Jill explained that she attended in person for her first consultation because the doctor had to determine how far along [she] was.

WHCs offered two remote consultations during the height of the COVID-19 restrictions, both conducted by telephone, unless clinically indicated. The service user was emailed a soft copy of the different materials to read through in addition to verbal explanations given over the phone. The service user attended to collect the medication and instructions from the clinic reception. A noted feature in WHCs was the introduction of a process call/information session provided by specialist pregnancy counsellors as a precursor to the first remote consultation with the WHC doctor.

Victoria described the care pathway she followed in the WHC:

Yeah you ring up their reception, explain the situation to them and then they just, they set you up three appointments, two which are on the phone and one of which is in the clinic. And the first one is with like a counsellor and then you have the option of a follow-up chat with the counsellor as well. And they just scheduled all at once on the first initial phone call so.

Victoria (WHC)

Those attending remote consultations found them convenient and flexible, allowing the provider consultation calls to happen at times that suited their own schedules.

It's a lot easier for people to find like half an hour to do that phone consult at home or from work or whatever, than it is to physically go to the clinic ... I think it was totally fine the way it was done. I don't think the first appointment needs to be in person, I don't see any reason. It would probably be a better use of their own limited resources and you know like my own time and stuff, it's just quicker and easier to do that initial consultation over the phone. It doesn't need to be in person.

Victoria (WHC)

I didn't have to go and see my GP either, it was all through telephone, and once the hospital had confirmed with the GP that I was pregnant I didn't have to go. Now me personally that meant a lot as well, it meant that I didn't have to travel unnecessarily just for the doctor to do a pregnancy test.

Isabel (GP)

Of note, one person specifically chose to attend a WHC because the GP that they contacted initially was not doing remote consultations.

When I first found out, at first I called the agency helpline [My Options] and I talked to them for a bit and they kind of like gave me like options and they also did a bit of like counselling. And then I decided I wanted to make an appointment so my closest thing would have been my GP but when I called there they said they only had like free spots for like appointments in like two or three weeks and I didn't want to wait that long. So then I just called the women's health clinic and they said they could do the [remote consultation] the same day and then like the next one then in three days and then I could just pick it up.

Sarah (WHC)

Fiadh said she was so much happier to have a video call with her GP for her first visit which she described as taking the call from the comfort of her own home and being so less onerous than travelling the 50-minute journey to the surgery with her two young children. Instead the call was scheduled so

It coincided with a time where my husband was at home for lunch, so he was able to just take them out to the garden and I was able to wave them back in once the call was over.

Fiadh (GP)

People also commented that the remote telephone consultation made the service more accessible for those in more rural areas and living in locations where there are no local providers. Isabel called the remote consultation *brilliant* and said:

The fact that I didn't have to travel as I'm in a rural area to a GP that was, like I'd have had to, it would have took an hour and a half or an hour and 40 minutes maybe to get there.

Isabel (GP)

Hazel considered that remote consultation made the difference between her being able to access abortion care at all or not. She had to travel two hours to her nearest GP provider and noted that had she not been able to do her first consultation remotely she might not have been able to access abortion care. Having to travel for the two visits face to face would mean *like for me it's a whole day gone*, *every time you'd have to go*. She called the teleconsultation *amazing* noting:

That was fantastic actually considering the travel, like I would have done it no problem but considering it was 2 hours away and it was in the middle of Christmas.

Hazel (GP)

Serena, who also attended her first GP consultation remotely, reflected on the fact that her abortion care provider was a 40-minute drive away from the town where she lives. While she had her own transportation, she noted that this would be a barrier to someone else in her location seeking to access abortion without their own transport, explaining that

There's like no public transport link, like there probably is but like I mean you know you'd be talking about maybe getting a bus at 7 in the morning and having to wait around till 7 in the evening

Serena (GP)

This was the situation for Quinn who had to travel to access a provider in a rural area without public transport and involved her using a taxi that cost €95 for a round trip:

Obviously the taxi. ... it was quite expensive, I couldn't drive at the time...

Quinn (GP)

Women reflected that remote consultations were preferable regardless of COVID-19.

Purely from the point of it being less hassle and stress on the woman [...] Because a lot of women I would imagine are you know busy parents and they're whatever and they can't, you know get to X, Y and Z and it is a stress and a hassle and, so I think that the phone consultation is definitely a preferable way.

Gráinne (GP)

Concurring with Gráinne, Fiadh also said that she would recommend [remote consults] even outside of COVID times. She shared that she was 100 times more comfortable in [her] own home setting and that she found that very, very comforting just being able to have the video call. Elaine felt that the teleconsultant actually sped up the process because a phone consultation could be scheduled quicker than an in-person appointment.

Serena described how the telephone consultation meant she did not have to rearrange her work schedule and this convenience had the added effect of facilitating her privacy as rearranging work would have entailed explanations to colleagues:

So, like for me that made it one less [work] appointment that I had to cancel, you know one less [person] that I had to let down you know. You know and one kind of less excuse that I had to make, because like that's what we did and I suppose I should say that, like myself and my partner obviously know that we had a termination but like I haven't told anybody else. ... I felt like the less people I had to lie to, like the better. So at least with the telephone consultation, like I did it in my car just before I went into work.

Serena (GP)

Remote consultations conducted shortly after the service user calls the GP surgery facilitated quick referral to hospital for abortion care. Tanya contacted her GP provider after nine weeks' gestation when she no longer could avail of community-based care. She described how her GP called her back and was able to refer her for hospital care half an hour after she contacted the surgery. Similarly, when Isabel contacted a GP provider, she received a call back and a teleconsultation the same day. This worked to Tanya's advantage as she also had to be referred to hospital due to gestational stage:

The doctor was very quick because when I told her the exact date, I knew when it was, she had it calculated. Because I was, she said I'm calculating it different than it should be calculated I was actually further on pregnant than I thought.

Tanya (GP)

People who were attending a doctor they had no prior knowledge of liked the remote consultation as an opportunity to meet them in a format they had more control over than the setting of the doctor's surgery, before attending them face to face for care:

It was good for me to see the person, actually who I'd be meeting on that Thursday and how well she explained everything to me ...yeah I did find that comforting actually.

Joy (GP)

If she had made a bad impression on me or if I didn't feel that the rapport, if there was, you know if I didn't feel like there was a good rapport with her I may not have gone through with it.

Fiadh (GP)

I think it suited me because I didn't know him. You know so I kind of felt like I got to get a kind of a sense of his personality over the phone...

Serena (GP)

As discussed above, some people who accessed care at WHCs under the remote model received an information session/process call (titled differently at each WHC) with a counsellor before their first consultation with their doctor. Of note, our data is limited to the experience of participants receiving such a call from one WHC service only. Within our study, women did not recall opting in to these sessions. Most experienced them as a source of information regarding accessing abortion, like Ruth who explained that the counsellor *guided [her] through everything*. Participants did not feel that their decision was being called into question in these calls, with Orla explaining that the counsellor *was just talking with you and you know she's not asking like why you made the decision or something like that. Just what is going to happen, they will be there for you and you know just walking you for the process.* 

However, opinions were mixed on the usefulness of this call. One person commented that as someone who identified as being *really direct and* [...] *just wanted the phone number and wanted it done*, she *was surprised that* [she] found it helpful (Aoife). Conversely, Dolores said that she would remove the session,

feeling it was unnecessary because the GP explained to [her] as well. And when [she] went to the clinic they explain to [her] again and [she] had all the papers to read after all.

Similarly, others felt that the information session was an unnecessary step, viewing it as potentially intrusive into a person's decision-making, especially for those who were certain of their decision:

I mean I'm glad that they offered it and I feel like you didn't really need it. It's good that it's there because maybe there's other people or women who are more undecided or they have more mixed-up feelings and they don't know what they want to do. So, talking to the counsellor can help you figure out how you feel about it exactly. Personally, for me like I think I just wanted to problem-solve basically, rather than like have a long discussion about my feelings and stuff because I felt like that's not what I want right now.

Victoria (WHC)

For some people, these sessions incorporated a counselling component. For Renée, while she found this helpful, it was in fact to cope with her anxiety arising from delayed access to care. She explained that, my main concern really when I was talking to the psychologist [counsellor], I asked her, I was like "ok tell me how not to feel stressed about it" and the only reason why I was stressed, I wasn't stressed about taking medication, I was stressed about waiting. Similarly, the counsellor who provided Orla's information session picked up on her anxiety regarding the long wait for care, further compounded by her isolation in Ireland:

Because you know I even had a call, I don't know what she is called, I think she's like a counsellor in the clinic. So I had the call and she said to me, you know when the first time you were talking you were like able, like you were breathing even intense (laugh), just like you are now breathing normally, I was laughing, yeah.

#### So she had noticed?

Yeah she had noticed. So I was nervous and trustful because they make it like very easy, at first she explained me everything, and then the counsellor call me, I cannot remember the date, I just remember that it was very long waiting, she just told me what dates I can choose and it was very long waiting and for me it was a bit stressful because I was working again and I just didn't tell anybody, just my friend and my family back in another EU country but they didn't know my decision yet.

Orla (WHC)

Beyond coping support with delayed access to care, other women also received validation or emotional support during the information session. For Anna, this was followed up with another call:

I didn't realise how it would affect me to be honest, I thought it would be, because just the way like I'm talking to you, it was just normal, it was like to my partner and you know and to my friend who I work with, it was normal, there wasn't emotion shown or anything, I was kind of like, you know it is what it is. But then when I spoke to her [the counsellor] out of nowhere just the flood of emotion came through and yeah I was in a bit of, I was a bit of a mess that day. To be honest I didn't expect that.

. . .

And you know and [the counsellor] was lovely and she did, she rang me the Thursday, my termination was meant to be on the Friday. And she rang me on Thursday and we had a consultation and she said you seem 100% more confident about going forward. I was like yes I am, I had a lot to think about.

Anna (WHC)

#### 6.3.i Overview of the Remote Model of Care

The remote model of care has increased accessibility of the abortion care service, particularly benefitting people in rural areas or parts of the country where the coverage of GP or WHC providers might be limited. People describe the remote visit as convenient and facilitating early access to consultations, consistent with their strong concerns for timeliness in seeking abortion care. For those who needed referral to hospital, the remote consultation seemed to speed up that process of the apparently faster initial point of contact with the community provider. Remote consultations from the comfort of one's own home and space were valued and considered comforting, and overall had high levels of acceptability as a format of care. Meanwhile there was no indication of lower quality of consultation, with people attending care remotely not feeling any less informed, confident about or supported in the care process.

Furthermore, as the remote model of care gave the flexibility of offering both consultations remotely, there is clearly further scope for GPs in particular to conduct the second appointment remotely. Within WHCs when the remote model of care was initially implemented both appointments were conducted remotely and then the service user collected the medication from the clinic. Participants proposed that consideration should be given to making this a permanent feature of the model of care.

Within WHCs, although the introduction of the information session/process call was to offer additional support to service users to allay any anxieties or concerns that might arise in relation to accessing abortion care during the pandemic, it is important that service users are aware the call is optional. While many of those who attended such an information session reported receiving valuable information during it, if people are unclear they can opt in it may have the unintended effect of appearing mandatory, and thus impact on people's perceptions of the accessibility of the service.

#### 6.4 Views on GPs as Providers of Abortion Care

Across the entire data set of women who accessed abortion care under 12 weeks, women shared their views on the appropriateness of GPs as providers of such care. These views were mixed. Some felt that abortion care was *completely different* to other types of medical care provided by a GP (Helen, GP), or that GPs did not have the specialist expertise required to provide such care:

GP is too broad you know for everything. They deal with all those sort of issues and situations.

Una (WHC)

Despite a positive experience with her providing GP, Brie queried why the care was not solely provided in a maternity hospital where GPs don't do it whatsoever and you just go into the Rotunda and they have like a clinic from Monday to Friday, 9 to 5 or whatever they have to work around. On the other hand, Clíona felt distress at encountering a woman with a small baby in the GP clinic she attended, and wondered if the service could be provided in a space where women were unlikely to encounter babies or there's pregnant people. Again we see a range of views on the effect of the model of care that is integrating abortion care into primary and maternity care settings.

For Joy, despite a referral from My Options, contacting her providing GP without the certainty that *all* members of staff were supportive of abortion was *nerve wracking*. This was because knowing that *it's a doctor's surgery and it's not like a specialised place for this* meant there was the possibility that other staff *mightn't exactly agree with the doctor, you know doing these services.* Joy felt the benefit of a specialised service was that all staff would *obviously be trained in a certain way then to deal with [abortion care] and not say certain things.* 

However, there were several expressions of support for GP-led care. For some, it was considered to enhance privacy and reduce the chance of encountering protestors, compared to attendance at a specific abortion clinic or hospital:

I think in a sense it is good [that the service is provided by GPs], it has its good and its bad, because you look at America and Planned Parenthood and there's big protesters outside, like you do see it, like even to this day there's still biblical people and we still have a couple here in Ireland outside maternity hospitals and things like that. And I don't think if you had a clinic that was specifically for it, it would be quite, I think women are less inclined to actually show up, because afraid of who would be outside.

#### The protesters yeah.

And stuff. I think in the sense at least you go to your GP and no one knows, only you and your GP.

Wendy (GP)

The local aspect afforded by GP care was also considered important. One woman spoke at length about how this increased accessibility to the care for her, not only within the context of COVID-19 travel restrictions, but also through enhancing privacy and convenience:

It would have been quite difficult to go to [a large urban centre], they're big ordeals because you know like that if you want to keep a bit of privacy, well what are you going [there] for... like just being able to walk into somewhere local and like I say I literally walked all three times, I didn't even step in a car, it's only a short walk. And go in and just sit down and whatever. And they talk away to you and next thing like that you can go to work, you can go home or whatever, you don't have to jump on the train or something, a bus or drive three hours down the road or whatever or planes for that matter. The local aspect definitely makes it a lot easier.

Barbara (GP)

Finally, Áine, who did not typically engage with conventional medicine and reported previous negative experiences with GPs, reflected on her surprise at feeling that a GP was the appropriate person to provide such care. Despite her reservations about GP care and conventional medicine in general, the expertise of her providing GP meant that she came to consider GPs as the appropriate providers of such care, reflecting that having time to have a conversation with someone who really understands the process and the medications was very useful.

#### 6.5 Views on WHCs as Providers of Abortion Care

For the most part, women who attended a WHC were supportive of those services as providers of abortion care. There was a sense of them being a "specialist" service – experts in the provision of women's health care, and particularly more so than a GP. Naomi recalled thinking *I'm just going to go to the women's health clinic because I'm not even getting into it with [the GP] here like, I'm just going to go where I know it's normal process for them like.* 

Some believed they afforded privacy as Anna (WHC) mentioned: *I knew I wasn't going to bump into any of my friends or my family*, or protestors:

Yeah and then I sort of, it was all around the time ...they were on the news about people were protesting outside hospitals because people were having like procedures and all. And I thought no one would ever know what you were going to the women's health care clinic for. You could be going for a blood test, you could be going for a smear, you could be going for anything.

Naomi (WHC)

While for a few, the ability of WHCs to offer counselling support was helpful:

I continued with the women's health clinic service and I went to see a counsellor in a city centre location so I'd just go after work. ... it was really convenient.

Maria (WHC)

However, Naomi wondered if it would be safer for some service users to remain at the clinic while their abortion was happening. These concerns were framed in terms of her own experience of having had an operation and [...] haemorrhaged twice after. Naomi had been informed that she was prone to haemorrhage, noting that it was very much in the back of [her] mind during her EMA.

#### 6.6 Views on Coverage of GP Providers

At the time of writing (December 2021) 404 GPs in Ireland have signed HSE contracts to provide abortion care. In the absence of a publicly available list of such providers, an analysis of the geographical spread of such providers is challenging. However, many women spoke to the limited availability of providing GPs, particularly in rural areas. Additionally, some women engaged in discussion regarding the balance between spread of providers and willingness of providers to provide.

The availability of the service, especially in rural areas, often did not meet women's expectations. Women were surprised to learn that towns or counties they considered to be densely populated had few or no providers. Notably, several women used the word "shock" in relation to their discovery of this:

I was really shocked that there was, the closest to me was 30 minutes' drive away or nearly an hour away [both in different counties]. I thought wow that's a very small opening for where you can go. I just presumed it was, you know I knew not every doctor was going to take it up, but I thought, you know there had to at least be one or two doctors per county, surely. It wasn't that way. So, I was very shocked about it.

Pippa (GP)

I thought one of, I was sure there would be a doctor in my home town in mid-East or in the centre of county in mid-East rather than a health care service in village in mid-East which is really a tiny village, I was shocked it was out there you know, sorry.

Quinn (GP)

These concerns were further echoed by Jade, who lived in an urban area but was shocked at the amount [of non-providing GPs] that are around my house, there's about four GP practices. Several participants living in rural areas spoke of having to travel long distances to access a providing GP, ranging from journeys of about 40 minutes to two hours. People frequently questioned how those without access to their own vehicle or public transport would manage such a journey:

I'm lucky that I have a car. If I didn't have a car, I've no idea how I would have got there. But I live rurally anyway so that's kind of our life anyway, we don't use public transport, there isn't any, so. But yeah, if you're in a situation where you didn't have a car and you had to call on someone to take you or something, that would sort of add another awkward layer to it, so yeah.

Elaine (GP)

Do you know I'm lucky like, I can get into my car and I can go wherever I want to go but I know different people that can't drive and mightn't necessarily have been able to get to that other area, do you know or might have had to try and get a lift or get somebody to take them or do you know, just

added stresses that it's just, it's hard to see why there's so little uptake among the GPs.

Gráinne (GP)

The knock-on effects of needing to travel such distances were also queried. For example, how would people manage this while feeling unwell, or amid COVID-19 travel restrictions?

So if there was some woman out there that had no transportation, who is violently sick like me, like I was driving down the road puking into a bag. So she had to get on public transport while she's violently sick and literally getting sick every two minutes, cannot hold anything down, so there's people staring at her.

Brie (GP)

How are women meant to travel, especially with the restrictions now like, how are women meant to travel from one county to another if they're not, you know like?

Helen (GP)

People were mindful of the tension between forced and willing provision of abortion care by GPs and how this balanced against the need for ample coverage of GP providers. Providers opting in to provide the service was interpreted as an indication of their support for it. For Brie, despite the 40-minute drive to her providing GP's clinic, she valued having certainty on her GP's stance as a committed provider in advance of her appointment, explaining that without such knowledge she would have been left to wonder *does this doctor support this? Or are they being forced into doing this. Like is this a doctor that works for a GP that provides the service, but they don't want to do it? [...] Like are they looking down on you, do you know what I mean?. Similarly, Gráinne reflects on how attending a non-willing provider could be a negative experience versus attending a willing one:* 

The GP I dealt with was excellent, she was brilliant in giving the service that she gave. Maybe not every GP would be as sympathetic or as, you know professional about it, I don't know, you know if they're not in full agreement with the service that they're providing maybe they won't treat, and that would be worse, that would be worse to go somewhere and be, you know not given the, I suppose, I don't know the reassurance and the timely dealing with it and what not that you need to get at that stage.

Gráinne (GP)

The value of the committed GP provider was perhaps best exemplified by Ophelia who had initially attended an uncomfortable consult with her own GP. Having attended her providing GP (a 25-minute drive from her home), Ophelia reflected that:

I'm glad I got to meet with her. Even if it was a case that my local GP had that service available. Looking back now, and again I wouldn't have known this only for the fact, but I would have preferred having those conversations with [the GP I attended].

Ophelia (GP)

There were also some concerns that forcing GPs to provide the service could have potential negative implications for service users, through GPs trying to coerce people into keeping their pregnancies:

Whereas if you will push the doctors first, oh maybe you change your mind, oh maybe you will have other options, are you sure, I wouldn't like to... speak like that, I came here with my decision, don't try to change my mind. And it is not the time for ideological speaking, you know ideology and other options no, that's what I want...if you will push the doctors to do it, it will be like that.

Fiona (WHC)

Conversely, Elaine took a more objective approach to this, stating that *I don't think your own personal* feelings should really impact on another person. And particularly when you're a GP, and that although she felt lucky that things have changed here, and *I* had those options... it would be great for them to be more accessible for women. For Elaine, the GP's duty of care to their patient should outweigh their personal views on abortion. Gráinne wondered that surely to God there's more like out there that would be willing to [be providers] and help people, and suggested that there needs to be a push put on somewhere, whether it's through the HSE or the GP's practice thing, whatever governs them [...] something needs to move on it. Another person felt that sole reliance on GPs to opt in as providers of abortion care was the wrong approach to take because the cultural shift required for them to provide the service would mean it would take a long time for it to be widely available:

And it [should] not just be you know a GP-led thing either, definitely ... because you know we still live in that old Ireland, you know where, I don't know because where I live anyway in this part of Ireland there's a lot of judgement still, do you know. And I think, I can't see anyone, any doctor in this town in the next five, six, maybe even 10 years offering to do that service.

Joy (GP)

#### **6.7 Assessing Community Providers**

Most participants were very positive about their experience with their provider, be it a GP or a WHC. Many complimented the provider and the service they delivered:

Pretty much like and again like the GP I dealt with was an absolute lady and she was fantastic, she couldn't have been nicer. So, I don't have any, I've no negative experience from it or anything like it.

Gráinne (GP)

It just was, it was really, really positive I have to say. And even down to the receptionists and stuff like that I have to say everyone was you know so discreet and you know I couldn't fault, absolutely couldn't fault.

Maria (WHC)

Some felt that the service they received from their GP or WHC doctor was exemplary:

I do think that the individuals I engaged with really would set the bar for this model. And I would hope that they would get some feedback that they were on the right track and do you know that the training or whatever they've received has been adequate and that, yeah that it can make such a big difference to women that might be attending. And maybe influence others who had a less than positive experience, you know that they might realise that there are other ways of managing it or delivering. Yeah, I think it was good to experience that from my perspective.

Áine (GP)

So like they were very, yeah they were really helpful. Like it's, whatever, I don't know if what they do is standard practice but it's really, I would say it is kind of the way to go probably you know for the amount of care that they give.

Aoife (WHC)

Diane perceived her GP as providing the service not just because it was her job and she had a role to play, it was actually like you need to be ok [...] it wasn't just "oh I'm a doctor, here's your tablets, get out" like. The overall consensus in the data was that the care people received surpassed expectations, given that it was both new in Ireland and a contentious area of care, and within the data very few had anything negative to

say about their provider. Therese was a notable exception to this as she criticised her GP for not referring her but instead managing her hCG levels remaining high following the EMA, by monitoring her for four weeks without referring her on to a hospital for further assessment. She recalled that the locum GP, who eventually referred her for hospital assessment, seemed surprised that this had not happened earlier and queried the providing GP's management of her case. Therese felt this delay had put her at risk of passing the 12-week gestational limit without having an incomplete abortion ruled out.

For Quinn, the service she received from the WHC she attended for counselling and post-abortion care (after receiving abortion care from a providing GP) was so satisfactory that on reflection she would have preferred to have gone straight to the WHC because the women's health clinic were just better than everyone. And so great. In addition, people who attended a WHC often reported that they would be happy to return to the clinic for further reproductive health care if needed or recommend a friend to attend there. Dolores felt similarly positive about the service at the WHC she attended, commenting that it was pretty good actually, yeah, [...] it was pretty good apart from the counselling [information session/process call] [...] that for me was like irrelevant.

Among those who attended GPs, some reported GPs going outside usual practice to demonstrate their commitment to ensuring women received the service and were fully supported during the care pathway. These included GPs sharing their personal mobile number with women, or in one case a GP sending a follow-up letter to a woman who had forgotten to provide her mobile number.

I got a letter in the post and I remember finding that really, really nice, that I got a letter, I had never given a phone number I think and just not in any way on purpose, I just forgot to give my contact details other than my address. And I remember just getting a letter from the GP saying you were in with us for so and so, I just wanted, and you never left a phone number, I just wanted to check if you were ok and if you could contact us. And I remember it was such a tiny letter, like there was literally two lines on it and I just remember being like Jesus that's nice.

Clíona (GP)

Furthermore, GPs sometimes went above and beyond to accommodate the specific needs of individual women. Examples included a GP who tried to ensure that the timing of pills would not interfere with the woman's enjoyment of the Christmas holidays and a GP who opened her surgery on a Saturday because the woman could not get time off work to attend the second appointment. These demonstrations of commitment to service provision were noticed and appreciated:

But even him saying that, you know like it felt like this person actually wants me to enjoy the festivities and not just be like "here, there it is."

Katherine (GP)

So obviously that was the nicest gesture, you know she could offer and that was like really helpful for me.

Barbara (GP)

Overall, a provider having an empathetic and approachable manner was a particularly important source of reassurance at a time when they felt vulnerable and anxious:

So I went in to the GP and he was lovely. He gave me a big hug and all, he was just like so nice. I was just crying non-stop. And he was... he just made you feel... he said right so what's the story, like, what's after happening?...Some doctors you go into they're strict, you know, they're set in their ways and he was just like you were just talking to your friends, do you know what I mean.

Brie (GP)

Furthermore, normalising the need for abortion care was also helpful in supporting women to feel like they weren't "the only one" to need such care:

But she calmed me in the sense, she was like "it's not unheard of and don't feel, like you're the only one" like and I was kind of, I was like ok that was probably the best thing someone could have said to me because it just made me feel like ok this could happen to 100 people I know and I just don't know about it.

Barbara (GP)

## 6.8 Overview of Community-Based Abortion Care: Caring and Supportive When You Can Find a Provider

Overall, people were satisfied with the care they received from their provider. Many commended them for their non-judgemental and empathetic approach, with women attending GPs sometimes giving specific examples of how this was demonstrated. While these practices were appreciated, there is a risk of some of the more unusual ones, such as personal mobile numbers being given out for management of complications, being unsustainable in the long term. Such practices may need to be reviewed if abortion care is to be successfully integrated into primary health care on a greater scale.

People generally received clear and detailed information from their provider regarding various aspects of the abortion, including on legal requirements for accessing it and what to physically expect during a medical abortion. However, there appeared to be less focus on hormonal changes to be expected after abortion. This information may also be valuable to include in standard consults to facilitate a more holistic approach to care.

It was not the norm for people who did not experience post-abortion complications to attend a third appointment, and while a few did attend such an appointment, others were unaware it even existed in the care pathway. Communication via phone/text was appreciated as a means of checking in after the abortion, with some of those who did not receive any form of follow-up expressing a sense of incomplete care. Crucially, timely management of post-abortion complications when experienced is vital for mitigation of people's anxiety around such complications. Fortunately this was generally the case, with most women recalling their provider responding in a prompt and thorough manner and making appropriate referrals where necessary. On the other hand, the cases where this did not happen illustrate how poor management of post-abortion complications can serve to substantially increase a service user's stress and decrease their satisfaction with the care received.

Regarding GP-led care, although people were generally very positive about their experience of receiving care from their providing GP, many described the major challenge of accessing a provider in a context where such appointments are not universally and transparently provided by GPs. Pathways may differ in terms of their starting points – some contact GPs directly while others are referred to GPs by My Options – although both may require multiple attempts before an appointment is secured. It also seems that few non-providing GP practices are referring people to My Options, an issue that needs to be addressed. Furthermore, not all women are aware of the role of My Options, with some assuming that they will be able to access abortion from their own GP. This leaves people vulnerable to delay in access to care, most concerningly exemplified by Grace's story. In fact, the accounts of several women provide evidence to suggest that conscientious objection is being applied in a manner that contravenes that permitted by the Irish Medical Council's Guide to Professional Conduct and Ethics for Registered Medical Professionals. Beyond this, the lack of transparency regarding provision of the service means that some women (especially those who do not contact My Options in advance) rely on cues from previous interactions with their GP to

try to pre-empt their provider status – mental calculations that would not likely be required to access other aspects of primary health care.

Our data also show that people hold mixed views about the appropriateness of GPs as providers of abortion care. This suggests there is a role for other pathways within the model of care, such as WHCs, which were generally portrayed as appropriate providers of abortion care with the specialised knowledge to do so. On the other hand, there is limited provision of abortion care by WHCs, with these services being mostly concentrated in Dublin. Unsurprisingly with these limited resources, there were several women who reported having difficulty securing a timely appointment at a WHC, and this was the case pre-COVID-19 as well as during it. Therefore, while WHCs are an acceptable – and for some, preferable – alternative to GP-led care, they cannot be solely relied on as an alternative to adequate nationwide provision by GPs.

While GP provision of abortion care has been steadily increasing since the service was first implemented in January 2019, the accounts of some women highlight how sparse coverage, particularly in rural areas, remains a significant barrier to access. Notably rural women used the word "shock" in relation to their discovery of the limited availability of providers in their area. Some women were required to travel long distances to access a providing GP, a particular barrier for those who do not have access to their own vehicle. Nonetheless, there remains ongoing debate regarding the need for more GP providers versus the need for committed GP providers, and within our data set women generally were wary of encountering noncommitted providers. The data indicates a need to increase GP provision of abortion care, with a special focus on increasing uptake in areas of sparse coverage by those who are currently not providing for reasons other than conscientious objection.

Finally, it appears that the remote model of care has increased accessibility of the abortion care service, particularly benefitting people in areas where GP or WHC providers were limited. Overall, people described the remote visit as convenient and facilitating early access to consultations, consistent with their strong concerns for timeliness in seeking abortion care. For those who needed referral to hospital, the remote consultation seemed to speed up that process of the apparently faster initial point of contact with the community provider. Remote consultations from the comfort of one's own home and space were valued and considered comforting, and overall had high levels of acceptability as a format of care. Meanwhile there was no indication of lower quality of consultation, with people attending care remotely not feeling any less informed, confident about or supported in the care process. The data here supports making remote provision a permanent feature of the model of care. However, providers, particularly WHCs, need to assess carefully how the information session/process call introduced during remote provision is working in relation to counselling provision, to avoid people engaging with counselling without fully informed consent.



## Abortion Care in the Hospital Setting

This chapter presents analysis of data relating to people seeking abortion care under s.11 of the 2018 Act, which specifies that people will attend hospital for abortion care under 12 weeks' gestation at any gestational stage if clinically indicated, and in all cases after they reach a gestational stage of nine weeks.

### 7.1 Pathway to the Hospital: Getting a Referral

Getting a referral to the hospital is typically the first step in people's care pathways for hospital care. This represents people's first interaction with the hospital abortion care service in some capacity. Referrals are made from the GP or WHC directly to the hospital either for abortion care for gestational stage (7.1.i), for a medical condition (7.1.ii), or for follow-up care due to post-abortion complications (7.1.iii). Additionally, although self-referral is not possible for initial abortion care, service users can self-refer to the hospital setting in the event of post-abortion complications or may *attempt* to self-refer for their initial care (7.1.iv).

#### 7.1.i Referrals Due to Gestational Stage

Several service users were referred for hospital care due to the gestation of the pregnancy. Wendy was referred to the hospital at nine weeks and six days (on a Friday) and had an appointment for the following Monday. Her GP referred her when a scan confirmed that it was too late for the GP to administer medical abortion pills in the community setting. Likewise, Celia was referred to hospital when the GP she attended determined that her gestational dates indicated she would not be able to receive community care, and she expressed a preference for surgical.

When Tanya was referred to hospital by the GP she attended she was coming up to the 12-week gestation limit. Aware of this deadline her GP referred her straight away and she was called the following day with an appointment. The hospital was aware of the pressing time limit and endeavoured to get her seen quickly while adhering to the three-day waiting period.

And then she got the ball rolling from 30 minutes after that. And got in touch with the hospital... They gave me a call back the following day and then they said that it had to be three days, this was on the Wednesday, it had to be three days from, I think the time that you were with the GP and registered the pregnancy, is that right and then I requested, so the earliest it could have been done was the Friday. So, she said it will probably be the Monday but that she'd give me a call back and tried to organise everything.

**Tanya** 

#### 7.1.ii Referrals for Medical Conditions

Two people in the study were referred for hospital-based abortion care due to medical conditions. Anna was referred to hospital from the WHC she attended when it was discovered that her medical condition indicated her abortion care would be best provided for under the care/supervision of hospital clinicians.

Her referral to hospital was straightforward and she clearly understood the reason her care would be managed best in the hospital setting. Irene attended her GP requesting a surgical abortion due to her health condition, explaining that she was *pushing for surgical as soon as possible*. The GP referred her to a colleague in a maternity hospital, one that Irene had attended previously. The referral to this location was suitable to Irene and she was seen quickly.

And [the GP] knew the gynaecologist in a maternity hospital personally and I had already delivered there and I'd had a miscarriage there a few years before it so all my gynae stuff, and I'd been in the colposcopy there. So, all my kind of records were in that hospital. So, I said "look that would be brilliant for me too". And she said "I'll ring my friend and see if she can see you and there has to be a three-day wait anyway." So that was a Thursday, Friday, Monday, Tuesday so they booked me in for an appointment in the maternity hospital on Tuesday.

Irene

#### 7.1.iii Referrals for Post-Abortion Complications

An established pathway to hospital for people who have undergone EMA in the community setting is referral to hospital for post-abortion complications. Two women were referred for elevated hormone levels. One contacted her care provider when she was concerned that she hadn't experienced the level of bleeding she expected. After observing elevated hormone levels over several days, her care provider referred her to a maternity hospital for a scan. She waited about a week for that appointment (Victoria). The other woman, Naomi, was also referred to the hospital when her hCG levels remained elevated. She was reassured by the doctor there that she was *fine*.

A number of participants received a positive result from the low-sensitivity pregnancy test taken two weeks after the EMA. For Una, her negative perception of the Irish public health care system meant she was initially nervous being referred to a maternity hospital, sharing that's where I felt compromised because I thought oh my God public health care, Ireland, it will be months and months of waiting. However, Una was referred quickly, with the hospital ringing her directly to make an appointment for the following day. For another woman, her referral took a matter of days (Maria).

Ophelia was referred to the hospital by her GP several weeks after her EMA due to ongoing bleeding. When she attended the hospital, the referral letter she had been provided with did not connect her initially with the correct department. This consequently drew the ire of one care provider:

Yeah I ended up with a letter and I went to A&E [Emergency Department] and A&E said "no you need to go to EPU [Early Pregnancy Unit]" so I walked across to EPU and EPU said "no you need to go to maternity". So then ... [I] went up to maternity and maternity said "you're really supposed to come in through A&E", she was a real cross lady on the desk in maternity. And she wasn't at all happy with me.

Ophelia

Within the data set, there was one case of a failed abortion. Jade discovered her abortion had failed when she was at close to the 12-week gestational limit. As described previously, her GP was slow to send her referral forms to the maternity hospital. She had to drive to her GP's clinic to collect the referral forms, as she had been informed by the maternity hospital that they would not be able to see her in the clinic she was supposed to be attending that evening without them.

#### 7.1.iv Self-Referrals to Hospital

Self-referrals to hospital for post-abortion complications can be either entirely initiated by the individual, or on the basis of the advice of the provider they attended or the My Options 24-hour nurse helpline. These

self-referrals are often due to acute symptoms. For example, feeling severely unwell a number of days after her EMA, one participant presented to the emergency department of a maternity hospital. She was admitted and it was later discovered that she had an infection due to retained tissue.

I started getting really bad chills on the bus, it was like a warm day, but I was getting cold sweats, my head was killing me, my stomach was not feeling good. I was starting to get real pains everywhere. My muscles were all aching. And as soon as I got off the bus I had to go into, there was a pub just off the bus stop and thankfully they were open. And I went in and I just asked them for some water and I just broke down because I was like, I was like unimaginable, I don't know it was such a strange feeling, my whole body just really sore. And I never experienced that before. So, there was something wrong and then I called my partner, we said we'll go to the hospital as soon as he meets me off the bus. It was like five minutes I was waiting there. ... when my partner came then we ran to A&E. After that I kind of, pretty much kind of blacked out.

Grace

Less common are self-referrals seeking termination of pregnancy. Pippa, having made the decision to have an abortion, had not yet begun to access abortion care when she self-referred to the Emergency Department of her local hospital with bleeding out-of-hours. Explaining to the nurse in the Emergency department that she had a positive pregnancy test, she indicated that she did not intend to continue the pregnancy. The nurse she initially dealt with was unsure of where to send her, telling her *I don't have any, I don't really know where to send you. I don't know what the next step is.* Pippa then saw the doctor in the ED, who said, *look we're going to have to send you to a different, larger hospital because you're bleeding* and the Early Pregnancy Unit at that hospital was not on call. Upon presentation at the other (non-providing) hospital, Pippa underwent more blood tests and was told she would need to return in a few days as *they weren't running the early pregnancy clinic.* Pippa ended up attending several appointments in that hospital, thinking she could access a termination. She was eventually directed to My Options. The self-referral route for abortion in hospital is not an established pathway, though Pippa was unaware of this and it was not made clear to her. Pippa's account demonstrates the potential for people to fall through gaps in the service.

## 7.2 Discussing the Options: Medical or Surgical

Participants who attended the hospital recalled discussing with their care providers the choice of abortion method. Reasons for choosing a specific option, where choices were made available to a woman, varied. Having been fully briefed on the methods available in the hospital she attended, Isabel chose to undergo manual vacuum aspiration (MVA). She felt this method was the one that most strongly aligned with her priorities for her time in hospital, explaining that:

I just wanted it over and done with, I didn't want to be bouncing around in and out of hospital wards. I didn't want to be seen, I just wanted to get in and get out as fast as I could.

Isabel

Expressing a similar desire to *get it over with*, Therese also chose a surgical method when she attended a hospital with elevated hCG levels and was offered either a surgical or medical method of repeat abortion.

Prior to attending the hospital, Victoria was aware of different methods that might potentially be available, with a preference for MVA. Having been informed by the doctor at the hospital that this was unavailable and you don't have a lot of time to decide, she was given 10 minutes to consider her options. She ultimately decided to proceed with a repeat EMA, having been recommended to do so by the doctor. Likewise, Jade recalled being guided towards firstly attempting another EMA. While in hospital she was administered multiple rounds of pills, though these did not fully complete the abortion and she was eventually referred for a surgical procedure.

One woman had planned to proceed with EMA on the advice of her doctor in the WHC. When she was referred to the hospital due to a medical condition her care providers at the hospital discussed the options again in detail:

[I] had a lovely chat with the doctor and the nurse and we all decided we'd go for the medical because she was telling me surgically like she did say there's a chance that there might be an obstruction to the uterus or something like that. Now they slightly thought, that kind of scared me. So, I said "look I'd rather go for the medical situation". So, we were going to do the medical tablet and I was going to stay in the hospital anyway, stay overnight just to keep an eye on me.

Anna

However, it was later discovered that Anna's medical condition meant that surgical abortion would be safer. She understood the reasons behind this decision and felt her care providers' expertise in this area meant they were making the best decisions for her; she *was in good hands*.

The data collected in this study indicates interest in surgical methods for some people at the upper gestational limit, like Niamh. Niamh had previously discussed the option of medical abortion with the GP she attended but was told at the hospital that it would be best to proceed with the surgical option due to the *chance of failure with the medical one*. Furthermore, Niamh was drawn to the option of being placed under general anaesthetic, concerned that she would not be able to *make it through [an EMA] mentally, if [she was] fully conscious*. Similarly, following a conversation with the specialist nurse at the hospital she attended, time constraints, and wanting to be able to *get home to the kids* influenced Tanya's decision to undergo a surgical abortion. However, unlike Niamh, she opted to undergo the procedure *in a clinic room under local anaesthetic,* not wanting to go into theatre.

Whether or not surgical is posed as an option to those attending for abortion care initially in the community setting is unclear. Due to a health condition, one woman had made it clear to her GP that she would need referral to hospital earlier than the typical 9-12 weeks for surgical abortion. Upon attending the hospital, she described how her GP first of all she had to get them to agree would they perform a surgical before the allotted time. It was also made clear to her that receiving a surgical abortion would depend on the size of the pregnancy and you know how visible it would be on an ultrasound and everything because it was quite early (Irene). During the consultation she was asked her reasons for wanting a surgical abortion. Irene noted:

she asked me what my issues were for choosing surgical and I said well there are many but one of them was that I could just come home, and it's done. I don't have to lie around having an essential miscarriage for days on end. And I'm a single parent and I'm in the house on my own and my partner was going to be away, and we don't live together anyway. And also my worries about just the way I would metabolise drugs because [of my medical condition]. So, I think my instincts were correct, they weren't doubting my medical concerns, but I don't know if they had this singular expertise in the condition I have.

Irene

Talking about the experience of discussing with her care providers her rationale for wanting surgical over medical abortion with a medical condition, Irene said:

I suppose I'm coming in with a very clear set of my own parameters and what I felt my body would be capable of and what I wanted. And that determined the decision for me. And I literally just wanted them to authorise their medical expertise over it based on my telling of how I felt my body would respond.

Irene

#### 7.2.i EMA Under Supervision of the Hospital

EMA under supervision of the hospital means that the service user takes both the first and second pills in the hospital until the pregnancy is terminated. In this data set we have captured the experiences of people who have already attempted an EMA in the community setting and then undergo a repeat medical under hospital care. Accounts of this procedure indicate repeat EMAs were often drawn-out events. Victoria was admitted to take several further rounds of the abortion medication under supervision:

So, they admitted me in on a Saturday morning early and then we did the first medication again. And then repeated dosages of the second medication to induce the cramping and get the material to expel. And in that context, they gave me five doses of the second medication.

**Victoria** 

After taking multiple doses of the medication, Victoria described feeling like her body had aborted the pregnancy but that visual inspection had not confirmed it, making for a stressful episode for her.

It really felt like that at least for me individually, like it took a really long time for the cramping to come on, it wasn't as intense as you were warned it would be by the nurses and the doctors... They give you like a little cardboard tray thing to catch the material and then some nurse will inspect it to ensure that the material is there. So, the nurses would look at it and be like "no that's not it, it's just blood clots, just blood clots". ... after the fourth dose of the second medication, like they were still telling me that I hadn't expelled the material. So, I was getting like really super stressed. And by that point my body had stopped cramping. Like I had this feeling of like physical, like my body was telling me you're done, you know. ... Whereas the nurses and doctors were saying no, that "you're not done, that's not it. Here we'll give you, this is the last dose of this medication and you know if nothing happens by tomorrow then we start again."

Victoria

In Victoria's case, a scan the next day confirmed that the tissue had been passed. Jade attended the hospital after a failed EMA. After a scan and consultation, it was decided she would have a repeat EMA under supervision of the hospital. The first medication was administered to her and she returned two days later for the second pill, assuming that it would just be a day case kind of thing. However, it was discovered that the doctor hadn't signed off on something that [she] could go ahead with the next pill. Eventually the staff managed to contact the doctor and it was confirmed that she could proceed. For Jade, who expected initially to attend the hospital as a day case, the process appeared to be drawn out beyond what she had been briefed to expect:

And they eventually gave the first round of it, thank God, like it was getting a bit ridiculous now. So took the pills, nothing happened. Four hours later another set of pills. ... Nothing happened.... And this went on till midnight.

#### So how many sets of pills did they give you then?

I don't remember. I think it was between every four and five hours. ... But they came in say just to check blood pressure. And then I don't think I seen anybody till, I really don't think I seen anyone till the next morning. They said they're very busy and that they'll talk to me the next morning. And if nothing was happening then they might have to go for a surgical end of things...

Jade

Having been under the impression that she would be out of the hospital that day, Jade had to rearrange her work commitments from the hospital. Jade was eventually brought for a D&C the next day. Similarly, other women also underwent surgical procedures after the additional round of medical abortion tablets they were administered in hospital were unsuccessful in fully expelling the remaining tissue. For Maria, after having

to return to the hospital *twice a week at that stage then for blood tests,* an earlier D&C would have been preferable, noting how she was *at the end of [her] tether* by the time it was offered.

Some hospital service users perceive taking a second round of the medical abortion pills as prolonging the abortion process. By that point they expressed a strong preference for the certainty of knowing that the surgical abortion has completed the termination successfully. Ophelia, who also underwent a repeat EMA under the supervision of the hospital noted how she *kind of felt a bit back to square one with it all*. Furthermore, having to take multiple rounds of abortion pills led Ophelia to consider her future fertility and left her with concerns about the impact of the tablets on her body, noting that she would have preferred if there had been discussion regarding a D&C at that point:

That at that point considering how conscious I was of future fertility and all those other things, that I would have preferred to have been able to have a conversation with somebody regarding a D&C instead of being sent home a second time because that was my main concern from the beginning was whether it affected and what outcomes would affect future fertility. And I think I would have preferred to have that reassurance knowing that everything was cleared and healthy going forward. Whereas being sent home a second time with more tablets, it was like oh what if this doesn't clear things now and the repercussions that that would have and all of that running through my mind on top of everything else.

**Ophelia** 

#### 7.2.ii Surgical Abortion

The reasons service users might choose surgical abortions included proximity to gestational limit, personal preference, or a medical abortion would not be compatible with their medical condition. Data relating to surgical abortion was generated with interviewees from both maternity and regional hospitals. Access to surgical abortion and the method provided is dependent on what is offered there, and there is no standardisation of methods offered across providing hospitals. Finally, some participants described having a D&C procedure for retained tissue, which is discussed here because some women were uncertain around the technical language of what they received.

Data collected from service user experiences contains some detailed descriptions of the surgical procedure, the preparation leading up to it and the aftercare. Overall people felt well prepared for the surgical procedure with the opportunity to ask any questions.

Yeah, everything was explained that they would have to you know they would be going in and they would be like numbing the area basically. And I was told all this and explained all this, I was told I wasn't getting something else because I was driving home afterwards.

Isabel

Yeah, now I met with like a couple of doctors who talked me through it and the person who talked me through the anaesthetic and like you know the side effects and all that kind of thing. But like it was just kind of like ah yeah it's just, in you pop, put on the gown and that kind of stuff and we'll be back into you in a little bit.

Polly

In discussing her surgical abortion Celia felt somewhat prepared but noted her care providers didn't discuss the procedure with her in detail, though from Celia's overall account it does not appear she necessarily wanted to have a deeper level of knowledge around the technicalities of the procedure:

I think I had four appointments altogether though, so I had my first check-up in the hospital and they told me the process that I was going to go through. But not even, like they just kind of told me like what time I would come in, what time I would get out and they asked me if I wanted any contraception for after.

Celia

Participants recalled taking the medication in advance of the procedure:

They handed me a tablet or two tablets or something to take, one the night before and one in the morning that would start the termination and then that was it.

**Pollv** 

Yeah so then I was sitting in the waiting room for a while and then they came out, one of the nurses came in and check my blood pressure and that again. And came in with the [medication] and gave me that.

Tanya

Private spaces, where they were made available, were appreciated:

[The nurse manager] then took some bloods and then, yeah popped me into another waiting room where I was on my own. And it was a bit more private. ...

Tanya

Irene, who also had a surgical abortion, described how her doctor explained everything to her about the procedure in detail, including asking if she had any specific wishes for the disposal of the tissue:

When I went into theatre, she showed me all the implements and she explained what everything was, and she asked me did I want to retain any of the pregnancy tissue. If I had any sort of religious affiliation and I wanted some, you know a service that they could organise this in terms of the hospital itself or I could take the tissues myself and I was like no [...]. Yeah so, they were very respectful of the fact that people might have had diversified spiritual approach.

Irene

Experiences of the procedure itself varied depending on if performed under sedation or local or general anaesthetic. In Una's case the surgical procedure for retained tissue was performed under local anaesthesia. She had initial reservations about the surgical procedure but found it to be less difficult than she had expected, describing it as an *unpleasant procedure* but not painful. She recalled that the procedure was over quite quickly, *like about 15 minutes for all the chats and stuff, about 20 minutes to have a rest after procedure. The procedure itself is probably 15 minutes, very quick.* Isabel, who opted for MVA, was advised to bring in earphones during the procedure:

And so, I just put on the earphones and I just kind of tuned out. The nurse manager explained to me you "know it will be a little bit uncomfortable", I kind of said to her "look it" I said, "you can't go through something like this and not expect to feel uncomfortable" ... Yeah, she was just, she was really kind she had explained to me she said "your body goes with it, try and relax" and I did that, I didn't move, I didn't flinch, whatever they told me to do I did.

Isabel

Similarly Tanya, who used the *gas* and air during her procedure, remembered being *kind* of zoned out. For another woman whose procedure was performed under general anaesthetic, it came as a surprise to learn the procedure was over:

And I went into the room, into the theatre, they just prepared me, got me on the bed and to be honest I thought I'd be wide awake the whole time but I was conked out, didn't realise, by the time I went back to the bedroom the surgeon came in and I said "I don't think you did the treatment because I felt like I was constantly awake" but she says "Anna you were conked out for 15 minutes, the treatment was done."

Anna

Following their procedure, women typically described several hours of monitoring before discharge:

Then they scanned afterwards to make sure that everything was ok. And then they did blood pressure once everything was finished and popped me back into the chair and brought me back to the room. And got me something to eat and made sure the bleeding was ok. I stayed for about two hours afterwards and then just got a prescription for three days of antibiotic ... and then yeah I was able to go home then after that.

Tanya

Now to be fair one of them after whatever half an hour or whatever she did knock on the door and she stuck her head in through the door and she just said "are you okay?" and I said "yeah I said I'm perfect". And she just checked in with me, then obviously because it was gone past 6 o'clock or whatever so the nurse, the head nurse out on the ward had to check me out if you know what I mean or sign me out. Just to do my blood pressure and check my temperature before I went.

Isabel

#### 7.2.iii Follow-up After Hospital-Based Abortion Care

The model of care advises there is an optional follow-up visit or consultation available to service users. Data gathered from service users on follow-up care specific to the hospital setting presents a mixed picture as to whether it was offered, if it was taken up, and people's preferences on its availability. In the accounts of hospital users, follow-up care can be understood to include low-sensitivity pregnancy testing, a follow-up visit, instructions to call if the person has any concerns, or a phone call from the hospital to the service user to check in on them. Some recalled follow-up from their community referrer, rather than the hospital itself. One woman for whom this was the case explained how she would have preferred a follow-up appointment with the hospital to discuss concerns regarding her future fertility:

But in an ideal world I think I would have preferred an appointment, be it with an actual, you know with a gynaecologist as opposed to [the GP]. That that be made for me. I felt like that was really missing, just to be told everything is fine. And again, maybe not everybody would want that in that they just want to move on but with the concerns I went in with, with regards kind of future fertility, that would have [been reassuring].

Ophelia

Similarly, others also did not receive any follow-up from the hospital. Victoria who was referred to hospital from a WHC did not receive follow-up from either service, but felt that *the prerogative to make sure that there was a good outcome isn't necessarily on them*. Another woman who attended for a surgical abortion recalled not being given the low-sensitivity pregnancy test when she was discharged from the hospital. However, it is not standard practice to give a low-sensitivity pregnancy test after surgical abortion as the provider can see on ultrasound that the uterus is empty.

So, I came back to them, was it a week after the procedure... when I rang them and they said "oh you can probably get it in a pharmacy" and I was like "alright". So, I rang two pharmacies that's near me and they don't do [low] sensitive pregnancy tests and they said "you can buy one on Amazon", I

was like "oh I don't know about that now". So when I rang the hospital and said "look, I went to two or three pharmacies and they don't do them" and they're like "oh right, well if you can come in we'll have it for you, we'll give you one". So, I legged it in one day and I got it.

Anna

Anna was informed that she could contact the hospital if she ever needed, but like Victoria noted *there was no follow-up, no.* Some received a follow-up phone call from the hospital services they attended. These calls were considered caring and were appreciated by those who received them:

Actually funny, the nurse manager rang me yesterday. ... Yeah to check, yeah checking in with me and to see how I was. How was I feeling, and had I any questions.

Okay, yeah, was that something you appreciated? I did, I did yeah.

Isabel

It's like wow, yeah like it's so nice of them that actually, that they contacted like, I don't know I thought like that I am going to be the one, like you know if something goes wrong that I'm going to be the one who is going to be looking for help and you know here like you know the hospital calling itself to ask how I am, yeah.

Niamh

Pippa, who (as previously described) self-referred to the hospital asking for an abortion, offered the below insight into the lack of follow-up care she received from that hospital. While Pippa felt they should have followed up with her in some form, given that they were a non-providing hospital, she wasn't surprised at the lack of follow-up.

But it was until the second scan that I was told "we can't [provide abortion], you know you have to basically just leave, here is a pamphlet and best of luck with everything". I wasn't, it wasn't followed up, I never got anything, there was no aftercare, do you know what I mean, like [the GP] absolutely did the aftercare but there was nothing, regardless of whether I went ahead with the termination, [the] hospital still don't know whether I did or not and they never followed up on it. They never followed up and said, "have you decided to get your termination, would you like to come back for another scan, are you still pregnant?" Nothing. There was "out the door, thank God she's gone because she was causing havoc here for two hours."

**Pippa** 

Polly was re-admitted due to a suspected infection when she was referred for pain in her abdomen postabortion. She attended the emergency department of the hospital where she accessed abortion care.

They had me on a drip and all this kind of thing and then she, they did a couple of scans, they did blood tests, all that kind of thing and they got no sign of infection. Which was great. And then I was brought in for a scan and just to check if the strings, that the coil was still there. ...the doctor said that she wanted me to stay overnight and I just was bawling crying. And she was like "what is wrong, you know we really need you to stay" ... I said that this is making everything worse, that I'm still going through all this and I can't just recover. And she said "that's fine, I completely understand, we'll put you in a private ward, you know it's no problem. But we do need you to stay because we think that your coil has perforated your womb and you're bleeding into your abdomen."

Polly

After receiving this information, it was then distressing for her to be put back into the same room she stayed in when she first attended for abortion care.

And then they put me back in the same room that I was in after my surgery originally. ... And so I was, that was traumatic, like that was absolutely horrible and so I stayed the night and I had scans and scans and tests and tests the next day and they couldn't find anything wrong. And the doctor said to me your coil is in the right place, try and stick with the pain for four weeks, if you can't stick it after that come back to us.

Polly

She was later released from hospital when nothing could be detected. Polly's GP followed up with her a week later and when she was still in pain referred her back to the hospital where they removed her coil. Afterwards she describes, *I was in pain for a day and I've been right as rain since.* 

## 7.3 Assessing the Suitability of the Hospital as a Location for Abortion Care

Some service users reflected on the location of abortion services within the context of both general and maternity hospitals. For some people, attendance at a maternity hospital might seem at odds with the widely held views about the purpose of that site; a place where a pregnancy is typically wanted:

And there's babies and there's pregnant women and there's girls who have miscarried. And you're going in [seeking termination].

Diane

Echoing the above sentiments, Maria found her experience of the abortion care service within the maternity hospital upsetting:

Well I mean ideally you know if the service wasn't attached to the maternity service I think that's, I mean there's been a lot of commentary about that already, I mean it's a new service I don't know how pragmatic that is but I found that extremely traumatic. ... Like when I went, when I was going to the women's health clinic and I was going to a clinic I was going for that purpose whereas the intertwining of my previous experiences...

Maria

However, Anna feeling so disconnected with the whole process meant that if she was with pregnant women [she] probably wouldn't have associated with the whole situation that [she was] going through. Reflecting on the location of abortion care services in the maternity hospital, she didn't find it distressing.

There was a perception amongst some services users that to attend a hospital would be lacking in privacy. For example, Katherine felt that attendance for abortion care at a local hospital might compromise her privacy as she is from a small community. On the other hand, for one service user for whom privacy was a major concern, attending her local hospital for abortion care was entirely suitable. Considering the alternative of a "dedicated clinic" such as is the case with some abortion care in other countries she responded, *I wouldn't have gone to a dedicated clinic* (Isabel). Isabel liked the idea of the abortion care service being offered in the general hospital because it normalised the service because *I could have been there for anything*.

Expressing a preference for self-managed medical abortion in the community, Diane anticipated that undergoing a medical abortion in a hospital would mean a constant medical surveillance of the body

(i.e. blood pressure, pulse, checking in on progression) and believed that type of abortion care to be *invasive* (Diane).

### 7.4 Assessing the Location of Services Within the Hospital

Related to the above discussion of the suitability of the hospital as a site for abortion care services, women reflected on different aspects of the location of those services within the hospital. Depending on whether the person attends multiple appointments, or must be admitted overnight, or is simply a day case, there is the potential for numerous different interactions with not only a range of care providers (including at non-providing hospitals) but also with other hospital service users. Although it must be considered that infrastructure is poor across many hospitals in Ireland and this is certainly not unique to hospital-based abortion services, service user reflections on their experience of the location of services with the hospital do offer some insight into potential areas for improvement.

Having to wait in areas where they are surrounded by pregnant women with wanted pregnancies could be distressing. For example, after a distressing experience during a scan at the EPU of a non-providing hospital Pippa, who had notified a nurse upon arrival that she wanted an abortion, was then led back to a waiting room with 20 other women and their partners. Pippa's experience highlights the necessity of non-providing hospitals treating people with sensitivity and awareness around their specific situation. Reflecting further on this Pippa clarifies:

Look, I get the health system and they don't have enough rooms or whatever but there should be private rooms somewhere. I'm not even talking about women that are looking for terminations, but women that come out of that early pregnancy clinic, being told bad news.

Pippa

Likewise, the distress of being placed in such situations was also identified by Maria, who had to attend hospital several times dealing with the complication of retained tissue. She described it as *so traumatic having to go in to have ultrasound with like loads of pregnant people all around me.* Similarly, Irene found coming across a maternity ward when attending for the abortion procedure itself to be upsetting:

when it came to the abortion procedure and where I was afterwards that was all quite intermingled with the hospital itself and that was a little bit psychologically "ah". So, there wasn't too much of a segregation for that aspect which I found a little bit hard.

...I went straight into a ward in the maternity hospital, which is probably like a disused delivery, post-delivery ward, like it's maternity area like you can hear babies crying. If you look through a glass pane at the end of the corridor you can see cots. ••• Yeah, and I just thought "no guys don't be doing this shit like..."

Irene

Furthermore, on the day Maria attended for a D&C to remove retained tissue she was accidentally put on the ward where women were having miscarriages. She found this distressing and said that when she notified the hospital staff, they were immediately apologetic and moved her, explaining human error had wrongly assigned her to that ward, which Maria accepted.

Experiences of wayfinding through the hospital itself varied. Irene was familiar with the hospital she was referred to, having attended before for other reasons. On the other hand, attending another hospital for care, Naomi described trying to find her way through it as follows:

It's like going to like Timbuctoo. ... Now it was a little bit difficult for me to find. The signage wasn't

great. But it was like dark mornings and everything like that, it was little bit lonely going around there, it wouldn't be the best place now for a girl on her own going into it. I was a bit like right this is a bit, because you're going right around the back of the building ... and it was just weird. It was a weird location, but I can understand why it's in that location because of privacy and things like that as well.

Naomi

While Naomi understood the rationale for the location, specifically referencing privacy, she noted the poor signage and her difficulty in finding where she was supposed to be. Naomi also recognised the importance of the integration and normalisation of abortion services, stating that people could be attending that specific area\_for any reason: there was other things I'm sure going on there as well so I don't know if everyone was there for the same reason as me. In a similar vein, Irene found that when she initially attended for her hospital consult, she was sitting in the same location as people attending for various colposcopy reasons, feeling as though this served to normalise the service.

From Celia, the route through the hospital to reach the department involved encounters with non-providing staff or people not related to the abortion care service:

I wasn't told where to go or what to do so I was kind of like, you have to go into the reception area and like there's a room that you go into and they ask you what you're there for. And you have to repeat twice that you're there for pregnancy termination. And you have to repeat that to like people through the hospital. What are you looking for, where are you going and you have to be like "I'm here for a pregnancy termination" and like they're not people related to the service. And so it's really hard to say it and you don't want to, like the most embarrassing thing ever, it could be run a bit smoother in that department.

Celia

The location of the ward where Jade was an inpatient was perceived by her as marginalised:

And I basically felt a little bit like I was, it was like 1930s Ireland and I was in a convent and I'm in this dirty little room off the side when everyone else is having their babies ... but I'm just in this room. There's a nurses' station there, there's something going on in another room here but I'm in this big room, old room on my own.

Jade

For Victoria, provision of the service through the public health care system meant that she felt anxious about staying in a public ward overnight, explaining that *in the past [she had] always had like a private room so you can kind of be miserable in private*. Meanwhile Anna noted the level of care her care providers took to enhance the acceptability of her environment during her overnight stay in the hospital:

they actually put me into a private room, like originally they said "we want to put you somewhere private because" obviously they said "we don't want to put you surrounded by pregnant women" because you know it's a sensitive situation. ... And "we don't want to upset you and all". ...they wanted me to feel 100% comfortable and because of [my health condition] they wanted me to have my own comfortable room.

**Anna** 

Hospital scanning services are also located in different areas. Despite waiting for [her] scan surrounded by you know loads of pregnant people, Maria had a positive experience of attending for her scan in the maternity hospital, explaining that [the staff] knew, you know it was obviously on my file that I was coming from the specific clinic.

### 7.5 General Reflections on Hospital Care

In evaluating the hospital abortion care people tended to be largely positive. These reflections focused on the specific care they received from providers encountered on their care path. Many commented on the staff, describing them as "helpful", "caring", "fantastic", "excellent", and "lovely".

The doctor, everyone there in the maternity hospital, like they're actual angels, like every single person I spoke to, like everyone knew, like I didn't ever have to like say why I was there, like everybody knew ... Everything that was going on, I was like so impressed, I was like oh wow.

Therese

You know everyone was lovely, again the nurses were all very, very nice and very thorough and the doctors were all great.

**Polly** 

Though experiences of staff were largely positive, one service user who was given a repeat EMA but would have preferred the certainty of a surgical procedure remarked:

But when it came to ... being told that this was what was happening, I don't think I felt like I could have questioned [the repeat EMA]. And maybe I would now but I didn't, nor did I feel like I could have then.

Ophelia

Beyond physical care, several service users noted the staff having also provided them with emotional support:

And I went to the room where they were getting me prepared and like I burst into tears and the girl was like "don't worry, its ok, it's going to be over soon, you're so brave" and she was so lovely. And she like gave me a pillow to hold and she was like "don't worry about it, it's all going to be ok". And she was like "I know it's really intense but don't worry".

Celia

There was one nurse ... and she could tell by me I was nervous and she just, I know it's probably, she probably shouldn't have but she like touched my hand and she was like "you're going to be fine, everything is going to be fine, I'll be here when you wake up."

Wendy

Several service users remarked specifically how the care they received from staff was really professional (Irene) and commended the lack of judgement from the care providers in the hospital:

Oh absolutely fantastic, excellent, I really, really, you know I can't say enough the hospital was brilliant. I have to say, and the times, there is fault found everywhere, I cannot find a fault, they were kind, they were caring, didn't judge me, they were understanding. They didn't invade me, they didn't invade my privacy. They just, I don't know they just got it, I don't know they just, I have to say it was very good.

Isabel

Similarly, overall assessment of the hospital provision of care was also largely positive:

All these awful stories you hear about public health care and it just feels like it's just going to be so awful. To my surprise it was actually quite a comfortable and fast service and they did actually give me a lot of care when I was in the hospital, in terms of giving me the room to think and all that.

Una

Although one person felt less favourably about aspects of the care, remarking that if it wasn't for the nurses [it] would have been, it would have been a completely different experience (Wendy).

Communication with hospital care providers features throughout the data. People's experiences of communication varied depending on several factors, but it is clear that good communication is essential to people's perceptions of the quality of care they receive. The clearer and more precise the communication, the easier it is to understand the information given about the abortion procedure and the more prepared people felt about what to expect. In general, service users felt the explanation of the procedure itself was good, they felt well prepared and their questions were answered by care providers:

Yes everything was fully explained. Firstly I have, well an explanation on the Monday once I was on the maternity hospital in Dublin and once again on the Wednesday before attending procedure, I was explained what's going to happen, how I can feel a little before, how I can feel after and stuff like this. So actually, any question I ask I got the answer for it.

Niamh

Although Polly identified that there was a good level of communication with her about explaining the procedure, she felt there could have been greater acknowledgement of the emotional side of the abortion process:

Just like anything, like even if they'd just given me the number of like a counsellor for afterwards or before or something, anything kind of to acknowledge it. ... Anything at all, like it was just very physical like. ... No, now they were lovely, you know but there was just, it was just kind of, there was never an opportunity to kind of talk about it or sit down and say so how are you feeling about it or anything like that.

**Polly** 

In particular, flagging counselling supports would have been welcome:

Yeah I never got anything like that, even like after the procedure, never was once told about like any mental health options or anything, nobody ever said anything like that to me.

Polly

For one participant, improved communication and updates around what was happening would have been welcome, making the logistics of her life easier to manage. Her hospital care resulted in a longer stay than anticipated. She was keenly aware of having to manage the logistics of her abortion and her life, while work and family remained unaware that she was in the hospital for this care.

Also, then I have work, I was supposed to be working and I've parents and people that are like "where are you" and you know I'm in the maternity hospital like. ... And because it's so personal but trying to keep it personal is actually really difficult, really difficult because you are in the maternity hospital for a whole weekend. ... I was like "I'm away with my friend for the weekend" so they were kind of fine about it but yeah if I'd had to go on any longer or if there was any complications.

**Jade** 

Those who attended the hospital for abortion care with a health condition found there was very good communication with care providers. Both women specifically referenced positive aspects of communication in their abortion care.

I had to have an anaesthetist appointment as well before this. So, I met with an anaesthetist and he had never met anybody with my condition, it's not very well diagnosed in Ireland but there are

hundreds and thousands of people with it here but a lot of them aren't diagnosed. ... So he had never met anybody but I just explained [my condition and] ... complications that can arise while I am under anaesthetic. I made the anaesthetist aware of the precautions that would have to be taken to prevent injury during the procedure. And it was great, like they organised that meeting, he came up, he was very friendly, he sat down, had a very clear direct conversation face to face.

Irene

When Anna attended the hospital for abortion care she initially was going to have a medical abortion, but it was decided due to her medical condition that surgical abortion would be a better option for her. When Anna spoke about the level of communication between the two different hospitals involved in her care (one being the hospital which specialised in her condition and the other being the providing hospital) and subsequently their communication with her, she said:

So, I went in, the first time I was talking to the doctor on the phone was when I was just gone on to five weeks. So, I had the theatre treatment at eight weeks because they had to make sure everything, that the process, that the communication between the two hospitals was spot on and that everyone knew exactly what was happening. So that's why they just wanted to-and-fro because it was hard to, sometimes I'd say it was hard to get the information. And they did the bloods, they checked my bloods to see if my bloods were ok. Unfortunately, my bloods were slightly down in my ability to clot blood so that's why as well they wanted to check with [the other] hospital as well. So, they were just being very thorough on exactly what they were doing. So, I appreciate that, and I felt that they were brilliant, they kept me at ease ... Yeah, I was never in the dark, never anything like that.

Anna

## 7.6 Overview of Analysis of Data Relating to Hospital Abortion Care Under s.12

Overall, women described hospital-based care providers in administrative and clinical roles as non-judgemental, highly professional and maintaining good communication, who made women feel cared for. The location of services within maternity settings was considered disconcerting by some women because of the opportunity it presented for encountering pregnant women and babies. It was perceived in some cases as the "nether regions" of the hospital, indicating it as in some way marginal to the setting, which diminished acceptability of the setting to women overall.

Within hospitals the absence of separate waiting areas for scanning and assessment and separate inpatient beds from maternity care facilities were also queried. The integration of abortion service users with maternity care service users within the hospital raised the possibility of encountering staff not connected with the service, who may not have been a sensitive or committed provider of abortion care. It also raises the possibility for human error and women being assigned to incorrect wards or areas. The case of Pippa self-presenting at a non-providing hospital requesting termination and encountering obstructed access raises the need for a protocol for non-providing hospitals to refer anyone requesting termination to a provider and/or My Options at the first opportunity.



## Mandatory Three-Day Wait

In order to access abortion under Section 12 of the Health (Regulation of Termination of Pregnancy) Act 2018, three full days must elapse following certification of the pregnancy as being under 12 weeks' gestation by a medical practitioner. This mandatory three-day wait featured in service user discussion across nearly all interviews carried out with people accessing abortion under s.12, and analysis of this data is presented here. As noted in the methods chapter, there were some issues that were systematically raised with participants in interviews. This mandatory three-day wait was one such issue, although participants often shared their views and/or experiences of it in advance of the interviewer asking any specific questions on the topic.

#### 8.1 Seeing it as a Legal Requirement

When asked their views on the three-day wait, women often accepted it as a legal requirement for access to care. For one woman, despite being so, so sick with pregnancy symptoms meaning that she had a strong desire for prompt access to care, she portrayed the three-day wait as simply something that she *legally had to* endure (Brie). This attitude was most often expressed by women who still had time (Naomi), although they often acknowledged that it could be different for someone approaching the 12-week limit:

Yeah, look it's not that, [the three-day wait is] not the worst thing in the world. Now if you're on a time slot, I don't think they should have that but if you're not on a time slot and you just have to live with it for the next three days it is liveable. You just have to deal with it.

Brie

## 8.2 Removing Autonomy

The three-day wait was viewed by some as having the effect of removing autonomy from service users, having been put in place *to keep somebody else happy* (Helen). Similarly, others felt the wait was of no personal benefit to them as service users, but rather put in place *just to shut other people up* (Aoife):

I remember the three days and I remember being a bit annoyed at the three days because that just felt like, that was pleasing somebody else, that wasn't I didn't think there to benefit anybody who was pregnant.

Quinn

Some questioned why their decision could not be trusted from the outset:

But for me at the time, because I was in like that time constraint, I was like why do I need to wait the three days, you know this is really what I just want to do.

Katherine

For Helen, the requirement to wait three days felt counter-productive to provision of a quality, user-centred service, by limiting access to timely care:

So, it's still taking that control away a bit isn't it like "oh we're going to give you the service, but you still have to wait three days", you know for fuck's sake, it's my choice, you know so, it's still that element of control that they're trying to do there.

Helen

Helen attributed this to the legislation having been debated and written by predominantly male politicians. She felt that *if men had to go through [abortion]* they would *have the best system in place, you know the politicians, not having to wait three days you know.* Likewise, Fiona viewed the three-day wait as a gender issue, something that enabled other people, especially men, to encroach on her decision-making:

What was your response during those [three] days? Anger.

Were you feeling that it was encroaching on your autonomy? And private decisions?

Yes exactly. They went into my life, ideological, you know.[...] And in those month, especially during those three days, you want to make decision only, you would like to, you would like to tell me what should I do and have any influence on my life, whereas you are a complete stranger, I don't know who you are, how do you live, what you did in your life. And I have to still wait because you are against. [...] Especially towards the older man.

Because that's who you associate as taking this power away from you?

Especially men, I was always, I always said that I never ever talking about abortion with men.

Fiona

## 8.3 Thinking of Other People's Needs

When considering the three-day wait, service users were often generous in thinking about a person who might be unsure of their decision. They reflected that while the wait wasn't something they needed and had little to no impact on their own decision-making, it might be useful to other people:

I mean it was annoying but I do think that it's for the best, like because obviously there's, you know there could be women that are going in that are really unsure about it and they could just make a decision, like for me I was sure about it but at the time I might not have been.

Clíona

I mean like for me I didn't change my mind in the three days but some people might be struggling a bit with the decision and maybe it does help to give them that space.

Victoria

Women frequently suggested that rather than being mandatory, the three-day wait could instead be operationalised with *an option to waive it* (Maria). Others felt a shorter time period might be more appropriate, wondering if *maybe two days is enough* (Wendy). One woman felt that it should be waived in cases of *sexual abuse* or for women who were approaching gestational limits (Brie).

## 8.4 Careful Not Careless Decision-Making

Throughout the data set, people portrayed themselves as careful, not careless, decision-makers. Abortion was considered as not being a decision you take lightly (Helen) or something that people are just going to like put [...] on their shopping list, you know milk, bread, abortion (Grace). On considering the purpose

of the three-day wait, participants often described the process of consideration they undertook *before* even contacting My Options or a provider. For some, they had spent already about three days making the decision:

I think by the time you've already taken the step to make the call to your doctor, you're kind of probably surpassed this three-day limit, you know you've already thought about it for three days. You know what you're doing.

Fiadh

Another woman pointed out that if she had been provided the medication during her first consult, she could have taken it home and changed her mind later if she wished:

I honestly myself I didn't understand the point of the three-day wait because if I had wanted to think about it I could like, if I did have like second thoughts or something I could have had the pill as well and then wait until I'm like completely sure.

Sarah

Furthermore, while some recalled having made their decision immediately after discovering their pregnancy, they were consistent in stating that they felt very clear on their decision from the outset:

There was no, I saw the test and it was like I called the doctor within like five minutes.

You knew straight away your decision?

Yeah like there was no, like I didn't need to think about it for three days, like nothing in those three days, like the possibility of like keeping it, like never ever crossed my mind.

**Therese** 

No, I was 100% sure from the start, from the moment I found out I knew it wasn't right for me at the time.

Hazel

In the data women were almost universally consistent in their portrayal of the three-day wait as having had next to no impact on their personal decision-making process, regardless of the length of time it took them to make their decision:

I'd say there is women who have changed their mind but I probably because it was such a big deal even to ring My Options and I was kind of, as soon as I kind of rang them and got GP names and I had a look at the GPs, as soon as that kind of happened, you could have said anything to me and I wouldn't have changed my mind.

Wendy

Yeah, personally my mind didn't change at all within those couple of days. It was because I'd taken such care making the decision I made, I felt it unnecessary.

**Ophelia** 

## 8.5 Heightened Emotions

Several women experienced the three-day wait as a period of heightened emotions, particularly anxiety and stress. Trying to maintain normal day-to-day life alongside waiting to receive medication or surgery was challenging:

It just made it you know, just having to wait for a week to even get an appointment and then having

to wait again so it was just, yeah for me personally it wasn't necessary and then it did add to the, I suppose the emotional kind of trauma of it I suppose. ... So just trying to, you know, keep everything, you know, keep everything normal with the kids, keep everything normal with work, it was just extremely stressful. I mean it's extremely stressful anyway, but I just felt [the three-day wait] really prolonged that.

Maria

Fear of detection of the pregnancy by others also became heightened during this waiting period for some:

I'd made that decision 12 days before this and I was still no further ahead but starting to show, I had started to show, it's not my first pregnancy and it was, you know I was starting. I had to hide my stomach and that was really tough because I was starting to show. It just made it a bit more real. And it was just very traumatic.

**Pippa** 

For others, the wait increased anxiety around the procedure itself:

I found those three days quite tough as well because it's sort of built up the anticipation for how much is this going to hurt, how much am I going to bleed, is this going to go ok.

Quinn

For a few women, the wait undermined their sense that they would access care at all, describing a range of events they imagined might occur to prevent them from attending the second consult. One woman had *all possible scenarios going through [her] head* (Sarah), while others expressed similar sentiments:

No it was very hard because I felt, I even felt like oh my God imagine if the doctor's surgery blew up, or, I was imagining what if I couldn't go ahead with it or imagine I couldn't get out of the house or I kept thinking of all of these crazy things. Like you know that someone would stop me, or I wouldn't be able to go ahead with it or he'll cancel the appointment.

Laoise

For one woman, such was her anxiety, she used her three-day wait to start making alternative plans for accessing care:

And for me it was stressful because I was so worried that I was like, I was just so worried that something will go wrong and they will not give me the medication and I am going to have to keep the baby which I didn't want. So, I already start making like back-up plans, like ok what am I going to do if this is not going to work, you know.

Renée

## 8.6 Being Aware of Time Passing

From the moment their decision had been made, women were keenly aware of time passing and expressed a strong desire to access abortion as early as possible. Wanting to prevent the pregnancy from developing any further often influenced this, with the three-day wait ironically meaning that service users were forced to *just get more pregnant* (Quinn):

I just thought, like I just felt, I don't know, I just felt bad because I had it inside me for longer, do you know that kind of way, like I don't know, I just felt like, I don't know, I just felt bad.

Zoe

Several women also pointed out how their three-day wait exceeded three days due to appointment scheduling. This further added to the time they were required to wait before being provided with care:

For me though because I went in on the Friday, and you know they said come back on such and such a day, so I had the weekend to think about it. And then I had another three days to think about it, you know it was kind of, for me it felt like a bit of a drag because you know I was 100% that this was what I wanted to do.

**Brenda** 

Yeah so, my three-day wait was a little longer than that, it was closer to a week.

Áine

#### 8.7 When Time Isn't on Your Side

For a few women, the three-day wait had/could have had disastrous consequences for their access to care. In one case it meant a woman was unable to access EMA in the community setting and instead had to be referred to hospital, as it had put her *just over* the gestational limit (Wendy). For Wendy this was not a desirable outcome, as she was fearful of having to enter a maternity hospital setting and encountering potential judgement from staff there.

I was petrified when she was like "look, we can't do a medical, it would be too much on you and you could bleed out" or stuff like that and I was petrified. I was panicking, I was like I'm going to have to go to a maternity hospital where there's a lot of babies and going to be looking at a lot of pregnant women and, do you know what I mean, they're going to be looking at me kind of going "why didn't you ring sooner?" in that sense.

Wendy

Regarding the three-day wait, women who had previously consulted non-providing health care professionals queried if this could constitute their first appointment, but learned from their providing GP that those previous consult(s) could not be considered as their first consultation. For example, Pippa had asked her GP if attending a non-providing hospital where she had been scanned could constitute a visit but her doctor explained that *unfortunately, this is day one of your day three* [...] you are going to have to come back to me again.

## 8.8 Overview of the Three-Day Wait: A Possibly Beneficial Option for Others?

People expressed different opinions on the three-day wait. Some viewed it simply as a legal requirement to be overcome, while others viewed it as a deterrent to care. Very few considered the three-day wait to be of any personal benefit to them in their decision-making process, while some wondered whether it may be useful for "other" women who might be less decided. For some participants the three-day wait was experienced as a time of heightened anxiety and distress, especially during an already time-sensitive period. People portrayed themselves as making careful decisions. Women feel it shouldn't be mandatory – but are conscious that it might be useful for another person, even if it wasn't for them. The data indicates the mandatory three-day wait should be removed from legislation. Instead, the model of care should retain a second consultation as optional for women to attend within a timeframe agreed by them and their provider while allowing the service to be delivered within one consultation if preferred.



## Self-Managing Abortion

This chapter discusses people's experiences of the process of self-managing the abortion, reflecting the specific model of care implemented in the Irish context. Self-managing abortion encompasses careful planning of attendance at various appointments, timing of pills, arranging a space suitable for the duration of the procedure, and managing the body itself going through the process of the termination. Management of logistics is a feature for participants attending hospital-based services but aspects of arranging spaces and self-managing the body are not solely within the individual's control within this domain. Data gathered from service users demonstrates rich descriptions and embodied experiences of the EMA process.

#### 9.1 Managing Logistics

Under the original model of care, service users accessing abortion care under 12 weeks' gestation were required to attend at least two face-to-face appointments. Since the remote model was introduced in response to COVID-19, it is at the discretion of the care provider as to whether the service user is required to attend one or both appointments in person or remotely (although data gathered in this study suggests that most are requiring attendance at one). Participants in the study detailed the various logistical arrangements that had to be made to facilitate attendance at these appointments.

Travelling to appointments could be a particular challenge for women who were unable to drive, had no access to public transport, and/or had to travel long distances. In some cases lifts had to be relied upon, as was the case for Diane whose *friend [drove to two appointments over an hour away] because [she didn't] have a full licence.* Further, the disjointed nature of abortion services could mean travel to multiple locations; Naomi remembered *jumping all around the place.* The necessity of travelling during COVID-19 lockdown periods represented an additional source of anxiety, with service users expressing fear of *being stopped at checkpoints* (Hazel). Plans also needed to be made for a safe return home, with most women who experienced EMA being *fine to drive* after having taken the mifepristone (Aoife). However, those who underwent surgical procedures sometimes needed to arrange collection from hospital, with Tanya noting *I didn't drive home [from the hospital] anyway but if, you know if I needed to, I wouldn't have been able to.* 

Women with work or education commitments needed appointments that fit in with their schedules. Some managed to avoid taking time off work by booking appointments on their days off or scheduling them outside of work hours, like Clíona who shared, *I could have gone back on Thursday and got the first tablet, but I decided because of work, I'm off on a Friday so it worked out quite well.* Managing privacy in relation to having the procedure was a key reason that women did not want to arrange time off work. Some women did have to take time off work to attend appointments. Hannah arranged time off with her manager, asking him not to question her specific need for the time off, by informing him it was *something personal*. Having to attend at ultrasound appointments was another opportunity for abortion care pathways to conflict with work commitments. As a self-employed woman, Gráinne noted that the availability of an out-of-hours scanning appointment at the hospital she was referred to would have been more suitable for her.

Work or educational commitments also needed to be considered in the timing of abortion pills for those who had an EMA. Katherine took hers *during the weekend that [she] was off work*. While Elaine had planned to go to work the next day after EMA, she ended up not going in *because it was just all a bit too much*. Most service users recalled taking time off work to recover, often facilitated with a sick note by their care provider, with Jill explaining that her GP *gave [her] a doctor's note, [...] so [she] ended up taking the Saturday and Sunday off.* Similarly, those who had surgical procedures often needed to take time off work to recover:

[The doctor] recommended, she said "just in case give yourself the rest of the week, so have a breather in the weekend and kind of get your head straight before you go back to work", so I did that.

Wendy

Furthermore, post-abortion complications affected women's ability to work to varying extents depending on the nature and severity of the complications. Ongoing complications meant that Ophelia needed to take several weeks off due to exhaustion, feeling as though her head wasn't there at all. Some managed their follow-up for complications around continued attendance at work by arranging appointments outside of working hours or on days off; described by Maria as a very stressful time. For one woman, the severe complications she experienced following the insertion of the Mirena IUD during her surgical abortion meant she had to turn down a job offer, at a time when she really needed to get a job (Polly).

Children also needed to be cared for during the abortion process. Travelling to appointments meant that some women needed to arrange childcare. This could be anxiety-inducing as a potential breach of privacy, with Gráinne worried that questions would be asked as to why her daughter was not going with her when she normally brings her everywhere. As a woman who practised attachment parenting, Fiadh spoke of *the pain* for her to travel over an hour to a scan at a hospital as her young daughter could not be separated from her. This was made even more difficult by the fact her daughter was prone to car sickness.

It was common for those who had an EMA to put children to bed before taking the second pill so they would not be awake while the procedure was happening, with Hazel explaining, I took it in the night-time, yeah so put my daughter to bed and then took it. Some were able to arrange for children to be cared for by other family members/friends. Helen's friend told her listen I'll come over and we'll have dinner together and I'll sit with the kids so you can go to your room. It was important to service users that their children were well cared for during this time, with one woman speaking at length about how she perceived the day-to-day tasks of parenting to conflict with the experience of home-based EMA, especially for women with no other source of support. She emotively asked, How does she have an abortion and be a mother at the same time? answering her own question by stating, It is impossible like, there's no way to do it (Brie). Conversely, while another woman agreed that it would be better not to be caring for small children during an EMA, she felt that you'd manage if you had to (Gráinne).

## 9.2 Setting up the Environment

Women spoke about the consideration they gave to ensuring the environment they would be in during EMA would be as comfortable as possible. Some described engaging in what could almost be described as a "nesting" process before taking pills. One woman organised herself early in the day so that by the time she took her second pill later, she could have some *cosy down time* (Áine). In Ruth's account of the steps she took to prepare for her EMA, she emphasised the importance of a clean and comfortable environment, recalling cleaning her house before taking the second pill so she could be at home and *not have to worry*. She also *prepared the second bedroom* in case she needed some personal space.

Some questioned how the dependence of the model of care on home-based EMA would be managed by a person without access to their own bed and bathroom, with Fiona expressing that *there should be a place* for such people to go. Those who did live in shared housing or with their parents spoke of the arrangements they made to ensure they would have a suitable environment for the EMA to occur. One such woman happened to have had a *hotel booked anyway* [...] in the city centre, which she described as a fortunate coincidence (Orla). Others went to a trusted friend or partner's house:

I was back living with my parents and it's obviously very personal and I didn't really want them to know that. So, I was staying with a friend then that weekend. So, I'd organised that with him and yeah.

Jade

Others had to be strategic to maintain their privacy. One of the younger women in the data set, Sarah, managed her EMA in her parents' house without them discovering. She achieved this by taking the second pill early in the day while they were still at work and then pretending to go to bed in the evening when they returned home. She noted that while this was manageable, it would have been a lot harder if they were like around and [I] would have had to, like, hide the whole day. Another woman spoke of having to take the second pill while her abusive ex-partner had come over to visit their children. He was unaware she was pregnant, meaning that she needed to find a space to take the pill where she would be undetected and construct a plausible story for her symptoms:

...he was actually here when I took the tablets. So it was really, like, awkward because you have to hold them in your mouth for like a half an hour so I was in the shower and just trying to avoid him doing it and I was like "oh my period is due" because I knew I was going to be bleeding. Within a matter of hours and I was like "oh my period is due" and all this and he was just like "Jesus Christ you're dying" and I was like "oh yeah I'm grand, they're just gone really bad".

Diane

While Diane managed to give plausible excuses as to why she wasn't feeling well, this does point to the potential risks a woman in a domestic violence or coercive situation might face if she has to attempt EMA at home with an abusive partner present. Luckily for Diane these explanations were accepted by the expartner who didn't suspect the true reason she wasn't well. As the medical abortion managed at home can leave people physically vulnerable to the reactions of their bodies it might not necessarily be suitable to a person in that situation due to the blood loss and length of time it might take to complete the process. Diane's account raises concerns about managing the medical abortion in a space that is not safe.

## 9.3 Preparing to Mind the Body

Women discussed the different preparations they made to care for their body during the EMA. Such practical preparations enable someone to focus solely on the abortion in progress. Women described putting practical arrangements in place like pain relief, hot water bottle, sanitary towels, and so on.

I was prepared for it. I bought medication, I bought sanitary towels and hot water bottle. I ate before and he did say that if you vomited after it wouldn't obviously, you know if you vomited it out, that you would have to get another. So I knew, you know like this is what should happen.

Katherine

While taking time off work might be understood as a given in this process, some people talked about it explicitly, demonstrating an anticipation of the process as potentially tiring for the body:

I was taking, like I was taking like four days off work. ... Yeah because I just say I don't know how exactly it happen, what will happen, I don't know, I just rather be at home, take four days and relax and see what is going on. And then I go back to work.

Ursula

It wasn't distressing no, absolutely you'd want, it would want to be at a time where you're able to not have to do anything, not have to walk, not have to be under pressure to be anywhere. Like it would be like a very bad period pain basically.

Gráinne

Women noted that self-care in this process was essential. Self-care, minding the self, and taking it easy were all spoken of as ways of being gentle on the body during a time when the body will be achy, tired, in pain and bleeding. For Gráinne, planning when to take the pill was important because *you just, you need to rest or you need to lie down or you need to whatever, you can't be, you're not going to be able to do it like in the middle of your general working day.* 

### 9.4 Putting Personal Support in Place

The data showed that most participants who had an EMA took steps to ensure they had some personal support in place for when they would take the misoprostol. Where people were in a relationship this was often provided by their partner/husband. Pills were timed so that their effects would coincide with a partner or husband's arrival home from work, while in other cases partners/husbands took the day off:

So, he took the Wednesday off work and he took the kids to, my children are in full-time childcare anyways because I work full time. So, he just took them to the crèche as if I was going to work and then he came home and we both just spent that day kind of in bed watching Netflix, just talking or whatever and yeah.

Serena

Laoise told her husband that he should go to work the day she took the second pill, explaining that she was *quite self-sufficient and quite independent* by nature. However, her bleeding became quite heavy, such that she needed to call him and say *you may come home*. Those who did not live with their partner spoke about arranging to be together during the EMA:

Yeah and what arrangements did you have to put in place as you thought about managing the

Just really scheduling a day off and my partner lives in [another city] so he made arrangements to come and be with me...

Áine

Women not in a (close) relationship arranged support from elsewhere. After being told that *it's very important to have someone around* by the staff at the WHC she attended, Orla arranged for her friend to come to the hotel she was staying at for the procedure. Another woman spoke to her friend on the phone before taking the first medication at home, recalling the importance of knowing that her friend was on stand-by and would come over if needed:

As soon as I got home I took like an hour wait, because I was having like second thoughts, I was like should I really do this, so I called my friend and she was like all supportive and she said if something happens she can always come to my house, all I have to do is call her.

Sarah

## 9.5 Taking the First Medication with the Care Provider in the Community Setting

People generally take the first medication (mifepristone) at their second appointment with their care provider. They then return to whatever location they have planned to go through the process. Symptoms described taking the first medication varied, though participants generally remarked they felt nothing or were fine. Several described going home to rest after taking the medication, like Zoe who said, *I came home like and like I just stayed in bed, and then I was fine that night.* After Hazel took the first medication, she was able to drive herself home noting *it was absolutely fine, didn't affect me, no side effects, no symptoms.* She felt confident she would be ok as her care provider had *reassured [her] that it takes a while to kick in.* 

A few described experiencing some symptoms after taking the first medication. Diane noted a slight pain in [her] stomach about a half an hour afterwards, like cramping but not cramping, it was like shallow cramping, explaining that she was tired and [...] just wanted to have a sleep to be honest. She later compared taking the first medication with the second, saying that the first wasn't as bad. Another person felt a bit dizzy but nothing major (Orla). Fiona, who had gone back to work after taking her first medication, felt sick and had bleeding, demonstrating impacts for women who do not find taking time off work straightforward:

I was really pale because I felt really bad from the mifepristone, that first pill and I was really weak, sick. And [my employers] saw me and they send me back home. ... Luckily because when I was collecting my bag and everything the blood started.

**Fiona** 

Similarly, Ruth noticed bleeding after the first medication because *just before I took the second one* [...] I started to bleed.

Others did not experience any physical symptoms as such, but expressed sensing that the pregnancy was in the process of ending, or had ended:

I do remember like coming back out to the car and just feeling a bit numb, just feeling kind of ok that's, that's what's happened now, that's done.

Clíona

Yeah I knew on the Thursday night after I took the first pill that I was no longer pregnant.

Joy

## 9.6 Taking the Second Medication

Women typically took the second medication (misoprostol) mostly in their own home, with some going to a friend/partner's house and one woman booking a hotel for the duration of the procedure because she lived in a house-sharing arrangement. This is taken 24 to 48 hours after the first medication, which is usually administered with the care provider. The HSE information that people receive from their care provider advises that the misoprostol will make the womb contract, causing cramping and bleeding. Heavy bleeding usually starts two hours after taking the medication, though it may begin sooner or later. Possible side-effects are advised as including include dizziness, nausea or vomiting, headache, diarrhoea, temporary flushes or sweats.

The misoprostol is dissolved in the mouth, typically held in the cheek as Áine describes:

I held the second medication in my mouth rather than swallowing it and [the GP] said even if I was to vomit 15 minutes later, the medication would already be in my system.

Áine

During interviews women often re-enacted placing the pills inside their cheeks and holding them demonstrating strong attention to detail in following doctor's advice. Victoria took the second medication and was satisfied that the bleeding did start within the timeframe that they specified. About two-and-a-half hours after taking the medication, Ursula noted feeling my tummy is like something uncomfortable and then that my period start coming now. Cliona timed the medication to be taken exactly 24 hours after the first medication had been administered, also taking pain killers, and remembered that when it all started to happen [she] just spent the day in bed, hot water bottle. And just kind of kept [herself] as comfortable as [she] could.

Women's accounts illustrate a broad range of symptoms that may be associated with taking the medication. Women took great care to self-administer the second medication as their doctor had advised, and there was a fear they might inadvertently do it incorrectly. Several women described getting concerned when the process did not go exactly as they expected. Their accounts demonstrate the heightened states women were in when self-administering the medication:

I was again in a panic attack because after half an hour they didn't dissolve properly, one was quite big, and I swallowed them. Then I started to search what if I didn't dissolve them. Then I knew that they are for ulcer medicines and they can digest them and they are not making cramps properly so, oh my God.

**Fiona** 

I was watching that clock like a demon and I was going it's coming up on this time and this is not really dissolved and am I allowed to swallow it? So, I was opening all the papers and I'm really like that anyway, I'm a bit like, I love instructions and if there's any chance that something could go wrong, I get quite panicked about it. But once it did, it did dissolve.

**Pippa** 

When Brie's medication only partially dissolved, she swallow[ed] the bit that's left over and then [...] got sick. Brie then experienced a high temperature and did panic, and her mother's presence and support were crucial for her.

It was like I took a reaction. Now I didn't take a reaction but it was like I took a reaction. My body just literally went... it just didn't know what was going on at all like. It was so, so scary like. I just remember asking my mam, like, am I dying? Like can you actually die from this tablet, like, do you know what I mean? I couldn't get up, I was so hot and I was just constantly, I was getting sick to the point that I could not breathe. I could not get a breath in, do you know what I mean?

Brie

Brie also called the 24-hour nurse helpline who reassured her. Others described acute symptoms. After taking the second medication, Joy described she was *floored*, reflecting that she'd *had miscarriages as well so it was very similar* [...] *it was pretty severe*. Likewise, *maybe three to four hours afterwards* when the second medication began to take effect, Hazel experienced *very heavy cramping and very heavy bleeding*, *temperature*. However, having *been warned about all that* by her care provider meant she was aware this was normal. After Una dissolved the tablets in her cheeks, the process started quite quickly. Her account demonstrates women's attention to knowing exactly what was going on for their bodies:

That started contracting the womb and that did start within, after I swallowed the tablets 15 minutes it all started and, oh my God, it's painful process and loads of, loads of awful, yeah scary actually to look at, you know but that's what's happening and all that, it's very graphic type of thing. Like they said it's the heaviest period ever.

Una

Zoe took the medication and felt nauseous and had heavy cramping and bleeding which confined her to the bathroom for hours:

I took [pain relief] and I actually had to sit on the toilet of that, like I couldn't even lie in bed, like I was sitting in the toilet, I was getting sick into a bag, like it was just awful... For like four hours, yeah.

Zoe

However, several women took the second medication and noticed that nothing happened. Lack of cramping and loss of blood were interpreted as indications that the medication wasn't working:

When I took the second medication I didn't feel like it happened, I didn't feel like, because I didn't feel so much pain, I didn't have so much blood, so I was very, very stressed it didn't work.

Ruth

I just sat there waiting. And I got on with my day and nothing seemed to happen, I had no pain and no cramping and that's, you know maybe four, five hours later I started to get really worried, thinking this hasn't worked. And then of course the phone comes out and I start googling what if it doesn't work and I know I shouldn't have but I was just, you know I was getting really worried at that point. And I started to have like light bleeding but like nothing like a period and I was really convinced it wasn't happening.

Fiadh

Fiadh called a nurse who advised her to take the extra medication that had been provided to her. When additional medication is unused, people are generally advised to return it to their care provider but the additional dosage provided is half the first dosage and insufficient to induce abortion alone.

The doctors ... had given me an extra tablet in case nothing had happened. So the nurse explained to me to take the extra tablet so I did and then kind of, you know, I started bleeding a bit more but still no pain or cramping.

Fiadh

Similarly, Laura took another dose, having been advised to do so four hours after the first if nothing had happened, thinking it's time to take the second one. This dose took effect, with Laura remembering after 15 minutes shit happened. While many discussed taking time off work for the medical abortion, Barbara didn't want to, explaining No, so what I would say is it's actually more of a personal thing really to me, I wouldn't be, like I wouldn't be one to kind of complain. From her experience:

You're uncomfortable, you're not, you know you're not, as I say you're uncomfortable. You're only in [work] for seven hours a day and you can come home and sure can't you sleep for the rest of the day.

Barbara

#### She explained how her body felt in detail:

I suppose the way I'd describe it is the day before you get your first day of your cycle, you kind of feel it coming and you're just a bit groggy and just bloated and just. ... You just don't feel right and kind of I went to work and I kind of then felt like I needed a hot water bottle or something beside me, I was just, I was sore and it was obvious I was sore the way I was holding my stomach every few minutes. And like I really was not in a good way but. ... So definitely discomfort and soreness. ... I wouldn't say I was in great agony, I would say that I just felt like I needed to go home and crawl into the bed kind of, just not feeling great. But that was only for a few days.

Barbara

Some described the abortion process as physically draining:

I was in pain and I was so uncomfortable that it wasn't like, it wasn't an upset day, it was just, it was a physically draining day.

Clíona

### 9.7 Reading Bodily Signs that the Abortion Was Complete

Participants talked specifically about knowing their body had passed the pregnancy, either implicitly or based on visual inspection. The data demonstrated people as fully present and engaged in the moment for the medical abortion process and closely attending to the process of symptoms, bleeding and materials expelling from the body. Several participants explained knowing they had successfully completed the process through visual confirmation, like Jill who said *yes, I would say [it had passed] because it was quite a bit.* Helen explained that she was getting pains and that as she stood up the pregnancy tissue passed abruptly. Likewise, others were able to visually confirm the pregnancy had been terminated:

Like I did see what, you know it came out of me and I did see it and it was just a lump of cells, that was it, you know it was the size of the tip of one of my fingers, it was tiny.

Fiadh

I saw the little sac, like I knew, I got a really, really bad cramp and I don't know whether that was just because I've had kids and used to seeing the scans on the, you know, so but for me you could see the, like tiny and not upsetting or anything, you know but just. And I was actually just, I suppose I was kind of glad because you're kind of at least, well then kind of the chances of complications afterwards.

**Aoife** 

Other women described feeling the pregnancy passing. Brie knew she had expelled it because *she could feel something enormous*. Another woman was able to identify the point explaining it was like a heavy period, noting *I passed a very large sort of clot and I was like "right, that's it now"*. And then it started to ease off then after that (Elaine). This gave her certainty that the pregnancy had been terminated. For Joy, feeling the pregnancy pass reassured her *that everything had worked*. Similarly, when Brenda passed several clots at once she felt certain the abortion was successful, thinking *this is it, this is, it's all coming out of me now*. Another described remembering her care provider preparing her by telling her she would pass blood clots and tissue and feeling emotional when she realised this was happening:

I went and sat on the toilet and that was kind of, "oh that's happened now". And yeah it was, I think that was the one time I sort of got emotional about the whole thing was when that sort of happened. And I kind of thought maybe that's the thing that's come out or do you know, that was sort of the one time I felt emotional that day.

Clíona

Diane remembered the feeling of the body during childbirth and likened this part of the abortion process to passing the placenta in labour.

Several women discussed not looking for the tissue. One woman said, *No I didn't monitor it myself, she said you know that it's substantial* (Hazel), while another said, *But no I couldn't, I wasn't going to inspect anything* (Ophelia). While she didn't visually inspect for it, Ophelia did say:

At that point I kind of acknowledged what was happening but physically just tended to myself and didn't kind of take any notice of.

**Ophelia** 

Similarly, Gráinne found that she wasn't watching out for it. Having experienced a previous miscarriage and knowing what that process was like, she said:

I wasn't going to see anything, I knew, you know, I knew that already. I'd imagine if I hadn't been through it before I would have definitely been more watching out for, to see if there was something that I could see, do you know. But no, this time round I didn't, it wasn't an issue for me.

Gráinne

## 9.8 On the Suitability of Self-Managing Medical Abortion at Home – What do People Need?

From the above accounts of managing the abortion logistics and the EMA at home, it is clear that women valued having privacy, support and personal spaces like bedrooms and bathrooms they could have unrestricted access to. In their discussions of their own bodily experiences, women have been careful to consider whether management of the EMA at home would be suitable for people in other situations. One woman commented that self-managing an abortion at home might not be suitable for people who had become pregnant because of rape.

Like if I was raped, I wouldn't have went through that whatsoever like .... they should be just taken. **So definitely surgical abortion.** 

They should be just taken off straight away and they should be looked after with all the care.

**Brie** 

Reflecting on her own experience of EMA, Brie accepted the bodily effects – *Which I think is grand*, but deemed it as *scary* [...] *traumatising*, potentially unsuitable for others in vulnerable or difficult situations.

Another woman considered that EMA *must be traumatic, completely traumatic* for people who don't have personal supports in place (Clíona). Considering the possibility that EMA could be managed in a clinical setting rather than at home, one woman commented that it might be preferable if people didn't have support.

But yeah, maybe just for other people if there was a way of sort of being able to manage it with support if you didn't have the support at home.

Barbara

Ultimately having a safe, secure, and private space is vital for women to be able to self-manage an EMA, as described below:

But being able to be at home was, it was more important to me than the pain I thought I was facing because I was going to be able to deal with it all on the quiet and nobody would know.

Gráinne

## 9.9 Overview of Self-Managing the Abortion

Self-management of the abortion entails careful management of both the logistical aspects and physical processes of the EMA. Logistical aspects include the scheduling of abortion care appointments with care providers around work, care and study responsibilities; and travel to and from both appointments, though the introduction of the teleconsultant under the remote model of care alleviates having to travel on two separate occasions. Managing post-abortion complications depends on the individual situation, though it might mean multiple visits to the GP or WHC for monitoring hCG levels or a referral to hospital for follow-

on care. In particular, we heard that people with childcare commitments not only had to consider how their children would be minded during their abortion care appointments but also had to carefully consider the timing of the self-administration of the medical abortion. Participants made practical preparations regarding how they set up the primary space where they would manage the abortion and the provision of hot water bottles, sanitary towels, painkillers and extra sheets they had to hand. Data demonstrates that people had various personal supports in place during this process.

In terms of the administration of the medication, the first medication was generally taken with the care provider, while the second medication was carefully timed in consultation with their care provider to be taken at home at a time most convenient to the service user. Participants readily discussed bodily experiences of the medical abortion, including reading the signs to know the pregnancy had successfully been terminated. The data also shows that people were conscious of practising self-care as the medical abortion was happening. Overall participants valued having privacy, support and personal spaces in which to manage the abortion. Furthermore, the data demonstrated that self-management of the EMA could be difficult for those who lived in shared accommodation. Service users also reflected that for those without personal supports in place, or for those who have experienced sexual assault or living in a domestic abuse situation, there should be an alternative offered to the home-based medical abortion.



# Views and Experiences of Pregnancy Counselling Services

The HSE funds unplanned pregnancy and post-abortion counselling services delivered through the Sexual Health and Crisis Pregnancy Programme. These services are not linked to My Options, however My Options might signpost a person to one of these services. The services are intended to support people through an unplanned pregnancy. The services provide the opportunity to talk to a trained counsellor about the pregnancy and how it affects their personal circumstances; and to access factual information on available services and supports, including continued pregnancy supports and abortion services. The HSE-funded support services include face-to-face crisis pregnancy counselling services and telephone counselling and support. Face-to-face counselling is available in over 20 locations across the country and is free of charge to pregnant people, their partners or a family member.

Telephone counselling provides free and confidential information and counselling to support women six days a week and runs 9am to 9pm Monday-Friday and 10am to 2pm on Saturdays. A 24-hour nurse helpline is also available for women who are going through, or have gone through, an abortion procedure. The My Options service provides information to women about GPs and WHCs who will provide abortion services in Ireland<sup>16</sup>.

This chapter sets out findings from analysis of data within the study relating to participants' views and experiences of pregnancy counselling services at any point along the unplanned pregnancy and abortion care pathway. While most participants did not seek or use counselling, many offered a view on it.

## 10.1 Counselling Services Within Abortion Care Pathway

For the most part, people recalled being informed about the availability of pre- and/or post-abortion counselling at some point in their care pathway, e.g. by their GP, WHC, or in some cases in hospital. The information was provided in written format, verbally, or a combination of both. Several made comments like the GP would have given me the leaflets around that (Elaine), I was offered that, and I was told it was available as well (Isabel), and she wrote down a contact number for the pregnancy counselling services for me and gave it to me as well (Ophelia).

In Maria's case, the doctor at the WHC she attended paired the information about counselling availability with a suggestion that it might be helpful for her. Maria's doctor noted that she was under a lot of stress and probably very close to burnout even before any of this happened. Maria understood this as self-care and appreciated the suggestion to take some time for herself.

However, there were a few women who had not been informed about counselling in any regard. One woman wondered whether she didn't receive any information about counselling simply because she never asked

about it as she *already* [went] to counselling (Clíona). Others just said that they hadn't been given any information:

#### The design of the service is that there is this counselling support alongside it.

Yeah, I never got anything like that, even like after the procedure, never was once told about like any mental health options or anything, nobody ever said anything like that to me.

**Polly** 

Women may have benefitted from at least being informed about the availability of counselling. Polly had a somewhat traumatic pathway to her surgical abortion – the nurse at the GP clinic she initially attended misdated her pregnancy, leaving her very close to the 12-week cut-off and needing a surgical abortion rather than the medical one she had intended. In Ursula's case, she was a migrant woman living in a small town where she knew few people. Concern for her mental health was a key reason she had decided to have an abortion, but the first time she learned about the availability of counselling in the model of care was during her interview for the study, not from her GP.

One woman was able to talk about her experience of moving from face-to-face to remote counselling at a WHC. Although Grace reported preferring face-to-face (I like to be able to see what the person is, you know like how they're looking when you're talking to them about certain things), she reflected on how her counsellor's skill translated quite well to the phone: she was still very good on it because she was really good with her words and her, you know like her reassurance and kind of, it just kind of felt like I was talking to a family member, like a really supportive family member.

A few women spoke about the role of counselling for their partner, being of the view that such support should extend to them too. One woman described how her partner was distraught now himself when he seen [her] in a bad way and how she felt that her partner was trying to prop [her] up at the same time (Wendy). Another recalled the bad reaction of her partner's mother to him telling her about the abortion, reflecting that I think he needed support as well (Ruth). Two women thought their partner may have struggled with the abortion or needed support around it more than they did. Áine expressed I think he felt [counselling support] was more needed than I was, while Irene remarked that she had dealt with it and my boyfriend never has. Irene wondered that the embodied aspect of pregnancy accounted for the difference in her and her partner's responses to the abortion. For Irene, the pregnancy loss represented the end of the pregnancy journey, something which she points out was not experienced by her partner:

But they don't have the visceral connectivity with how your body moves through [pregnancy] and then pregnancy loss or whatever... when I came to the end of that journey that was a big chunk of the work was already kind of done. Which for him it was more ethereal almost, you know like it is the dream of the child I will have is now gone and then that's always a man to lament, you know so there's (laugh), I think we process things differently, so.

Irene

Some women expressed their sense that abortion counselling was not 'for' non-aborting partners, with Irene feeling unsure if the freephone therapy was only for women. The sparse mention of the availability of such support in the literature was perceived as invalidating:

... it was mentioned and it's available but I'd say there's ... nobody availing of it because it's just in this little line. So, there's not really a sense of validation. ... I think there is a line, a line somewhere.

Irene

Others did recall their partner being expressly offered counselling support but choosing not to attend. For one woman, the offer of counselling support for her partner was reassuring for her in that he could also access support if needed:

he was struggling a little bit with it and I was, and they said to me like he was welcome to go in for a session with them and everything. Now he didn't and it's fine but just knowing that he could was comforting as well because I suppose I was sort of thinking, God how is this affecting him. ... It was nearly like, do you know what, it's not all on me because he has someone to go to if he really wants to.

Naomi

A few women commented on the fact that counselling was provided free of charge. One woman felt comforted in knowing that there was a free service available to her should she have been unable to afford private counselling, explaining *luckily I have a therapy privately already. So I had that support in the sense I never used the therapy that is provided if needed. But it was nice to know if I couldn't afford it (Wendy).* Similarly, this remaining as a feature of the model of care was particularly important for Pippa, who as someone who accessed private counselling was aware that *it's expensive as it is.* 

Anna reported that this free counselling service was what facilitated her attendance:

And the fact that it's free, that it's funded by the HSE, I think is really important because like for example if it wasn't a funded service like do you think you would have paid to attend?

I don't think I would have, I don't think I would have been able to either.

She also appreciated the fact that there was no limit imposed on the number of sessions she received.

Yeah like it was great. And never a thing of like, you are only getting three and then you are gone. Like my counsellor was always saying you know, if it's worthwhile come back, keep coming back.

Anna

## 10.2 Wanting Peer Support

Within the data, as participants discussed what their ideal support infrastructure could include there was a recurring interest in a role for "peer support" initiatives rather than professional counselling. For example, Sarah had searched online for stories of women in a similar situation to her, expressing that *I wish there was more like online resources…specifically for Ireland*. She explained:

Like first of all like stories from people or like, because if you go into the My Options like website all it says is like a helpline and like a really long leaflet. I just wish they would have, like, some more information on like, for example like reasons why you might want to like keep [the pregnancy] or not.

Sarah

Similarly, Fiadh also sought out information online regarding the experience of women in similar circumstances to her. She eventually gave up due to the lack of resolution to the stories people would post on in the Internet forums she encountered.

Beyond online resources, one woman questioned if there could be a helpline staffed by women who had also needed abortion care. She thought this could serve as something in between information and counselling:

A listening ear, not anybody that was going to shove any opinions down my throat or tell me to do it or not do it or advice or sway my decision one way or another, do you know but just, do you know what

don't worry about it these things happen, you know it will be ok don't worry, you know I went through it, I survived, you know this time next week it will all be dealt with, don't panic it's fine.

Gráinne

#### 10.3 Assessment of Pre-Abortion Counselling

When questioned about the role of pre-abortion counselling in the abortion care pathway, many understood counselling as related to their decision-making process and most women did not feel it was necessary. For some, this was simply because they were clear on their decision and did not need to discuss it. One woman remarked, *I didn't really need it because, I mean like, I can make up my own mind...* (Zoe). Similarly, Brenda already had certainty. She explained, *I didn't feel like I needed any counselling or anything like that because I was, I was like 1000% sure that this was what I wanted.* 

Others, like Polly, didn't see the need for pre-abortion counselling because they discussed their decision with their own personal support network – I had like a good kind of support system around me, I was talking to people that like I was close with, while another woman noted she and her partner took so long to make the decision she felt that we'd nearly counselled ourselves if you know what I mean (Tanya). One woman expressed a sense of the decision being hers alone, and not something that could be fully understood by either a counsellor or her husband, explaining that at the end of the day I know myself and I know that I needed to figure this out myself (Fiadh).

Meaning attributed to the pregnancy itself influenced one woman's decision not to access pre-abortion counselling. Gráinne, who had experienced several miscarriages, viewed her abortion as a *similar effort* but something that she *needed to control timewise*. The fact that her pregnancy was non-viable meant that she felt pre-abortion counselling was not necessary. However, she acknowledged that *I'd imagine it would have been a different ...if I had a dating scan that showed a viable foetus, I think counselling services would absolutely have been needed. Ophelia was of the view that a pregnancy counselling service was not a service appropriate for a woman considering abortion. In her view, such services were only relevant to those who were planning on continuing a pregnancy, reflecting that she <i>probably didn't associate [those services] with the path [she] was going down*. One woman attended an appointment with her own private counsellor in the days between her two GP consults, describing it a *huge help* (Clíona). However, she was clear that this appointment was focused on coping skills, not on the decision itself, which was already made prior to attending the appointment.

While most participants did not feel the need to seek counselling support for their decision to terminate their pregnancy, there was a small minority who did. For most, this role was performed by My Options as discussed above. Within our data set, no person sought out WHC counselling for support with decision-making, while one woman received it as part of an information session/process call discussed earlier. Una reflected that in hindsight, maybe she should have accessed pre-abortion counselling, although she was unsure it would have served her specific needs, recalling *I kind of needed somebody else to decide for me, which is not their role either, I know* (Una). Furthermore, Una was *dragged* into counselling before her surgical procedure in the hospital and despite the counsellor being *very helpful*, she did not appreciate her overly sympathetic approach and having counselling forced upon her, stating that she *just didn't want to get into that counselling process*.

Several women expressed hesitancy about the role of pre-abortion counselling, viewing it as a potential source of unnecessary complication in their decision-making process. Though pre-abortion counselling had been flagged with Celia by a trusted person, she reflected, *I couldn't really bring another person's opinion on board.* Others were concerned that pre-abortion counselling could add an unnecessary emotional

dimension to what they saw as an otherwise straightforward decision as it might *over-sensitise or over-dramatise something that might have been clear beforehand* (Áine). Women who expressed these concerns felt pre-abortion counselling should remain optional for this reason:

I think it's really useful to have for those who would like to avail of it, but I wouldn't want to see it as a compulsory.

Áine

I think it should be on offer with the option to decline it if you don't need it.

Victoria

Another woman expressed concerns regarding the ethos of pregnancy counselling. Fiadh recalled how her previous encounters with a person who worked as a counsellor for a religious crisis pregnancy agency made her feel concerned that pre-abortion counselling would expose her to similar sentiments:

I would have been familiar with what she would have, the kind of rhetoric she would have spoken about. ... and like I've seen her stuff and it just, maybe because I know her, I just, I didn't like the idea of talking to someone like that person, if you know what I mean.

Fiadh

For Maria, who had already made the decision with her husband, pre-abortion counselling would have only just prolong[ed] it.

For a few participants, pre-abortion counselling was a source of reassurance rather than support for making their decision. For Ruth, a counselling phone call with a WHC helped her to work through her feelings regarding accessing a second termination and *feel less guilty about it* (Ruth). Affirmation that it was normal to feel a range of emotions was helpful for some people:

I think that's sort of what I was looking for was someone to say "yeah it's alright, you're allowed have all these feelings, that's fine."

Quinn

For some, pre-abortion counselling was a source of coping advice. This was often related to practical guidance for coping with the EMA itself. Among these service users, one reflected that in comparison with her experience of receiving counselling from My Options, the counselling she received at WHC was superior in that the counsellor went beyond providing reassurance, to providing specific advice regarding coping with the EMA too.

The My Options were sort of, they were very nice to me in a very comforting but also maybe slightly patronising way. Like they were very caring and that's all they did, they were like "it's going to be ok", whereas I feel like the women's health clinic were just, they were able, she was able to give me advice on sort of how to spend the day or to be nice to myself and then like spoke back to me. Which was comforting and also very helpful. Sort of told me, you know, "just do nice things for the whole week, be very nice to yourself."

Quinn

Clíona attended an appointment with her own counsellor before attending her first GP consult. Her counsellor affirmed her ability to cope with the abortion process and her potential feelings afterwards, telling her *you will get through this* (Clíona). The delay imposed by the mandatory three-day wait was also a stressor. Although she did not reach out for counselling at the time, Sarah reflected that she *should probably have like called [My Options] again or made an appointment for counselling* because of the anxiety

induced by the delay. She remembered how she honestly just felt awful because [she] just didn't like the waiting time because [she] just felt very anxious.

#### 10.4 Assessment of Post-Abortion Counselling

For the most part, people saw post-abortion counselling as being personally irrelevant to them. Some saw the abortion as a relatively minor event in their life and not something that required counselling:

You see I think I'd probably be a bad subject for this because I don't think it impacted me in the way it could have impacted someone else. I think, like I'm quite realistic about life and like this happened and unfortunately it happened and I dealt with it and while there's some days I would be slightly upset but like I wouldn't, you know I don't think about it all the time and I don't want to kind of sugar coat it but like it was a procedure that I had to do because, not that I'd no choice but I didn't want that and I didn't want any of it really.

Barbara

One woman recalled forgetting to even mention the abortion to the counsellor she was seeing for domestic violence issues. Against this background, the abortion was very much peripheral:

I'm going to counselling at the moment with what happened with my relationship. But I actually only thought about it when you texted yesterday to confirm, I was like I never actually mentioned that to her and it only happened a week before the incident (laugh). I was like why, why didn't I? I was like does that actually affect me or doesn't it? I was like it mustn't if it was something that came into my head to bring up.

**Diane** 

Others felt that their own coping resources were sufficient for dealing with any residual feelings or expressed a desire to "move on":

I just don't like need it, do you know what I mean, I'm able to deal with my own feelings, like I don't know how to say it, like I just, do you know if I get upset, like do you know, I get upset on my own and I deal with it and then like I'm fine, do you know that kind of way.

Zoe

It wouldn't have a role for me, no, just the way I feel is I feel like that's the last chapter, I've just drawn a line under it and I'm just going to try and move forward, but no.

Isabel

Another person reported feeling as though counselling was not relevant for her because when she was initially informed about it, she thought she would be taking the service away from other people [who] need this so much more than I do, telling herself, I'll be fine and I can deal with this myself (Celia).

Personal support networks were frequently cited as a preferable alternative to post-abortion counselling. Talking with personal supports rather than professional counsellors meant that these discussions were grounded in a trusted relationship. Sarah noted *I prefer talking to, like, my friend because I knew her better and she would, like, support me.* The idea of that *one familiar person* was important to Diane. Likewise, Helen explained that she could *talk to someone [she knew] and stuff ... and talk to [her] husband, so [she] felt ok, you know.* Although many women felt that post-abortion counselling was not something they personally needed, this sentiment was often qualified with a statement that it could be useful for other women: *I think it's a great resource for those that don't have the support* (Ophelia). There was a consensus

that the service should remain in place on this basis. There was one woman who attended a WHC and recalled receiving a post-abortion counselling session simply because it was scheduled in. Her account of this session was brief and conveyed it as something of little value to her:

it was pretty much "oh how are you doing?" and like "well mostly grand, except [the EMA] didn't work so..."

Victoria

Furthermore, there were a few women who did not feel the need to engage with HSE-funded postabortion counselling simply because they already had their own counsellor or therapist who they preferred to continue seeing. As women who had already been accessing counselling/therapy support prior to discovering their pregnancy, they were generally positive about the role of counselling, be it through their own private counsellor or the HSE-funded counselling:

I think everyone should go to therapy, I think it's a big wakeup call but it's nice to talk to someone who isn't family or friend. It's nice to get someone who is experienced in stuff. If you didn't have a therapist I think you should definitely 100% ring the pregnancy therapist and have a chat because you'll feel about 10 times better after.

Wendy

A small number of these participants considered attending both their personal counsellor/therapist as well as post-abortion counselling. Ruth expressed that she would have accessed post-abortion counselling had she not been already attending a therapist. Attending post-abortion counselling would have added a further demand to her schedule, so she decided to forgo it because I have a therapist, I am seeing someone already, if not I would have called back.

One person did receive post-abortion counselling concurrently with attending another counselling service. This was initially discouraged by the counsellor at the non-pregnancy-specific service, who said there's no real point in going to two counsellors at the same time (Quinn). However, Quinn felt that attending both services was manageable because it worked out in such a way that the counsellor from the women's health clinic was on holidays and it sort of all worked out that I wasn't having two appointments a week and beneficial because I was not really talking about the abortion or the pregnancy with mental health service actually. I was just using the women's health clinic for that. In addition, the specialty of the WHC as providers of pregnancy counselling was impressed upon Quinn by the mental health service she was attending. She agreed with this assessment:

That one, it made me sort of feel like the women's health clinic were trained pregnancy counsellors and that they have years of working in this field and working with young, scared pregnant women that actually the mental health service counsellor doesn't. And that's sort of ok, they're not, it's a specialised pregnancy counselling and you really do feel like they know what they're talking about. And that they've a lot of experience.

Quinn

Post-abortion counselling was an important source of reassurance or emotional validation for some women. For a few people, it especially helped alleviate residual feelings of guilt and confirm they had made the right choice. For Grace, who had become pregnant because of sexual assault, the counsellor reassured her that none of this was [her] fault. And that [she] shouldn't feel that guilt about what happened and, you know, what [she] had decided to do. Meanwhile Wendy valued the counsellor saying I don't understand why you're being so hard on yourself, it's a decision that needed to be made, causing her to reflect that she wouldn't have wanted to make a different choice. Others appreciated validation of the range of emotions

they were feeling, with Quinn's counsellor telling her, you can feel all these things, that's totally fine. Maria shared that it was just so, so important just having the space to just reflect and just I suppose acknowledge what, you know. Another woman felt that [counselling] was very useful in the emotional support I think (Orla). In addition, Orla appreciated the continuity of speaking with same counsellor who she had spoken with her during the pre-abortion information session/process call at the WHC she attended.

Grace (who had become pregnant because of sexual assault) explains how counselling gave her the space to have her feelings heard and validated, something not fully provided by her family:

I was able to talk to her about, you know, everything that was going on and sort of how, like my family was reacting to the whole thing like, even my siblings, like I don't think, I think they were all maybe so freaked out about what happened that they didn't know how to support me. And that was kind of like the worst thing because it was just kind of like you know, they were sort of, yeah they were telling me how I felt instead of trying to listen to how I was telling them how they made me feel.

Grace

A few spoke of how their counsellor framed their emotional response as a grieving process, which they found helpful in terms of understanding the emotions and facilitating moving on:

I kind of ignored it for a little, I ignored it for a week and she told me that I was ignoring it and that it was going to come out if I didn't just let it come out and start grieving properly and dealing with that. That it would come out months down the line, so she was like "we need to do it now". She was like "you need to start talking about it now properly, getting it out" and I was like "I don't want to", she was like "you have to", which I did.

**Pippa** 

Some reported how their sessions went beyond talking about the abortion itself: we didn't particularly talk much about the actual termination (Maria). Similarly, for another person having a space to talk about other life events was also considered valuable:

So being able to actually get all this out and you know we were able to even talk about further things like, you know, things that had come up in my childhood or things that, you know, had affected, like you know a lot of things kind of come into your head when something like this happens. ... You know it's not just the actual thing that happened itself, it's like you know anything else that you've kind of experienced that had been incredibly unpleasant would kind of surface as well. And that was great for, you know, that counselling was really good.

Grace

Notably, counselling was considered particularly important for, or by, those who did not have emotional support readily available elsewhere:

I think you definitely need therapy, if you're going to go through it you need someone to talk to, if you don't, like if you didn't have a partner or you couldn't tell your parents.

Wendy

I knew myself because my husband is like, he's really good, he's brilliant with the kids and that but emotionally he's not a really good support at all. So, I knew I was going to have to get that kind of emotional support from outside.

Maria

The importance of such support being available for people with little personal support was especially highlighted by Ursula, a migrant woman living in a small town where she knew few people, who explained, that is very important because we are from a foreign country, we need to get some, we need to know like where we can talk and where we can explain our case, what we can do.

A small number of women reported they were considering attending counselling in the future. Despite Polly reporting feeling *much better* after having had a difficult care pathway (her pregnancy was mis-dated by a practice nurse meaning that she needed an urgent surgical abortion and she experienced severe pain after having had the Mirena IUD inserted during her procedure), she felt it was important for her to seek counselling to ensure everything was fully resolved. Another woman said she *probably will avail of [counselling] at some point* because she felt *it's important to talk about it* (Tanya). Celia reported having felt previously that it was not appropriate for her to attend counselling because other women needed the service more than she did, but when its availability to her was brought up by the interviewer she was open to the idea, saying *I would definitely like to go to some of those counselling sessions*. Furthermore, a few women felt that receiving an open offer of future counselling was supportive and helpful, even if it was considered unnecessary in the present.

#### 10.5 Needing Support with the Aftermath of a Difficult Care Pathway

There were some women who experienced particularly difficult or protracted care pathways and recalled needing support with the aftermath of this. For Jade, an experience of failed abortion and a prolonged period of poorly managed post-abortion complications meant that she had begun to fall behind on college work and was struggling to cope. As Jade put it, *the abortion affected every part of [her] life*; coping with the abortion *itself* was not what Jade required support with but issues related to how the care was handled:

it was more how small I felt for so long. You know that I was, kind of felt like I was a little bit less than human for a while. But now it's just that it went on for so long an' it's kind of affected other parts of my life...

Jade

Another woman, Pippa, also experienced a traumatic care pathway, being subject to repeat unnecessary scans and appointments at the hospital she believed to be providing her with a surgical abortion. Particularly upsetting for Pippa, unwanted information was relayed to her at these scans. She felt able to discuss this only with her husband and counsellor, recalling that nobody apart from my husband knows that here was a heartbeat there. Because I can't, but I have to live with that and I've talked to my counsellor about it. The obstructions Pippa experienced in accessing care made her feel angry and sensitised to reproductive rights in other countries:

I'd see things, like that I'd see things online ... and I'd just think ah, you know about women in England and just other services and things like that and I'd just think oh God, like America, what's going on with them and their policies and it's just makes me really angry because you're thinking why are we still finding all of this, medical procedures, why are we even talking about it, why is it just not a thing. It's an option, it should be there and once it's there it should be treated like every other option and there should be no crap about it, you should be, you know if you're put on a waiting list for heart transplant you're on the list, there's no going this way, just be straightforward and that's what should be provided worldwide, not just here.

Pippa

Pippa explained how she did not think she would have coped with the fall-out of her experiences of seeking abortion care had she not already been attending counselling, stating had I not been going to counselling before this had happened, I don't think I would have handled it as well as I did.

# 10.6 Overview of Counselling: Valuable for Those Who Choose to Access It

Overall, women who chose to access counselling considered it valuable and supportive for a range of reasons: reassurance, affirmation, validation, information, or as an opportunity to discuss their decision. Notably, abortion stigma has not become extinct with the advent of the Repeal of the Eighth Amendment from the Irish Constitution; despite abortion care now being a legal right, some women continue to experience guilt and shame. For these reasons, counselling services should continue to be available for those who wish to access them. Additionally, the availability of such services to partners may need greater highlighting. The importance of counselling remaining free was especially highlighted in the talk of women who already had a private counsellor or therapist (and were therefore cognisant of the potential for cost to be a barrier) and Anna, who reported that she would have been unable to attend counselling were it not freely available. It is also sadly the case that for some women, counselling was required to support them with the fall-out of a difficult care pathway. For these women, counselling was needed to paper over cracks imposed by the model of care itself and every effort should be made to ensure that this is not the norm.

On the other hand, many women did not see counselling as having any relevance in their abortion care pathway. Again, this was for a range of reasons, although largely related to them simply not considering it as necessary or having sufficient personal supports in place. Many perceived the role of pre-abortion counselling as related to decision-making, suggesting a potential mismatch between these understandings and those of service providers. The views and wishes of these women should continue to be respected, with counselling continuing to be a voluntary process engaged by the service user, not the reverse.



# Abortion Care Experiences After 12 Weeks' Gestation (s.9, 10 and 11 of 2018 Act)

#### 11.1 Introduction

In our study group, participants seeking or accessing abortion care over 12 weeks' gestation had all received a diagnosis of foetal anomaly on a wanted pregnancy that had prompted them to consider termination. Our analysis of this data set is laid out in this chapter and begins with a case-by-case description of people's accounts of their experiences of navigating their individual care pathways, followed by presentation of key themes highlighted across the data set.

We recognise that a missing perspective in this data set is of people who accessed termination of pregnancy after 12 weeks' gestation on maternal health grounds, including emergency grounds, under Irish law. A further missing perspective is of people from Ireland who travel for abortion care after 12 weeks' gestation without having received a diagnosis of foetal anomaly.

The legislation and guidelines for termination of pregnancy care following diagnosis of fatal foetal anomalies (FFA)/life-limiting conditions (LLC) are outlined in Chapter 2 above. The IOG prepared Interim Clinical Guidance on Pathway for Management of FFAs and/or LLCs Diagnosed During Pregnancy for health care providers regarding Section 11 of the 2018 Act (Institute of Obstetricians and Gynaecologists, 2019), and these are also discussed in Chapter 2. In summary, the pathway set out in the Interim Clinical Guidelines recommends referral to a foetal medicine specialist within a 24-72-hour window of suspecting an anomaly. The foetal medicine specialist is expected to be involved in the full care pathway for a woman considering termination of pregnancy. The Guidance anticipates that the majority of women will be referred to a tertiary hospital for review, specialist assessment and possibly investigative testing. A multidisciplinary team at the tertiary site will discuss the case to reach a consensus about diagnosis and prognosis, and to consider the option of termination of pregnancy being discussed with the parents. Results will be communicated to local units and ongoing care is managed with the local obstetricians and neonatologists/paediatricians, supported as needed by the tertiary site.

# 11.2 Overview of Data Set of Women Seeking Abortion Care After 12 Weeks' Gestation

The study data set relating to s.9, s.10, and s.11 of the 2018 Act comprises 12 service users with wanted pregnancies who sought or accessed termination of pregnancy services in Ireland or abroad for reasons of foetal anomaly or FFA, 11 of whom proceeded to terminate the pregnancy and one of whom continued to birth. Care pathways described were complex and cross several different services and care providers in the care landscape. They often begin with the detection of a possible concern, identified during routine

scanning and/or in conjunction with non-invasive prenatal screening (NIPS) towards the end of the first trimester, or during an anomaly scan at around 20 weeks' gestation in the second trimester<sup>17</sup>.

It is important to note that while the study group comprising 12 participants may seem small, the principles of theoretical sampling as set out in the methodology chapter (Chapter 4) above were adhered to in generating this sample and data set. The fine-grained diversity within the study sample set testifies to the careful attention and rigour given to purposive and theoretical sampling during this study, and in particular in relation to this study sub-group, in the interests of achieving overall rigour and validity in the analysis below.

#### 11.3 Analysis of Interview Data with Women

Analysis of interview data with participants focusing on their experience of the care pathway set out above is presented below. The following care pathways are represented in our data set:

- Anomaly detected at booking-in scan, qualified for care in Ireland and had termination of pregnancy (TOP) under 20 weeks' gestation (n=3): Lily, Gabrielle, Eavan
- Anomaly detected at booking-in scan, qualified for care in Ireland, travelled to England to access preferred surgical TOP under 20 weeks' gestation (n=1): Martha
- Anomaly detected at booking-in scan, did not qualify for care in Ireland following assessment, travelled to England for TOP under 20 weeks' gestation (n=3): Emily, Francesca, Maeve
- Anomaly detected at anomaly scan 20-22 weeks' gestation, qualified for care in Ireland and had TOP after 20 weeks' gestation (n=1): Karla
- Anomaly detected at anomaly scan 20-22 weeks' gestation, qualified for care in Ireland, decided to continue to delivery (n=1): Neasa
- Anomaly detected at anomaly scan 20-22 weeks' gestation, travelled to England for TOP before UK 24week limit, before determination on qualification in Ireland (n=2): Natalie, Denise
- Anomaly detected at anomaly scan 24 weeks' gestation, did not qualify for care in Ireland, travelled to England for TOP after 24 weeks (n=1): Cara

The data is initially presented case by case to depict the various care pathways through participants' own words. Integrated analysis of key themes emerging across the data set follows in Chapter 12.

#### 11.3.i Qualifying for Care in Ireland Following Detection of Anomaly in Early Scan

Gabrielle was attending a tertiary hospital with a specialist foetal medicine team when an anomaly was detected on her first booking-in scan:

So, we, it was my first pregnancy and my husband and I went in for our 12-week scan ... we were so excited like, and there was just something about [the sonographer's] face and she was like "can you move like this, can you move a little bit more" and I was like "yeah". And my husband like, he was there with the phone and she was like "no, no, no". And next thing she was like "oh ok" and she continued, she told me to go and continue on [to see the midwife] and I went in and I was getting, I was talking to the midwife, giving my details. And then I just remember her coming in the door and she was talking to the midwife and I could just tell by the face she made, and she just said, "look we're going to send you up after lunch to foetal assessment".

Gabrielle

<sup>17</sup> Non-invasive prenatal screening is the most common screening for chromosomal anomalies. It involves a blood test and a scan between 10 and 12 weeks' gestation. It is available through some maternity hospitals or can be done privately. See https://www2. hse.ie/wellbeing/pregnancy-and-birth/scans-tests/screening-tests/pregnancy-screening-types/

#### Gabrielle felt catapulted into a new world of unfamiliar terminologies and assessments.

I didn't even know what foetal assessment was at this stage, I just thought, you know, I've just gotten pregnant, I was relatively, what was I? I was [in my mid-thirties]. I was like what, "what's this?", we didn't understand, we were clueless. So, we had to, we'd lunch, and we just didn't know, we thought maybe there might be something small or whatever. So, we went up and our appointment was at half two I think in foetal assessment. And we were, now I understand now the amount of emergencies and stuff that go in there. But we weren't seen for a good while. I just remember crying to my husband and this was later on, most people had left the waiting room, and I just remember crying to my husband and I was like "what is going on?" I just felt there was something wrong. And eventually we were called in. And there was a doctor there, she was unbelievable, so nice, and so was the midwife. As I said to you before the recording, that I still have contact with that midwife. Just unbelievable care they have given us. We went in and they were like "oh, we're just going to scan you again" because [something was detected that can mean] it's one of the trisomy, it can mean, it can happen also and it can be nothing. So we were like "oh ok". And the doctor was going through all the stuff. And she said "look, this is probably, it looks like there is a problem. You can either go home this evening and think about doing [a diagnostic test] or you can do it now, it depends what you would like to do". So, this is the CVS sampling. And I didn't want to go home, I was like I wanted to have this now. So I said "no I'd prefer to do it now". And that was the most uncomfortable thing, I didn't know what it entails you know. That was so uncomfortable. And it was just, like yeah it was horrendous, it was probably the worst day of my life.

Gabrielle

#### The results took six days to come back and Gabrielle returned to the hospital:

I got a message from the midwife and she said "look, can you come in, we have the results". And I just knew it wasn't good then. So we went in and they said "look, yes there is something but we're not quite sure yet, we have to do another set of, we've to do blood tests" and whatever. ... they said the results have come back [for a chromosomal anomaly]. And I was like still wasn't grasping any of this. And so they said "look we have to do more tests, but we have to wait till", I think you have to wait for, it was amniocentesis. So I had to be, I think maybe 14 weeks or 15 weeks for this to be done. So, I was like "oh my God". ... But it was such a long process. So, I'm still carrying a baby and it wasn't. Yeah and like it wasn't until, I didn't have, we couldn't end the pregnancy until the last results came back. They were being sent to Scotland and they would take a couple of days to come back. So it was, I was 16 weeks on the nail when the pregnancy was ended for us.

Gabrielle

For Gabrielle, the legal regulation of termination in Ireland was not something she understood prior to this, with the details being revealed to her as time progressed:

I know nobody is expecting it but I just, like I hadn't, like I didn't even understand the legality of it, I didn't even vote, I was out of the country when the vote came, like and this is what, I'm like "oh my God", you know I was just so far removed from it that and next thing I'm catapulted into it, it's like oh my God, yeah... The doctor that I had been dealing with, she explained it and the midwife and like I didn't even know, like that I'd have to give birth to the, yeah, I didn't know any of this, I just thought ok maybe it might be a D&C or whatever but because I was 16 weeks you have to give birth, which was another, I was like "what?", you know. Another thing being thrown at me but like they explain it to you, but it was more towards the end that it was kind of explained, yeah. ... week by week and those weeks seem like forever, like taking forever.

Gabrielle

While enduring the wait was difficult for Gabrielle, she welcomed the certainty provided by the conclusiveness of the tests:

Those four weeks but I was 100% certain that all the tests were done, and you know there was no going back for us, you know. So that certainty is, to me was lovely, as much as it was horrible to go through those four horrible weeks, I knew for certain that all these results came back, and the baby did have [the specific diagnosis].

Gabrielle

#### Gabrielle emphasises how important qualifying for care in Ireland was for her:

I just went with what the hospital, they're the experts and that's the way I was, the only thing I was concerned about was they were like "we have to be sure because otherwise, if it's not 100% sure it can't happen in Ireland". And I just didn't want to go to the UK, so you know, I know so many women have had to do that. But that was something I did not want to do. It was horrible even thinking about ending the pregnancy, that I'd wanted for so long and then you know it was being taken, I had to take, end it, that decision was horrible, but hopping on a plane over to the UK to do it would have just absolutely killed me, like you know, so.

Gabrielle

Gabrielle had a medical termination at 16 weeks' gestation provided at the hospital where the anomaly was detected and specialist foetal medicine team, including foetal medicine midwife (FMM), supports were available. This offered her continuity of care and support that she deeply appreciated.

The second participant who followed this care pathway, Eavan, also had an anomaly detected through early pregnancy scanning at the maternity unit where she had booked in for antenatal care, which was not a tertiary hospital. Eavan was referred to a tertiary hospital for assessment and did qualify for care in Ireland. She described the process starting with the sonographer telling her about identifying an anomaly during the scan and raising the possibility of termination during the initial scan.

So we got pregnant straight away and then it was fine, it all went well. And then I had my, I'd had a scan privately here, it's a kind of a private office who do it, it's not we'll say through the HSE, just because I was a bit worried about [having miscarried a pregnancy] the last time. And that was at 9½ weeks and everything looked fine. So I went right, ok, you know things are going well. And then I had my 13-week scan here in the hospital and then the sonographer was just like, "it has a big, a lot of fluid around its head and that's not a good thing" anyway so she was just like, kind of straight away, now she was amazing, but the language was kind of like "whatever you decide to do" and like, it all happened so fast, like one minute you're getting scanned and the next thing you're like being told "you've to make a decision" and you're like "sorry what, what is going on here?" So that's like heart breaking obviously and do you know to kind of, ah you can only take in I suppose so much information when you're told all this, so you're literally like, you know taking in maybe 10% of what's happening. But then it was like, literally straight away it was, you know you'll be going to [another hospital for specialist assessment] and like it's so scary when the nurse tells you that and you're like, obviously for the baby and it's so, like awful obviously.

Eavan

#### Eavan was referred to the tertiary hospital for specialist assessment.

So the next thing we knew was like we had to go to [the maternity hospital] the following Tuesday, that was the Friday so we were going up on the Tuesday. So it wasn't a long wait. But I don't know,

you just feel so, it's out of your control in a way and you're like what, I don't know, it was terrible, but yeah.

Eavan

The strain of the wait between getting an indication of an anomaly and attending a referral at a tertiary hospital was highlighted by Eavan as a time when "depression" is a word not strong enough to capture the experience:

[The pregnancy] was lost to me when I first heard the bad news, like at that stage I was kind of like, like maybe comparing myself, just kind of the way she said like "whatever you decide", and I was just like "I have to decide whether to like end this" and like oh my God, like I mean talk about putting a lot on your shoulders. So that was kind of, and I called my friend [who is a doctor] and she said about the strong possibility of it kind of ending naturally. So you're kind of like half coming to terms with expecting this to end any minute and then like we'll say naturally and then, or having a termination if you need to. And then you're half kind of like, or it could be ok, so you're like split in two, like you're just, ah my God, you're just getting waves of, ah just, I don't even know the word for it like, I don't think depression is strong enough, you're just like in hell really those two days.

Eavan

Eavan's account of travelling to the tertiary hospital for review and assessment by the foetal medicine team shows the distress women are under as they navigate this care pathway. As this was during COVID-19 restrictions Eavan had to attend the hospital alone, which further exacerbated the distress.

Myself and my husband drove up and I don't know how now we made it up and down because our heads were just all over the place. But yeah that was, we went to [the tertiary hospital] then again, I was going up on my own and like into the hospital by myself and like by the time I reached the floor, I think it's the second floor, I was literally having a panic attack, like I couldn't breathe and like just had to go into a toilet and like calm down. Like oh my God you're just, keep saying this isn't happening, like this is someone else who has to do this. And then I remember going up to the reception and I was trying not to cry and he was just kind of like "ok just fill in this form" and then I don't know, like you just kind of have to keep going and you can't just hide in the toilet. So you're just going into the waiting room and like I didn't mind that it was with all the other, we'll say heavily pregnant mothers, just because I think at that stage you're like, you don't know what people are going through so you're like, you just want to get this day to be over. So that was kind of that. And then I was called into the room with the consultant and so she was so nice and obviously I was bawling crying but she was, she just completely kind and was like "you've obviously had the worst day" and you're like just want it to end and you're like "yes I have", do you know what I mean, it's not just, you don't feel ridiculous for crying basically. So she then just took the scan and I don't know, could obviously see whatever was wrong and then I think, yeah then [my husband] could come in so that was just unbelievable to have him there.

Eavan

Eavan had a chorionic villus sampling (CVS) test performed at her first assessment in the tertiary hospital. CVS involves removing and testing a small sample of cells from the placenta and may be offered during pregnancy to check if the baby has a genetic or chromosomal condition. It may be offered if an antenatal screening test suggests the presence of a genetic condition, a previous pregnancy was affected by a genetic condition or there is family history of specific genetic conditions. While there, the midwife explained to her what was entailed in qualifying for a termination. She found comfort in hearing from the specialist midwife that other women face these diagnoses and opt to terminate the pregnancy; she wasn't the only person who chooses this option:

I had to get a CVS, I don't know if you, you probably know what it is, like just, they take a bit of the placenta to basically see what's wrong. That was so horrendous. But it was what it was. So that was kind of it really, they just took bloods and they kind of explained what, because we were like, all we could kind of think of was what happens next, like do you know, we can't take in everything they're saying so we're literally like asking them the next step. ... so there's two results, the first one is kind of maybe 95% accurate and then the one two weeks later would be 100% accurate.... So she just explained kind of what would happen and in a week [when results] came back and we'd see fatal or then if it's not fatal and there's something [else], kind of what the options are or you know what, basically, can you terminate for now, what would you need to go through and just kind of either way they work with you and support you. I don't know, you kind of feel like less like an evil person when you're kind of like ok, they've seen this before, I'm not the first one to ever think this.

Eavan

A specialist midwife in the tertiary hospital gave Eavan her contact details as an ongoing point of contact and they returned home calmer for knowing that testing was underway.

The midwife was kind of like "here is my card, here is my number, contact me if you have any questions" or kind of "I'll be in touch with you with the results". So I was like, you know the midwife was kind of taking over my care in a way in terms of like information and stuff. So yeah we were, I won't say happy but a bit calmer once we had that over and I knew like it was going to be tough anyway having to go up there and having whatever procedure done so once that was over I was like, it was just out of our hands then and it was just a matter of getting the results.

Eavan

The consultant at the tertiary hospital called Eavan when her test results returned, confirming a diagnosis of a FFA that would be considered at a multidisciplinary team meeting within a few days.

So that was the Tuesday and then by Friday the first results actually came in so we were told it would be Friday or the following Monday because they go to London. But then [results] did come in on the Friday, which was obviously unreal to not have to wait another three days. And then it was the consultant who called and she just said how it is, we'll say [specific syndrome] it's called. And it fits into the fatal category. And obviously at that moment you're like, I know it's awful to say but you're like, in a way you're like relieved because you're like this can end now. ... So you're like I don't know, my first feeling was relief because I was like this can, you know legally be ended now, we don't have to have that thought of do we need to go to England or do you know what I mean, like having the care. It just felt like someone had just taken care of us or something or like it was in someone else's hands, I think that's what I'm trying to say, like the way she was like, I think from the conversation we had on Tuesday just kind of about what the termination options are, we were just wanting to know, so she I think knew that that's where we would be thinking. And with that diagnosis, so she just explained how it goes to a panel in [the hospital] the following Tuesday and they decide whether it qualifies for a termination or not. But she was like "with that diagnosis and the size of the fluid", like basically it's just kind of a formality nearly that they do, just to kind of sign off on it. So she was like just kind of "expect to be going ahead with it" basically. And that was obviously again a lot to take in because you're like oh God, you're obviously still sad to hear that. I don't know, like that it's gone so wrong, that like you know there's no way that they're viable and then you're also like relieved that it can be over in a few weeks. And you're like, I don't know, I can't even explain the emotions.

Eavan

For Eavan the test results confirming she could qualify for care in Ireland were a huge relief and made her feel like she and her pregnancy were being taken care of. She highlighted what being able to access care in Ireland meant to her as opposed to the prospect of having to travel. Eavan received the results of her test by phone from the consultant in the tertiary hospital who confirmed she qualified for care under Irish law and would attend her local hospital who had referred her for care to have the termination carried out.

[The meeting was held on] Tuesday and then the decision was made and they let us know. And then the following day, Wednesday I got a call from [my local hospital that had referred me] and [the midwife was] like "can you come in on Monday to kind of like meet the consultant" and I was like yeah, look will I be going", I asked her ... would I be going in again on the Wednesday, just we'll say" for taking time off work to know. And she was just like yeah if you decide to proceed with it, it could be Wednesday and you're like "why do I still have to decide?", you're kind of like ok now it's still, I have to, you know it's not like you're going with it, it's like if you decide so I was just like "oh my God". So, I went in on the Monday and it was, I met the consultant at I think 9 or 10 o'clock and she was amazing, like she was great. ... But she, she was kind of like are you like 100% sure and I was like well I don't know what the alternative is, like no one had explained, like you know there's this big decision that I'm like, I don't know what I'm deciding on, like what if I don't take the termination, ... what are the chances with this [condition], that it will survive? Do you know I didn't know what I was deciding because I didn't know the other option, which is crazy because I'm about to sign this consent form and I don't even know what the alternative is. ... now I didn't ask also either, I didn't, because I was so, you know wanting it over that I was like, I didn't ask until that moment kind of what the other option is and [the consultant] she was just kind of like a bit shocked kind of. And then explained how the kind of symptoms it would have ... and then she printed me out a handout which again would have been useful maybe a week beforehand but like to have all this information.

Eavan

At this point, receiving this information felt overwhelming for Eavan, who was unable to sign the consent form that day. She returned the following day feeling more informed and confident in her choice.

[The doctor explained] "you don't have to basically sign the consent form today, you know you don't even have to get, we'll say, the termination this week, you can", I was bawling crying at this stage. And she was like "you know it can be, you have up to" I think 21 weeks or something to do it so I was just like "I'm not, like I can't sign anything, like I don't know", it was just way too much information the morning that I was meant to we'll say sign the consent form really. I was meant to take the first tablets, I was like, it was so much, like I should have known what I was going in for a week ago to kind of come to terms with it ... They keep, like I said saying this decision, but you're like, like from the very first initial diagnosis at 13 weeks it was "whatever you decide" and I was like "I don't even know what I'm deciding on and what's the other option." ... ... like you're reading we'll say even the abortion steps and you're not taking it in, like you don't care, you're just like, you don't take it in one bit ... ... Tuesday then I went back in and ok I suppose I'll say this, I felt a lot more confident, ... that Monday prepared me for the actual procedure itself, I was just like I know now that it's definitely 100% because we'll say the information leaflet that I said the consultant printed out ... ... gave me the confidence to be like this is not going to survive and if it does, you know it mightn't have this or mightn't have that. So having that information I was a lot more confident going in on the Tuesday.

Eavan

Eavan's account suggests that the emphasis on the clinical criteria to qualify for care can overshadow the woman's need for information and counselling on what the clinical diagnosis and evaluation regarding qualification for termination may mean. Eavan attended the consultant conducting the specialist

assessment in the tertiary hospital who explained that results needed to be returned before options could be discussed. She had a session with the specialist foetal medicine midwife there who talked with her on a preliminary basis from the vantage point of awaiting results. When the results came back indicating qualification for care in Ireland, the outcome of the multidisciplinary team assessment was relayed to her by telephone by the foetal medicine specialist of the tertiary hospital. Eavan was then contacted by her local referring hospital who had received her results from the tertiary hospital directly. When the doctor at the providing hospital then framed the termination as "her decision to take" she became overwhelmed. The pathway to confirm a clinical diagnosis to qualify for care had been taken by Eavan as constituting the "decision" to terminate the pregnancy. She had not appreciated that if the diagnosis qualifies under Irish law for termination of pregnancy following assessment it would revert to her to decide whether to act on that assessment or not. For Eavan a crucial step of bringing her through alternative outcomes for the pregnancy had been missed if ultimately this was a decision left to her.

Eavan's case highlights how, in a care pathway where a woman is being referred to a tertiary hospital for foetal assessment to determine if the diagnosis qualifies for termination of pregnancy and then returning to the referring hospital, there can be a gap in the pathway providing an opportunity for the pregnant person to fully discuss the nature of the diagnosis and all options for managing the pregnancy. Her local doctor assured her she could take all the time she needed and gave her further information about the diagnosis and options open to her. This step then allowed her to feel more confident as the person taking the decision to proceed with termination, as a step further to the determination on qualification for termination. Eavan's experience raises the need for the steps of the process to be set out clearly in advance, so the pregnant person understands how and by whom decisions are made. All of this information and the options for care should be discussed with the person from the outset.

# 11.3.ii Qualifying for Care in Ireland Following Detection of Anomaly from NIPS Screening

NIPS is a source of early indication of potential issues in a pregnancy. For Lily, a scan at 10 weeks' gestation as part of the NIPS procedure by a foetal medicine specialist in a private health care facility suggested her pregnancy was at an earlier gestation than her own dating indicated. She felt uneasy about this, but the doctor's demeanour reassured her there could be an explanation that did not raise concern:

So, I booked in for the Harmony test [NIPS] which [was] when I was 10 weeks. So, I went into [the maternity hospital] on the [date of the test] then just for the blood tests and the scan to rule out any chromosomal abnormalities or anything. So, I went in and as soon as [the doctor] scanned me, she said "you're not where you think you are, you're not 10 weeks, you're only nine" ... I said "that can't be". So, I started getting worried and she said, "look this happens loads, it's probably nothing, there is a small chance it could be something, maybe the baby is slowing down, you know, who knows?" I immediately thought "oh maybe I'm going to miscarry, like the baby is not growing." So, she said "look why don't we just come back in a week and if you're measuring 10 weeks then we can just go ahead with it." So she said, like she didn't really give me major cause for concern, but it didn't sit right with me.

Lily

When she returned for the test again the following week the doctor noted a clearer indication from the scan of anomalies.

So the minute she put the scanner on my stomach I just knew there was something wrong because like I've had so many pregnancy scans done and they're always talking through them and she just didn't say anything, she was just really quiet.

Lily

Her doctor immediately discussed what was observed in the scan and the likely prognosis of imminent early miscarriage.

So, I just knew and after a while she was saying like "oh there's a leg, there's an arm" and then after a while she was just took the scanner off and she was like "there's a lot of fluid around your baby" and like I'd never heard of that before, so I was like "ok". And I said, "like the amniotic fluid?" and she was like "no, like under the baby's skin". And I was like "ok" and she said like, like "this baby, your baby is probably going to die". And I was like "ok" and she just said that you know this would be like, this is like a major problem that the baby wouldn't be able to deal with this amount of fluid under their skin. And that there would just, you know that this is like a high probability for chromosomal abnormality. And she just said like even the amount of fluid that there is, she just didn't see the pregnancy progressing much further, like that she would foresee me to be high risk of miscarrying in the coming days. So, I was like obviously shocked.

Lily

Lily was referred to a foetal medicine specialist at the tertiary hospital she was due to attend three days later. The obstetric consultant she was attending there reviewed her scan in the meantime and also advised her of the high likelihood of miscarriage.

So obviously I was devastated, and I went home, and my consultant rang me, and he just said like "I actually went up to look at the scan after you left" and he said like "it doesn't look good that the overall look of the baby is not good"... he just said like I'd be majorly high risk to miscarry even before I see the [other] doctor in three days. So, he said like at the end of the day, like there was just no hope given and I totally respected that because I was, I didn't want anyone to be like "it could be fine", I just wanted, like you know there was no point in having false hope if there was none. So, I said "ok", so he said "look [the foetal medicine specialist] is great, he's going to follow up with you on Friday. But if you have any bleeding or anything happens just go into hospital".

Lily

The foetal medicine specialist advised proceeding with the NIPS. Lily asked in that consultation about the options available to her regarding termination of pregnancy and the consultant sketched these out, but made it clear that they were not at a point in the process where this could be considered concretely until more definitive results were returned:

I just said to him like "what are my options here, you know what am I going to do?" because he wasn't going to say anything. And he said like "what do you want to do?" And I said "well if I have a fatal foetal abnormality like I want to terminate the pregnancy", I couldn't go on with it like mentally or emotionally. So, he said that you know, like he went through the, like he did say like that you know if it is, he said ... that if I have any of the fatal foetal abnormalities ... that I could have a termination. And I was like "where can I do it?" and he said "you can have it in this hospital". And he just, he kind of touched on it and he just said but "look we need to see, we need to see", he said like "you're skipping on to the next chapter, we don't know where we stand yet. Like let's just get the results of the Harmony test [NIPS] and when you come in next Friday, we'll discuss the options". So I said "ok".

Lily

Lily received the results of the NIPS that indicated a fatal chromosomal abnormality but then realised this test was not sufficient to satisfy criteria to qualify for termination in Ireland:

I got the results on the Wednesday and my consultant [...] rang me with them, and it was [a fatal chromosomal anomaly] that the baby had. Now I know I didn't realise it at the time, but the Harmony test [NIPS] result is not a diagnostic test, it's just an indicator of what you could be high risk for....

So, all the while I thought when I got my Harmony test [NIPS] results that I could make a decision on whether to continue with the pregnancy or not. ... [My consultant] said with this test, like "you can't act on this test". So, I was like "what?" and he said "no, like you'll need to have a CVS or an amniocentesis". I was like "oh my God why was I waiting on these results and why did we bother doing this test if like I have the results and now, I can't do anything with them?"

Lily

Lily had a follow-up consultation with the foetal medicine specialist and confirmed she would go ahead with a CVS test. At this point she explained that if she was proceeding to termination she wanted to have a surgical termination, but learned that this would not be available to her:

He was saying like "what do you think, like do you want to go ahead with a CVS?" and I was like "but I already know that it's [a fatal chromosomal anomaly]", you know, and he was like "oh I know but like we can't use, we can't base anything on that". And I was like "I understand that now". So, I said "like basically my options are to have further invasive testing done or to like just continue with the pregnancy?" and he said "yeah. Or you could go to the UK" and I was like "yeah" but it was in the middle of a pandemic and I didn't want to leave my kids. So, I said, like I wanted to have, I wanted to have the CVS done so he said "ok", so I also said to him, because he had mentioned earlier about a D&C or a medical abortion. So, in my head I had decided that I wanted a D&C, so I said that then, I said like "when the CVS results come back, like how do I decide what I want to do? Like can I have a D&C or?" and he said "oh no you're way too late for a D&C now". So, I was like "ok why?" and he said "because you're 13 weeks now" and I was like "but I first came to you when I was like 10 weeks pregnant. Like I could have gone and had, like as soon as I found out this baby wasn't going to make it, I could have just walked into a clinic and had an abortion because I was under 12 weeks but now, I'm over 12 weeks because I'm staying in the system. And now I can't do that, now I have to jump through hoops to have one and I can't have, like I have to basically give birth", which just terrified me. ... I was just so traumatised by the whole thing because I hadn't even thought that I would like have to deliver the baby, I couldn't even take it in.

Lily

Three days later Lily got a call from the hospital saying the CVS test came back confirming the diagnosis and booking her in to have what had been explained to her as "compassionate induced labour" that would take place after her consultation with the foetal medicine specialist on Friday. However, at that appointment Lily learned her case had to go to a multidisciplinary team hearing that took place on the following Tuesday and another week delay would be entailed.

I was going to go in and see him on the Friday, so this was Tuesday night, to go in and see him on the Friday. And to take my first tablet to then 48 hours later [be induced]. So, I said "ok". So, like I was obviously relieved in some weird way that like I just knew what was happening now. But obviously like we were really upset and everything and we have other children, so I had to try and arrange childcare for them because my husband was able to come in with me then for the Sunday on the Friday. ... [At the consultation with foetal specialist doctor] he said "we can't do it" and I was like "what?". And he was like "yeah" he said "there's, we're not all in agreement that this should go ahead" and I was like "ok". So he said [another doctor] doesn't agree ... So that they couldn't go ahead with it. I was like "so what the hell does this mean?" and he was like "well he thinks we need to wait for second round". And I was like "when is that?" and he was "like in 2 to 3 weeks". And I was just like "oh my God I can't", I said "I can't, like I can't go on." And he was like "look what we're going to do is we're going to have a multidisciplinary hearing on ... Tuesday morning about this case and you know I'm going to see if anybody else can back me up on this. And if they can I'm going to ring you straight after the meeting and you can come in that day and we'll do [the procedure]". And I was just in complete

shock. ... I was just like too traumatised to even like argue, I was just like, and my husband just kept arguing and I just kept saying "they're not going to do it, they're not going to do it". ... [The doctor] just said that like this was the procedure and this had to be done and we have to wait till Tuesday. ... I was completely and utterly devastated, like I just left the hospital, and I was like "oh my God, like I'm just, I'm supposed to be going home having taken the tablet and coming in on Sunday, then it was changed to Monday and now I'm waiting to hear from him next Tuesday if I'm lucky". So yeah it was really grim. I came home and said to my parents like you know "it's not happening" like. ... So my options were to wait for the hearing and if they agreed it could go ahead, I could have [the termination] that day. Or if they all didn't agree in the multidisciplinary hearing then I would have to wait for round 2 if I wanted to have it done in Ireland which would be two weeks later.

Lily

#### Lily described the mental anguish this protracted process and uncertainty caused for her:

I first went to them when I was like 10 weeks pregnant ... I just went home, and I was like obviously devastated. And like I just felt so low that I was just like how could somebody go through this if they didn't have, like my husband was there, I had [my] kids, my parents, you know like I felt supported, but I was just thinking like if this was somebody else and my husband wasn't supportive, like I just felt like nobody cared, it was all just like, you know that they didn't care that I had to go through this for another week, they just cared that they were ticking the boxes. It was just like no thought whatsoever to like what that would do to me mentally. ... the baby and ... the mother carrying the baby, their wellbeing just really didn't come into it.

Lily

At the multidisciplinary team hearing, agreement was not reached that the first-round results could be relied on for the qualifying criteria and instead the second-round results were required. Lily describes the impact of this news on her and her family:

I was like "when are these [second round] results going to come back?". And like it was all wishywashy like because it comes from the UK, so they didn't know, two, three weeks .... So I was just like "oh my God I just can't go on", like and then I was just crying too much, and I couldn't even talk, and [the doctor on the phone] was just like, like "I'm sorry". And I was just like ah like "I have to go" and then I just hung up the phone and I was devastated. And I just started looking up like flights to the UK and everything. And then I was just in a complete panic, I was like "I can't do this any longer, like I can't go on". And then my parents and everybody was just like "I actually can't believe this", like what, "they're mentally torturing me". And like I just kept saying to him on the phone "if somebody could have told me that I had to wait six weeks for this from the beginning I would have gone to the UK, like this isn't giving me a choice, like you've been playing me along every week for so long. Like why couldn't you just tell me from the beginning "this sucks in Ireland, it's going to take a really long time, you can wait the long time or you can go to the UK". But instead it was like "no, no, no you're going to be given health care". Like I could have walked in and had a termination before 12 weeks because I knew before 12 weeks that there was something seriously wrong. But I didn't because I wanted to do it, like I went with the system and then I got screwed because like I had got caught up in the politics of it all and got, like so, basically like myself and my husband were like, "I was like I'm going to have to go to the UK" but like because of the pandemic and everything I was just so scared because my ... kids, like if I went to the UK I we [would] have had to self-isolate for two weeks when I came back. And like I would have been too nervous to see my kids in those two weeks and I would have no support because like I would have had to just self-isolate on my own with my husband after going through that. And then I just felt like I would have needed support and I couldn't have not seen my kids for 2 weeks. .... So I had to wait for the second round results and then have a medical termination and give birth and everything.

Lily

Lily's account portrays the impact the protracted testing and assessment process required to qualify for termination under s.11 of the 2018 Act has on women. Power et al. (2021) researched FMS experiences of providing a new service of termination of pregnancy for FFA one year on from implementation of Irish legislation and found opposition from colleagues relating to decision-making on the fatality of conditions and conservative interpretations of legislation led to service provision inconsistencies. They identified concerns over criminalisation and intense media scrutiny as well as different positions among colleagues across disciplines as key drivers in this opposition and conservatism. While the foetal medicine specialist who was caring for Lily and her own consultant obstetrician attempted to implement their decision that the diagnosis qualified for care under Irish law, they met opposition in the multidisciplinary process. Lily's experience illuminates the distressing effects of the legislation and model of care for women. The process began at 10 weeks' gestation with a scan preceding administration of NIPS - six weeks and three rounds of testing were involved before she was deemed to have qualified for access to termination in Ireland. During that time there were three occasions when her doctor advised he would be able to carry out the procedure, but each time was thwarted in doing so. Lily demonstrates the heavy toll this took on her and her family enduring six weeks of protracted uncertainty in bringing the loss of a much-wanted pregnancy to an end. We also see from Lily's testimony how travel to England to access termination is referenced as a continuous fall-back position by doctors and women navigating the Irish care pathway.

## 11.3.iii Qualifying For Care In Ireland Following Detection Of Anomaly From NIPS but Travelling for Choice of Method

Martha was a fourth participant who had an anomaly detected very early in the second trimester of pregnancy and qualified for care in Ireland. However, she opted to travel to the UK for termination of pregnancy because the only method of termination offered in Irish hospitals was not her preferred option.

I went in for my booking-in appointment at 12 weeks, it all went really well, the nurse was really happy, they confirmed it was like a few days, it was about 11 weeks at that stage then they thought which was fine. And I rang up [the private clinic], so that was Thursday, and I went in to get my bloods for the foetal, for the test on Monday, so it was like within three days, I wasn't even 12 weeks at that stage. So, it was as you're kind of supposed to do it. So that was fine. And then about a week later I think those tests came back and I got a call from [the consultant I attended in my first pregnancy], that something showed up that it seemed to suggest that there was a chance for the baby, that the baby had [a chromosomal anomaly]. But that whatever, it was kind of a high risk, I think that test, I think there's a high chance of false negatives or false positives. But in order for them to confirm that they would suggest that I get amniocentesis done ... So that was already, so I was already past 12 weeks at that stage when I got the call from the doctor. And then they had to wait till I was like 14 or 15 weeks to do the amniocentesis ok. So again, there's a lot of waiting and it's completely out of your control, there's nothing you can do, it was a really bleak, it was kind of the start of a really bleak few weeks. ... And then unfortunately ..., we got the tests done on Wednesday and on Friday afternoon I got a call from [the consultant] to say that unfortunately the test did come back to confirm that the baby [did have the chromosomal anomaly that was initially suspected]. ... So ... the doctor said he'd bring us in on the Monday or the Tuesday the following week to kind of talk to us about our options. Now [this particular diagnosis] is one of the conditions that in Ireland it does allow you to access abortion after 12 weeks. So that's, they were kind of bringing us in on that Monday or Tuesday the following week and again all this kind of waiting and I know they have to sort of give you a time but at

this stage we've already had about three or four weeks where we've been, where all this has been, it's the only thing that's been consuming our minds. ... And then the doctor said, and this is again one of the problems with the current legislation, is that even though the test came back, so the rapid results came back within three days, we would still have to wait to get the full [diagnostic results] back. So, this was another week and a half of waiting. And in the meantime, like I'm still pregnant and at this stage I'm quite visibly pregnant, it's my second pregnancy, I'm 16, 17 weeks. Mentally it was [very difficult]. And they said so we'd have to wait to get the full results back which would have brought me up to over 17 weeks.

Martha

Martha was highly critical of the method of termination being restricted to only the medical method in Irish hospitals. Having assessed both methods, while she qualified for care in Ireland she ultimately travelled to the UK for care to access the surgical method of termination. Other women in the study also presumed surgical abortion would be offered for second trimester terminations and would have preferred this option, but accepted the medical method to access the care. Even taking account of the challenges of travelling during COVID-19, including the need for a 14-day quarantine and the cost of accessing care privately in the UK, for Martha accessing the surgical method warranted this:

I didn't really know what your options were after 12 weeks. And it's really hard to access any information on the websites in Ireland as to what, if you are in a situation like we were, after 12 weeks and forced with this really difficult decision as to what's actually going to happen to you, as a woman what, like what part do you have to play and what part is the hospital there to play. All the HSE website says is that the termination will be done in a hospital. Now that is ... not adequate information. [A friend who had been through a termination in Ireland] had said that obviously they had given her medication to induce the labour, to induce kind of preterm labour because she was, and she had said nobody had talked her through ... what was going to happen and that it was her that was, in a way going to have to deliver the baby, there was no kind of difference, I think the term was used, "medical abortion" ... what does medical, you know medical what does that mean? So once [my friend] had this conversation with me then I started to think about it because in my mind the most humane, people have the right, you know to choose but because we were confronted with this, that we'd have to make a decision whether we first keep the pregnancy going which they were telling us the chances of the foetus arriving full term was quite, was none or even the babies that do make it they don't survive 28 days after birth. So between me and my husband we had decided that ... we would terminate the pregnancy. Sorry to bring you back into my point, is that: how was this now going to be done? ... So, we asked, so because of that woman's experience who shared it with, I was able to ask those questions and then I was able to do research on it. So when I went in to speak to the doctor and I was like "ok so is it a medical or surgical abortion?", these are, this is language I didn't have before. It's not a language that you can easily assess in Ireland, that you know you see "what is a medical abortion?", "what is a surgical abortion?" ... One of the foetal medicine midwives came and she was really helpful, not saying that the doctor wasn't, but I guess the problem is that he doesn't have an alternative to offer you. It's not this hospital but, and I think they are aware because later on when I saw him, he's aware that these services aren't sufficient. ... in Ireland they make you think that this is the normal route and they make you question, you know, your own beliefs or whether, maybe I'm just not strong enough, maybe other women are stronger, maybe this is something I should be doing. But I was able to get more information and I think I had it already made up in my mind that this is what we were going to do.

Martha

Martha also questioned how acceptable she would have found going through a termination within a maternity hospital setting:

[The hospital] so this is the same hospital where you go to have your babies, ok, where they'd hope that they'd have a private room for me on the labour ward ... that kind of brought on an additional layer of anxiety because this is the hospital where I had my [first child], who, you know, where I hoped to have other children. And now you're telling me I'm going to go in here and I'm going to listen to other women having their babies, hear them, like it's an old hospital, you can hear through the walls, you can hear babies crying. To go access a service that I didn't want to access, this was a muchwanted baby, we were in a position that nobody wants to be in. ... For me personally to think that the law has come along, a long way but it hasn't come far enough. So we had done everything that was available to us to do but there is no way they could have detected any of this prior to 12 weeks, there's just physically no way because the test that you need to get it done for these foetal anomalies you can only get them done after 10, 12 weeks. You don't get booked in for your pregnancy till 12 weeks. So we had got it done at 12 weeks but you're already behind, like the clock is already against you because there's all these things that you're waiting to meet these milestones that have been set up. And by the time you get it you're so far along that your options are so small.

The validity of her doctor's excuse for non-provision of surgical abortion after 12 weeks as being due to lack of trained staff in Ireland seemed questionable to Martha.

And the excuse that nobody in Ireland is qualified [to perform surgical abortion after 12 weeks], I just don't think it's good enough. Like they've had a year, you know they can get people trained up. I'm sure there's people, I don't think it's against everybody's [conscience]. They can bring doctors in from the UK I'm sure and they could pay to have somebody come in once a week. ..., I don't think it's a good enough excuse that it's done in the maternity hospitals. I don't think it's a good excuse that it's done on labour wards. ... But nobody, unless you're in it like I was unfortunately, you have nowhere to get this information, ok. So if you were trying to research as to, you know where an abortion, it said "it's performed in a hospital", that's what the HSE website says, that in case of fatal foetal anomaly which qualifies you for an abortion after 12 weeks, "it's performed in a hospital", full stop, that's it. It doesn't say if you're lucky you get a private room, you get the private room on the labour ward. ... And this is how it's going to be done, you're going to be given a pill but you're going to deliver the baby and it might be in the bathroom on your own with whatever that thing is called where you're asked to catch any remains and they can do testing on.

Martha

Martha knew what the second trimester medical abortion procedure in Irish hospitals entailed, including women having to collect the products of conception as they passed them during the procedure for inspection. The process combined with the setting being within a maternity ward was not a procedure Martha felt able for following the harrowing weeks of testing and confirmation of the FFA. Surgical abortion under anaesthetic was the method most acceptable to her. The midwives caring for her explained surgical methods are available in England and provided her with information:

[The midwife] printed off all the kind of details for the UK clinic and contact numbers and kind of given us information on it. ... And actually the brochure I was given was quite helpful because I was able to ring a UK helpline that were able to talk me through it because even in Ireland you can't actually get an awful lot of information as to what happens. What is the, what is kind of, even health wise, because I was thinking ok you kind of go through these things that you're trying to make an informed decision, you know am I being crazy the fact that I want, you know what do people in my position do?

Martha

Martha travelled with her husband to England and described how the surgical method felt like *somebody taking care of me*:

For me it was a really big thing that it was over, so I went to sleep, you know this awful nightmare that you know I wouldn't wish upon anybody else, but I was able to, somebody was able to look after it for me. I had done so much at that stage to try to make, you know I've done it and I don't think I had any more strength, there was nothing else I could do and I needed somebody to take care of me and you know I woke up and it was over. Well in a sense the physical aspect of it was over.

Martha

The hospital she attended in Ireland had provided Martha with information on diagnostic scanning and tests to bring to England with her and she returned there for post-termination assessment. Martha acknowledged the compassion offered to her by the foetal medicine midwives and her consultant, and she felt that the limitation of the care pathways within Irish settings impacted detrimentally on committed care providers as well:

[The midwives] wished me luck obviously and hoped that everything went well. So then when I came back to Ireland the following week, they touched base with me again. ... [The midwife] had booked me in to come in after my movements, my restricting movements ended, my period of isolation. And at that stage I saw [the consultant] again, he just did a kind of a scan just to make sure everything kind of looked ok and kind of just talked, that was quite helpful, just to talk through you know how everything went and to see if there's anything more, you know that they could do. ... So he did, he was a lot more, I think initially because he couldn't offer the service, he obviously isn't aware of our financial, you know he can't refer, you go to the UK, you know when they have a solution here. But I do think that the health care workers are aware of the restrictions, you know they see the women coming into them. And it must be really hard for them, you know you see somebody struggle but you can't help them, I don't think it's an easy place for them to be in.

Martha

Limiting the method of abortion in Irish settings to just medical abortion methods, and locating all terminations within maternity hospitals or units, raise issues of acceptability of care for all women.

### 11.3.iv Not Qualifying for Care in Ireland Following Detection of Anomaly at First Trimester Scan

Emily had two children and following a miscarriage was pleased to become pregnant again quite quickly:

[Following a miscarriage] we tried again, and we got pregnant again. But because of our age, or my age, I'm in my early 40s, we said we'd do genetic testing. And so, I did that at, I think it was 10 weeks and three days or something like that and the scans prior to that were saying everything looked great and so on but we did it anyway. It's the earliest testing you can get done. And then at 11 weeks we got a call to say that our child had foetal abnormalities. And based on that, we had already talked about it, never thought we'd actually have to implement it, but we made the very difficult decision to terminate. So we went into the hospital, I suppose I was 11 and three or something like that by the time they could meet us, ... and we discussed the options and the results of the test, the genetic test said that it was 95% sure of this particular foetal abnormality. ... But because it's not a diagnostic test, it's a screening test, you know there's that 5% chance that it's not. And you know we did plan this pregnancy and we did want the baby but we thought about everything, we thought about our kids, we thought about the child itself and for us it made more sense not to go ahead with the pregnancy. So on discussing that in the hospital with the team, even if we had decided to terminate there and

then we weren't going to be able to do it in Ireland because of the resting period of three days, or there's some term on it. The three-day waiting period, we weren't going to make it by the 12 weeks. But I wanted a definitive answer anyway, I for my own conscience. So, didn't realise that you have to wait until almost 15 weeks for an amniocentesis. So that was the longest wait of my life, from 11 weeks to 15 weeks.

**Emily** 

#### The diagnosis Emily received meant that she did not qualify to access care in Ireland:

I think it was about 14 weeks and five days when we did the amniocentesis and they were able to get back to me I think in two days with this particular diagnosis. And it was confirmed. And at that point it's far too late to get anything done in Ireland. So, our only option was to go to England. And they can't book anything for us. Now they were very nice, the team that we were working with in the hospital.... The consultant there who I hadn't booked in with for my pregnancy, he was just the person linked to me doing the Harmony genetic test [NIPS]. So, he was the person I dealt with and he was the person who rang me with the devastating news. And so, we dealt with him, very nice person and very nice nurses around him, very, very informative. They gave us the information, you know on paper and that this is what we can give you about England and you know they told us a few bits and pieces but that was as much as they could do to help us.

#### So they had like leaflets for you or?

Yeah like the contact details and what it would involve and that kind of thing, the websites and people to get in touch with in England. So you were just, unfortunately it was very hard, you're just on your own then and you have to go and make a phone call, ... ringing abortion clinics in England. And then they would ring me back and they were incredibly professional. Like amazing, on the phone an hour kind of having a consultation with [a clinic in England]. But yeah, so that's where we went. And then it was actually probably 15½ weeks by the time, you know they could fit me in.

**Emily** 

Emily reflects on the impact of being denied access to abortion in Ireland and having to travel for care describing it as 'her country not being there for her' at a difficult time in her life. Emily challenges the 12-week gestational limit for accessing abortion in Irish law as having no regard for the care needs of people who receive a diagnosis of a life-limiting foetal anomaly that does not qualify under the fatal anomaly criteria. She argues that if diagnostic tests are available, parents will be taking the decision to terminate a pregnancy based on the best interests they evaluate for themselves and children they already have. Having to travel to seek care in those circumstances leaves parents feeling unsupported and ostracised at an emotionally difficult time.

So yeah we went over to the England, my husband was able to come with me, my sister took the day off work and she minded my kids, so we had to go kind of in the middle of the night really on the, say it was the Thursday night and then we were back late on the Friday night. So you know, and the worry was when I was over there, supposed to be like a 10 o'clock appointment, I wasn't taken until 4, I was worried that I was going to miss the flight and that he was going to have to [go] home without me, I was going to have to stay overnight if there was any complications, so there was just all that stress added to it as well, having to travel, you know it's just awful. But I felt like I don't blame the hospital or the team, obviously it's the laws. I mean as the doctor said, you know if he had even doctored the dates a little bit so that we could fit into the 12 week, if we had decided not to wait on the amniocentesis, and that it was found out, that's 14 years in prison, you know he explained that to me.

#### So there's still that risk of the criminalisation there for providers?

Oh totally, yeah for both of us, he was saying for him and for me you know. So you know it was just, you know getting that bad news and on top of it not having the support of your country I suppose was very tough, very tough like and it will take a long time to get beyond it really you know. ... Because a lot of people will get an amniocentesis and you know the choice isn't there unless you have results of a test, I mean this was a wanted pregnancy you know. ... But in order to do that you need more time, otherwise it's just like the past, you feel like you're a criminal getting on a plane and not telling a soul and sneaking off to England like, I mean that's what they had to do 50 years ago like and we're still having to do it. ... But you need more time, you need more time, I really, in Ireland anyway. I mean if you're waiting for the results of genetic tests, if we're now allowed to do that and have these genetic tests, well you can't make a decision until you get the results you know. But then if you do decide to, you know the country isn't supporting you to make that choice, if you do decide to terminate you have to leave the country. So, do you know the abortion service didn't work for us. ... You know but yeah I don't think I'll ever regret the decision but I'll regret, having to travel was a real thorn in the side now on top of, you know, the long wait to get the definitive answer was the worst period of my life so far. But yeah it was, yeah not having your country there for you. ... In your time of real need was really hard. ... I wonder like, you know when they were making the decision as to what date [to limit the 12-week category to], did they realise ... I wonder was that done on purpose to stop people making a decision based on genetic testing.

**Emily** 

The effect of criminalisation within Irish law regulating termination of pregnancy was heavily present in the care relations between Emily and the foetal medicine team. She perceived staff as very guarded in how they discussed termination of pregnancy with her, while making every effort to be as supportive and caring as possible.

I went back for a follow-up, I think it was 10 days or two weeks later or something like that. Just checked to make sure all the tissue was gone; they did a scan. ... The same people. The same team yeah. ... they just asked me how it went. They couldn't really, again I could sense they were bound, they were very professional, they just say how, the last time we were talking to you, you were talking about travelling, so they don't talk to you too openly about it, you know, it's kind of behind closed walls.... There was a warmth from the nurses, no doubt about that. But they were, you know they were well trained into what they could and couldn't say. And I mean I know that's just from the way they were acting or whatever, that they, you know they were very sympathetic and nodding. But they weren't responding to, you know certain things, you know they just couldn't talk about it very openly, do you know.

**Emily** 

Francesca had one child and was pregnant with what she described as a planned and wanted second pregnancy:

With my first pregnancy ... we had decided to use the Harmony test [NIPS] to screen for chromosomal abnormalities and so we decided to do the same on this pregnancy. Again, thinking it was a formality. And I think at 10 weeks I went and got the test, they scanned at the same time to see the baby, everything looked fine, heartbeat, actually measured bigger than my dates. So, everything looked good. ... And when we got the call, [the doctor] told us that the test had come back showing a high probability for [a chromosomal anomaly] (upset). So, he said there was a 70/30 chance that the baby had [a chromosomal anomaly]. So, we were scheduled, that was a bank holiday weekend, so we were scheduled to go into [the maternity hospital] on the Tuesday, the following week.

Francesca was attending a tertiary hospital and was referred back to a foetal medicine specialist for foetal assessment following the NIPS indicating an anomaly. The appointment was scheduled for the next working day after receiving the NIPS results. Diagnostic testing was carried out and within one more week a more certain diagnosis was returned. Structural abnormalities had also been observed at a specialist assessment scan.

I saw [a doctor] and then a [foetal medicine midwife]. And they explained the, actually it turns out that it wasn't a 70/30 chance, it was an 82% chance. I don't know if [the initial doctor who called from the clinic] was just trying to give me a bit of hope over the long weekend, I'm not sure. But because of my age it was an 82% chance that the test was correct. ... So, we could either go for a CVS which we could have there, done there on the day or we could wait and have the amniocentesis later. I didn't want to wait, my husband didn't want to wait, I mean I was already 12 weeks pregnant at that stage. And the baby is growing and second pregnancy, I was nearly starting to show already. So we decided to go for the CVS. So [the doctor] scanned us first and she noticed a [structural anomaly], and I was actually quite relieved because it meant, it's common I guess, they said that it's common for [pregnancies with this chromosomal anomaly] to have something like that ... I guess, you know it was a second piece to the puzzle. And it meant that, you know, with the CVS, they took a sample, the quick PCR result [to detect COVID-19] was still going to take, I think it was a week to the day that we got that result. And the fact that we didn't really have to wait a week, you know when we saw that structural abnormality, it was another tick box beside, confirmation yeah. So, I think actually that was helpful because it meant that we weren't holding on to hope for a week until we got the PCR results. So yeah, it was a week to the day after they took the sample that we got the CVS results to confirm the diagnosis of [the chromosomal anomaly].

Francesca

Francesca considered that the law regulating abortion shaped the encounter she had with the doctor conducting the specialist foetal assessment. The foetal midwife specialist was a key support in talking through Francesca's options, but ultimately learning that she could not access termination in Ireland and had to travel to England left Francesca feeling alone and abandoned.

[The foetal medicine specialist doctor] had done the scan and taken the sample, she herself I would say was very, I mean I guess, she was very medical, that's not the word I'm looking for but she was very, you know she kept to facts, she was, you know really insistent on ensuring that we understood you know there is a 1% chance that the sample they took from the umbilical cord ... could potentially be different to the baby and you know she was really trying to make sure that we understood all of the chances of, you know, this happening or that happening with the results. ...

#### Your sense was it was very much a kind of clinically driven conversation?

Yeah, that's the word I was looking for, thank you, very clinically driven and very focused more on the results of the CVS tests. And you know the probability of all of the different, not outcomes but you know the probability that the baby, the results could be different to the baby even though it's only 1% and you know the percentage chance of miscarrying after taking the sample for the CVS and the difference between the amniocentesis and the CVS, you know it was all very clinically based on that. We didn't go into detail about, I think what I would have liked to have heard, I think what would have maybe helped would have been to hear what the outcome for the baby could be .... But the other thing I think I got quite upset, because I didn't know where we stood really, when [the consultant] told us [the NIPS results], he had told us that we had time to abort if we wanted to but that we would have to go to England, and I guess that was the first time we understood that we'd have to travel. And I probably read up that weekend and saw that it was still illegal ... in some way for the health care professionals in this country to be able to, I guess give their opinion or even if it's clinically based. I

thought at one stage through the sampling, I just said "are you going to leave us, are we going to be left on our own now to try and figure out what we have to do?" (upset). Because [the foetal medicine midwife] only came into the room I would say like halfway through, it was just [the doctor] first so she at that stage stopped and told us what [the foetal midwife] role was, and after they had taken the sample she sat us down and she was, you know, she counselled us, she gave us a lot of information which was amazing. She gave us, you know the information for [an organisation for individuals with this anomaly] and you know if we wanted to research, if we wanted to continue with the pregnancy, she explained what that would mean ... But then she also gave us all of the information if we did decide to choose abortion. She gave us all the support services as well .... She discussed a little bit more with us the, you know, even seeing a [structural abnormality] on the screen. .... And I think that piece is helpful, you know you need, I know that you can't, you don't know the severity until they're born ... I think, like half the problem here is because of the legality around it and because of the fact that abortion is not available after 12 weeks for people like me (upset) because the baby isn't going to die with a month of being born. You feel like you're doing something wrong, you feel like you're totally on your own. ... you feel like you're doing something wrong... And I think at the end of the day we all should be allowed make the decision that works for us. And it shouldn't be mandated on us that we have to continue with a pregnancy or travel to the UK, it's crazy.

Francesca

The foetal specialist midwife provided Francesca with the kind of support and information that Eavan above had noted she needed. This highlights the importance of this role being provided as a resource to all women receiving a foetal anomaly diagnosis across all maternity sites. While the hospital team emphasised to Francesca that she should wait for full analysis of all of the diagnostic testing, Francesca outlined the balance she felt she needed to strike between getting as full information as she could and coping with the ongoing developing pregnancy. The determination as to the basis for making her decision was ultimately taken herself:

[The doctor] called with [initial CVS] results and she was very insistent that we waited for the final karyotyping results before we travelled. And I said it to her on the phone, I said "but we have a positive PCR [to detect COVID-19], we've a positive Harmony test [NIPS] and we have the structural abnormality that you saw on the scan". I said, "what else do we need?" and then she said "well yeah there is like..." she said "at this stage I'd say its 99.8% accurate". And I still don't understand why... I understand that you're a practitioner and you have to think clinically but you also have to think about the person who is behind what is going on. And you're telling me for a 0.2% chance to continue going forward with my pregnancy week on week getting bigger, the baby getting bigger, I just don't really understand that at all.

Francesca

Efforts taken by the specialist midwifery team to support her were noted and appreciated by Francesca, but she further noted how limited these were by legislative restrictions:

[The foetal medicine midwife] had really kindly offered was the day that we were due to fly, she said to come in on the off chance that I had a missed miscarriage and the heart had stopped beating because then we wouldn't have had to travel. But you know unfortunately that didn't happen. ... we flew on a Thursday and I had a scan just before I went to the airport. .... They're literally clutching at straws ... to try and help us. Because they know that they can't, it's really obvious that they want to be able to give a better level of care and they can't.

Francesca

Francesca described the process of organising and travelling for a termination in England while coping with the devastating news of the diagnosis of a foetal anomaly as something she felt very alone in doing. She describes how in the process of this, she had not anticipated making arrangements for handling the foetal remains until in the consultation in the clinic when it was raised by the nurse. The pressure of the situation led to Francesca regretfully having to forego the opportunity to bring the remains home for a memorial.

The nurse, so you first go in and they check, they do some finger-stick blood samples and check your blood pressure and things like that. And you have to sign documents and take some tablets and stuff like that. But while I was in there with her she asked if we wanted to bring the baby home. And I had read up just a tiny bit before we left in their online booklet about it, but I guess with everything that was going on we really didn't have time to think about it and that's something else then that you have to organise. You have to organise, like she said that we would, it would be put in a container and we would have had to put it in our check-in bags which we didn't have. But I would have checked in a bag but then I was like "what do we do then? Like do we have to call a funeral director?" We had to leave our baby in England and that's closure that we will never get.... And we will never be able to bury our baby because our baby is in England. (upset) ... We had no idea do you have to call a funeral parlour, can you bury it yourself? Like is that even legal, like and that's why we panicked and just said no. Because we didn't know what to do.

Francesca

Francesca was unequivocal in seeking change to the law in Ireland to allow access to abortion care based on the parent's decision in the case of a diagnosis of a life-limiting foetal anomaly or without grounds for a longer gestational limit:

I'll tell my story and the real reason I want to take part in this research is because I don't want anyone else to have to go through having to travel when you get such bad news on a wanted pregnancy. So, I definitely want the legislation to change so that the services are available. You know, it's a personal choice, but we should all be given the choice to make the decision that we want and the decision that makes sense for our families. ... I think I did understand that abortion was available, you know if there was a fatal foetal abnormality, but I guess I didn't know that in our circumstance we'd have to still travel, I really didn't.

Francesca

Maeve had an anomaly detected at her first screening scan at the maternity unit she was attending and was referred from there to a tertiary hospital in her region with a foetal medicine specialist unit.

It was a wanted pregnancy, it was our first pregnancy, I went for my dating scan which was actually late, I went to it thinking I was 13 weeks and they told me I was 16 weeks when I was there and they also thought they seen an abnormality, an anomaly. So I was referred down for further scans and testing to [another hospital]. And the first scan I had down there didn't really show any more information, just that there was a problem. I had an amnio and they came back a week later and it had developed enough so that they could see [there was an anomaly].

Maeve

Maeve felt her own hospital had relayed the news about detecting a potential diagnosis sympathetically. It was explained she was being referred to the hospital for diagnostic testing by a specialist clinician. Maeve received an appointment for one week later, a wait time she found long and difficult. In the interim her GP called to check in on her, which she found supportive.

And then the [person performing the scan] said "oh I think, I just want to check something, I think there's too much fluid on the brain" and then, so I was probably just shocked then, it didn't register

with me for a while, it took a few minutes and a bit more chatting before I said "oh is there something wrong here". And they said "maybe". They were very, very good, really nice to me. And they just straight away said "well we want to send you down to have a scan in [another hospital] because they've got a specialist consultant who does scans." ... That was then a week I think, just over a week, something like that. ... we just felt sick with waiting. I mean I carried on working, just for distraction. In the middle of that first night, that was when the tears sort of hit me. There was a few really sleepless nights, just wondering what was going to happen. The weekend was tough. Just because the length of time that was, we just didn't even know. ...my GP phoned me to check on me because she got the scan results back from the hospital, she phoned me to ask how I was which was nice. And I was glad for that actually, I was glad for that bit of touch.

Maeve

Although her first scan was later than usual at 16 weeks, the condition under investigation meant that she needed to wait another two weeks for it to become more fully visible on a scan, which Maeve found to be arduous. While there was no formal liaison or support person made available to her, the sonographer who first detected the potential anomaly took the initiative of contacting her following her first appointment for specialist assessment, where she had a scan with a specialist consultant and a sample taken for an amniocentesis.

It was two weeks after my first scan before the baby had developed enough to see the problem. ... there wasn't particularly any support I would say. Like a few people, the person who did the scan in [my own hospital] phoned me, she told me she was going to ring me in the afternoon after the appointment to ask how it went and did I want to talk. But like she was, I don't know the technical term, is it sonographer or? She wouldn't have been like a counsellor or anything. She was just, I think, being nice. Which was lovely. Yeah I don't think I was really offered any particular support. Medically we still didn't, after the first visit to [hospital for specialist assessment] we still didn't know what was going on.

Maeve

Maeve outlined how herself and her partner had decided that if an anomaly did present in foetal assessment during the pregnancy, they would opt for termination:

We had already decided ourselves if there was anything wrong that we would be going for a termination so we already knew that ... we've talked for a long time about having a baby and do we even want children, like this wasn't a light decision to even go for it, so we knew if there wasn't anything, not that I'm like "oh I must have a perfect baby", if the baby's life is going to be in any way compromised and compromised our life as well then we wouldn't, we didn't want that. We already knew that.

Maeve

Waiting two weeks for diagnostic testing in these circumstances was trying, as Maeve outlines:

The waiting around was awful because I was starting to show and didn't want people to, like lockdown was helpful because you see less people but I didn't want people to see me and ask and know about it when I knew that we knew, we'd already said goodbye even though we didn't have a definitive diagnosis, we had already said goodbye and we knew we'd be getting a termination.

Maeve

Between her first and second appointment in the hospital carrying out foetal assessment, Maeve had to return to the referring hospital to book in for antenatal care. The midwife she saw had not been alerted to the diagnostic process she had been referred for, which was distressing for Maeve. During the visit she

attended a consultant who suggested termination in situations of non-fatal foetal anomaly *are* provided for in Irish law. Maeve deferred to the specialist assessment doctor's advice but found the experience of the booking-in visit while undergoing foetal diagnosis distressing.

Then they sort of, everyone in [hospital carrying out the assessment], the first question they asked me was like "have you got your chart" and I was like "no", so it turns out there's this really important chart that you're supposed to have and it sent everyone into a flap that I didn't have it and I was like "I don't really care because there is a problem here." So after that first appointment in [the hospital carrying out the foetal assessment] I had to go for my booking appointment in [the referring hospital]...And at that appointment they treated me like a normal pregnancy, I don't think they knew what was going on. Which was really upsetting because the midwife I was in with, she started going through all these questions and I think she asked me "ok well this will happen at this point", I just started crying, I was like "but we're not going to get that far." Like they just didn't know.

### So there was no communication that you'd had the scan and been referred [for assessment to another hospital]?

No, or nothing that made them treat me like that. Because they just started going on at me like normal. And I'd had to wait in the waiting room again with all these women around. ... I had to explain everything. And then they got me in to see the consultant there. And I don't really know why I saw him, ... I pretty much said look I want to go for termination and I asked him about getting it in Ireland and he said "oh of course you can get it in Ireland, it's not the bad old days anymore". He knew how pregnant, he knew how far along I was. And he knew the circumstances and he told me that I would be able to get it in Ireland. ... I doubted him because I felt like the first [doctor] knew what the situation was a bit more .... When we went to [the hospital for assessment] the first time, [the doctor] explained to us that the baby would have to not survive out of the womb for longer than 28 days for me to be able to have a termination here after the time that had [passed], because of how long I was [pregnant].

Maeve

Maeve then returned to the hospital performing the assessment and received a diagnosis that did not qualify for termination within Irish law. However, she and her partner had decided they wanted to terminate the pregnancy if this diagnosis was received. Because there was no care pathway aligning with the couple's decision, Maeve felt she was not being listened to and that the conversation was going around in circles:

So they did an amnio but the results for that took another week. So we were back then a week later to ... and we didn't really know what that appointment was going to entail. We weren't sure if they were just going to tell us the results of the amnio and then there wouldn't be anything else ... Going in I didn't know what it was going to be. So the first thing they did was scan me again. And the baby had grown another week's worth and they could see that there was a problem, [another structural abnormality]. ... then we started talking about what the diagnosis was .... They gave me information; they gave us information on that. So they told us what the baby would be like possibly, although we feel that the consultant was, not exactly sugar coating it but saying, really emphasising that they didn't know how bad it would be. And they explained that I could either have foetal surgery from a specialist [abroad] or that I could wait till the baby was born and it would immediately need surgery .... And they kept saying things like "oh we've made this harder for you, that's a lot of information". And I said at least twice "no you've made this easier, now we know what the problem is we want to pursue a termination." And they kept encouraging us to talk to the neonatologist. And I kind of felt like the conversation was going around in circles guite a few times. I feel like we knew what we wanted and they wanted us to consider, and I don't think we were being emotional or anything, like we were just quite calm and clear.

Maeve

The couple took up the recommendation to discuss the diagnosis with a neonatologist on the same day, who Maeve felt gave a more realistic picture of the prognosis for their pregnancy and confirmed her decision:

So we did agree to talk to the neonatologist and we went away for an hour or two till we could see him and came back and he told us straight up, because I had asked the first consultant, I was like "will he be able to go to school, will he be running around, will he be playing with his mates?" and she was like "yes absolutely". Then when we spoke to the neonatologist he was, he kind of said very straight ... and laid it out quite clearly what his quality of life would be. And I was really glad for that, like I think the way he was talking to us, I don't know if he knew what we were thinking or, but he was just very straightforward and wasn't really optimistic, which is actually what I wanted to hear, like I don't think it was helpful what the first consultant was telling me, that yes he will be able to do all these things when clearly he won't.

Maeve

Maeve asserted her decision to opt for termination and was given contact details of providers in the UK on leaving the hospital. She reflected how she would have liked more engagement by the hospital with her on what that care pathway entailed. While a specialist midwife did take some time with them before they left the hospital, which was helpful, she did not discuss the prospective care path for termination in the UK with them. Maeve felt she had minimal information and needed to find a lot of things out for herself, which she described as *not easy*:

Yeah so they just sort of, they were, in [the hospital] the consultant was very keen on telling me about all the surgical options I could have and they just handed me a sheet of paper, when I said I wanted a termination they just handed me a sheet of paper and said "there's a contact number on the bottom there, off you go". That was very much it, ... After we saw the neonatologist [a midwife] just took us into a side room and was like, I was just like oh, because I was a bit like "is that it, are we just leaving now, are we done?" And she was like, she just kind of explained, sort of said, I don't know what she said, but she made me feel like we were leaving a little bit better. .... I would have liked them to have given me the contact details for BPAS and maybe explained what that procedure would be. Which nobody did. ... I'm good at going on minimal information and finding things out for myself but it was not very easy.

Maeve

She proceeded to arrange the termination with BPAS independently and ultimately had the procedure one month on from the scan that first detected the anomaly.

So our next steps, we got back [home] that afternoon and I phoned up BPAS straight, well after about an hour once I'd calmed down, to arrange that. And they got back to me a couple of days later with an appointment for, that was in like a week and a half time. Which I felt was quite long ... a whole month went from the first scan to the day of the termination.

Maeve

There was no follow-up care from the diagnosing hospital for Maeve despite her understanding that she would be contacted by a pregnancy loss specialist. She would have liked a follow-up appointment with the hospital post-termination for assessment, but this was not offered. Her GP checked in with her by phone, which she appreciated, and gave her contact details for counsellors.

Yeah someone was supposed to phone me on, a couple of days afterwards. I don't know if she was a pregnancy loss specialist or something but that phone call never came ... that would have been useful. I would have liked them to have given me the contact details for BPAS and maybe explained

what that procedure would be. Which nobody did. And I would have liked someone to say "we'll arrange you an appointment for two weeks afterwards when you get back to Ireland, to make sure you're alright." .... Yeah because I might not be, like I'm fine but I might not be. ... And nobody was interested, nobody from the hospitals were interested in looking after me when I got back. My doctor has, my GP has phoned me to ask if I'm alright. ... to check what was going on and she was fully supportive. She was very good, she gave me the number of a counsellor to speak to if I wanted to, but I haven't made touch with her because I'm ok.

Maeve

Travelling during COVID-19 meant Maeve was anxious about being able to make the trip and access the care. Travelling also meant being away from home and the comforts she felt were needed most at this time to provide for her privacy and dignity. This made Maeve challenge the restrictive nature of Irish laws.

If I'd been able to have that in Ireland, that would have been great. I wouldn't have had to worry about travelling during COVID, travelling generally. Like with the COVID situation like I did genuinely have moments where I was like "oh my God what if this doesn't work out and we can't get there and was stopped and I have to have this baby". ... I could have come home to my own bed, I've a very strong desire to sleep in my own bed. My house is set up and everything I want like. I want my [pets], ... it would have just been nice to come back here. Be in my own space instead of being in a hotel room. ... I wasn't even in a friend's house, we had to go back to a hotel room, there's no space, there's no privacy or comfort. You need comfort, you need proper tea-making facilities. Just you need to be in a house with a bit of space and space to be either with your partner or someone or a bit of space to be on your own. The dignity of your own bathroom when your body is going through all this stuff. ... I would ask that the restrictions be widened. So that you could terminate for a range of foetal anomalies. Like you ... you scan for something and then you tell me it, like you know you're delivering bad news but then you tell me you can't do anything about it, that's mad. Why would you scan for something and tell me it was a problem with my baby and present it in a way that, like, you know you're breaking bad news but then you're telling me you can't do anything about it.

Maeve

#### 11.3.v Anomaly Detected After 20 Weeks' Gestation

The other participants in the study seeking or accessing abortion care after 12 weeks' gestation had a foetal anomaly detected at the 20-week anomaly scan or later. Of these five women, two qualified for a termination under Irish law, of whom one ultimately decided to continue the pregnancy until delivery. Two women were undergoing foetal assessment but, mindful of the 24-week gestational limit to access care in the UK and how restrictive qualification criteria are in Irish law, they travelled to access termination in England before the protracted diagnostic process was completed in Ireland. A final woman completed the diagnostic process in Ireland to discover she did not qualify for termination in Ireland and travelled for termination on foetal anomaly grounds in Britain. The women's stories are set out below.

Karla had a miscarriage on her first pregnancy and was now pregnant through IVF. All scans up to the 20-week scan had raised no concerns but an issue with a vital organ was detected at a scan at 21 weeks. The team at the hospital she was attending worked with colleagues in another tertiary hospital to assess the condition.

We'll start with the 20-week scan, that was done when I was 21 weeks, and this is when we found out that he had some type of anomaly .... [The doctor] was really good with us, she just made sure that we knew exactly what was going on, they didn't really know exactly what was going on because they had to, she had to send us for an echography to make sure what was the real extent of the

problem... we wouldn't be able to see [this type of anomaly] at the 13-week scan because it wasn't big enough at that time, it was only on the 20-week scan that they were able to see, ... went through all the details, everything that we thought it could be ... but yeah it was significant enough for them to know that it was really serious. And that we needed help straight away to see if there was anything that could be done or not. ... So back home thinking "ok that is not what we want to hear when you go on your 20-week scan". But we weren't going to panic at that moment because we still had to go through other scans to know exactly what was going on. ... And we had, I would say around week 23, we had the first echography [at another hospital] ... they did a test and see if there was anything else wrong ... and there wasn't ... so it was literally just one [organ, which is vital for development]. ... [The organ] was [not the size that it should be] on week 21 and by week 23 it [was still not the correct size], and so we had one scan at week 23 I think and then week 24, so every week we were having a new scan.

Karla

The couple's first approach was to explore the possibility of surgical intervention both through the hospital they were attending and international specialists. The hospital supported their consultation with the international specialists by sharing diagnostic material with them.

We had a call with [a surgeon in South America] and even shared the scans and the documents ... And there's one in the US [United States] that could possibly do some surgery but at the same time he wasn't really hopeful, and you know it would cost a lot of money to go to the US [United States] to try to do anything about it. So, we just, we understood that we were being taken care of, with the best people in Ireland, if not you know, yeah, in the world.

Karla

At each assessment as each week progressed, the impact of the anomaly became more severe. The specialist doctor assessing the anomaly reassured the couple that the decision regarding termination was one that would be made by a team of doctors and was not the responsibility of the couple to make.

We could see for ourselves that it was getting [further and further from the appropriate size]. And the problem wasn't even just [that organ, the progression of the anomaly was impacting on the development of other vital organs too]. Even if we had the chance of having him and trying to do surgery, his [other organs] would never be able to develop in a way that he would survive the surgery anyway.

#### Yeah, it was becoming more complex as the condition developed?

Yes, and you could definitely see every week. And we have done everything we could, so everyone we could talk to, we talked to, ... All the reports we were given as well and we kept all the reports, so that's another thing, because they gave us all the reports, if any day in the future we feel like "oh did we make the right decision?", I have all the reports and all the data so I can go back to and say "no that was getting..." ... yeah the decision that we made, not even by ourselves obviously, but that was one of the conversations we had with the doctors, because in the echo [the doctor] said "this is not a decision you are going to make, this is a decision that not only one doctor is going to make, many, many doctors are going to make. And of course, with our consent, but not to put the pressure on us.

Karla

As the weeks progressed the couple felt a consensus was reached by the doctors and them that termination was the appropriate way to proceed.

It was the right time because I felt like in the end, we were ready at the time that it happened. It didn't happen too soon, and it didn't happen too late, I think it was the right time for me. Yeah, my husband

said it was the right time for him as well. And again, if we needed one more week with the doctors, if we had to wait one more week, they were open enough that they would have waited. And we also asked I think for more scans than what they were planning to do, and they were happy to make more scans as well. ... we were very involved, we wanted to be involved, we wanted to see for ourselves, we were able to see for ourselves. ... for us it was much better to be able to end, well I would say psychologically it was the best thing and at the right time. If we had to carry this pregnancy to term for a stillborn baby to come, it just wouldn't, it was already really hard. ... you know you're walking around, then at that stage you already have a big belly and people keep congratulating you. And you obviously just say "oh thank you very much" because you're not going to tell everyone that "oh yeah by the way the baby is not going to survive".

Karla

Karla

Karla talks about the importance of being able to have the care in an Irish hospital where she was cared for by a team whom she had continuity with before and after the termination, which was close to her own home to return to after the procedure, and where she could make arrangements for a memorial process of their choosing:

The reason we made the decision not to go to the UK, for example, was because we didn't want to go through all this with people that we didn't, that we weren't in contact with, that didn't know the history of everything that was going on. That's one of the reasons that we made the decision not to go ... in Ireland we can get in the car and go to Dublin, like on the same day ... And especially because he stayed there and then we had to go back and get him [and arrange the funeral]. ... my husband's family ... were able to travel to ... to see the baby as well and so they allowed them to come and ... [the baby] stayed in our room and they could see, and you know pick him up and you know that was really nice as well that they were able to ... we had cremation, yeah and so he stayed in the hospital, I think it was Tuesday when we had him, and then Friday was the cremation so we went there and we, they had the chapel set up for us and we could park the car on the side, so it was, you know away from everyone else in the hospital as well. And we were able to spend a bit more time with him before putting him in the car to bring to the cremation. And we had a service there and that was the Friday.

For Karla her care pathway was collaborative and open – the foetal medicine team kept them as a couple apprised of the nature of the anomaly and how it was progressing. They were provided with diagnostic materials to share with clinicians outside of Ireland to assess potential for treatments to resolve the anomaly. As the weeks progressed, the foetal medicine specialist teams assessing the condition came to the determination that it was an FFA. Once qualification for termination of pregnancy in Ireland was confirmed, the couple felt they were informed and prepared in taking the decision to proceed with that option.

Neasa was pregnant with her second child and had an anomaly detected at 22 weeks' gestation.

I think I was over 22 weeks pregnant when I went for my anomaly scan and it was at that scan that the sonographer discovered that there was issues with our baby. ... I was at that scan on my own because of COVID and the next morning then we came up with my husband [to meet the consultant]. And sure you have the fear all night of what actually was going on. And we met the doctor and the doctor just said to us there's something seriously wrong here ... So he took some amniotic fluid and sent them off for tests and we were waiting on results ... our doctor was amazing, he was great, great support and like I was a public patient so I was amazed at how good the support was. Like he rang us a couple of days after sending off the test to see how we were getting on and then we had to

wait three weeks for test results to come back. So they came back and in three weeks we both went back up to see the doctor. And the results had come back inconclusive. [The doctor] really thought it could have been [a fatal foetal anomaly]. All these terminologies I'd never heard of in my life until I met with the doctor that first day. ... But then I suppose after the three weeks waiting and thinking the worst and hoping for the best we had no further information and I suppose at this stage I was [over 25 weeks] pregnant.

Neasa

Neasa had to wait a further three weeks for test results to return, and describes the anguish of that when she was already in her third trimester. Based on results of scanning she was considering termination of pregnancy, but due to legal regulations her doctor did not discuss this with her, instead directing her to online information on provision elsewhere, which she explored with the help of support organisations.

And then the doctor gave us email addresses, well websites pretty much, because you see I suppose the way things are in Ireland he can intervene if there is a fatal foetal abnormality but up until that stage he can't, nor can he be seen to guide us in any which way. So he just gave us websites for a hospital in England and for a link towards a hospital in England. And [a pregnancy counselling service] was kind of the next email we had and then we had another. So we rang the UK first ... and the UK pretty much told us there's nothing that they can do because I was past their 24 weeks. ... at that moment in time I needed support and I needed to know what our options were. Because we had no idea of what to do, what we were facing. ... So then she put us in touch with the Abortion Support Network, I can't even remember the first girl's name, but they were amazing as well. ... And my options at that stage I think was Spain and Belgium and Germany I think. All quite scary when you're in the middle of COVID. Do you know, so then I think it even happened quite quickly. So then after I suppose a week we had a call with doctors in Belgium ... they were like we need you to come next Monday and we'll assess you and then if we believe that your pregnancy isn't viable then we will proceed on Tuesday. And you will have to stay for the week, five days. And I was like oh my God, I suppose we had as a family been thinking about what if our pregnancy isn't viable you know and the fear, like we had massive fear ... we both had kind of decided that if our baby's diagnosis is non-fatal but if quality of life is so poor, we don't really have an option but to terminate our pregnancy, which is the hardest decision in the world because [the pregnancy] was always wanted you know.

Neasa

After three weeks the results came back concluding an FFA. Neasa was by now 29 weeks pregnant. Her doctor discussed termination of pregnancy or continuing the pregnancy with her. If she opted for termination, she would have had to travel to another hospital for the first stage of the procedure and return to her own hospital for the second stage. Neasa opted to continue the pregnancy until delivery.

So then the results came back ... and the results, it was very rare, our condition is very, very rare. ... So at that stage then [our doctor] said it looks like it's a fatal foetal anomaly, you know it's a fatal diagnosis. So we have two options and he said we can, the pregnancy, now my doctor was great, he was amazing, but he really wasn't [directive], which was great, "terminate if you want, we can talk about that, or you can proceed with the pregnancy", he wasn't pushing me in one way or the other you know. And he was totally letting it up to us. So I suppose selfishly there came a massive relief when we heard that our baby wasn't going to have a life-altering disability, you know that our baby won't have to spend its time in a wheelchair and have brain damage or, you know. It's not that we didn't want our baby, we wanted a baby that had some sort of a quality of life. ... But if our baby was to be [severely disabled] you have to consider that, because that's life-altering for everybody, that's life-altering for [baby], for our [eldest child]... then for us as a family, for my husband and his, you

know everything. But in a way [baby] took that decision away from us you know. So really I suppose when we found out [baby's] condition, there came a huge relief but there also came a massive sadness. Because our baby wasn't going to survive. Where do you go from there, do you know? So we had to make the decision then, well not then but like [the doctor] let us go and we were allowed kind of think about what we want to do. At this stage I think I was coming up on 29 weeks pregnant. So he had said to us that to end the pregnancy early we would have to do a procedure where they actually stop the baby's heartbeat. But that couldn't take place [in the hospital I was attending] we would have to travel to [another hospital] and they would have to end the baby's heartbeat. And then we'd have to travel back and possibly stay overnight and then go into the hospital for the procedure, for the induction and deliver the baby. So personally, and it's so personal for me, I couldn't do that. ... So I felt because I knew [the baby's] lung tissue was so small that [they] wouldn't have survived that long when they were born. Like one of the big issues as well that we were afraid that our baby would struggle for breath when they were born ... but we were told that [they] wouldn't, [but] would pretty much just kind of go into, just fall asleep really, do you know very calmly. Which luckily was the outcome for us.

Neasa

Denise had a previous miscarriage and was pregnant with her first child. All had been going well until the sonographer detected structural anomalies at the 21-week scan and referred her for foetal assessment. As other women described, the changing demeanour of the sonographer along with some minimal information conveyed about what concerns were observed in the scan, was the first stage in the care pathway for Denise.

So anyway, I went for my first scan in the hospital and that was all fine, you know the foetus was moving and everything, that was the 12-week scan, so that was maybe done at like 13, 14 weeks. And then I was having, yeah perfectly normal pregnancy and going in and out of [the maternity department of the hospital] for check-ups, ... time was coming up for the 20-week scan, anomaly scan. Which was done at like 21, I think it was about 21 weeks. So, I went in for that scan and because of COVID my husband was waiting outside, just right outside in the car but I went in and it was that whole situation where the sonographer goes quiet and she's like looking really stressed at what she is seeing on the screen. So I was wondering what was happening and she said you know "oh it's not looking good, none of your measurements of the baby's limbs and things", you know she didn't say what but she just said "your measurements are wrong". And she was like "oh just bear with me, I need to make some calls". So she was in and out of the room making calls. ... she said "look I'm going to have to book you in to the foetal medicine unit and they'll take this further" ... So she booked me into the clinic which was going to be a whole week later.

Denise

Once referred to the foetal medicine specialist, Denise was contacted by them on the same day and had to wait until the following week to attend the clinic. As others described, information shared at the assessment gave some indication of the nature of the anomaly but the doctor emphasised the need to wait for test results to be returned before discussing diagnosis and prognosis.

[The foetal assessment specialist] called us, phoned me on my mobile just a few hours later and [they] just kind of put us at ease and [they were] like "look you know I'll see you and it shouldn't be anything to worry about". [they] said "I can't really comment at this stage but we'll go through everything". So [they] said yeah "you could see one of my colleagues in the next few days if you want" but [their] clinic was the week later. So we waited for that. So we went to [the] foetal medicine clinic the following week so I was at like maybe over 22 weeks at this stage. ... it was a very long session and [they were]

just checking everything. So then [they] confirmed the worries that the sonographer had had that, [they] said "yeah so, your measurements are very short of everything, so limbs..." What else did [they] say? "It looks like the limbs are bowing as well, so you know, so that would be a marker for a number of different kind of disorders and things". But I think I was lucky because I had looked up everything and researched everything myself, so we weren't really being told much information, you know about how profound this was or how serious it was. So it was only because I had that, you know research done that I knew when [they] said "ok it looks like there's ...", that I knew then in my head, I was like "ok I saw that that was a marker for most of the, like, foetal disorders" or you know different things like that.... And I just said "look is there anything that can be done if we, you know when this baby is born, you know maybe it's short but you know is there hormonal treatments or you know technical things you can do to limbs or whatever?" and [they] said "no this is something that can't be changed" or like rectified or whatever. So we just left there that day and we were just, yeah really confused. We weren't really sure like what was happening. No, it was like kind of skeletal information, like that you had to kind of put it together yourself.

**Denise** 

At the initial specialist foetal medicine assessment, some of the structural anomalies observed were explained and Denise related them back to information she had gathered in the intervening week since the first scan. She described feeling confused and unsure on leaving the consultation, but with some information she could work with herself. The couple had enough concerns about a serious diagnosis at that stage that they began to assess their options.

So we actually just went off for like a really big drive to [the sea] because we just were like, I was like "oh my God I can't go home, I just don't know what to do", so we spent hours just driving around and we were just saying, we were like "look", like we were just figuring it out ourselves. So we were like "ok this is either going to be a baby that's born and going to be really sick obviously and needing loads of treatments and trips to different hospitals or possibly not going to, you know I'm going to have a miscarriage or what". And then the fact that [they] had said that the problem was something that couldn't be reversed, we kind of got down to really serious, you know chats around "look if we have the choice here we think we'd prefer not", so we decided after hours, we were like "look I think you know our circumstances and everything", we're just starting out, we're just buying a house, you know we just decided that we're not in a place where we can have, you know, a child with foetal abnormalities or, you know. I think it's a choice for everybody. So that was it. And then, but we were still, like we were very much in a haze, like we weren't taking any action or you know we weren't ringing anyone to ask, or you know, looking up stuff, we were just kind of distracting ourselves for a couple of days. And then the consultant texted and just said "I've passed on your details to your GP and she's going to give you a call".

Denise

When Denise talked to her GP, she asked about the situation regarding accessing termination in Ireland. Her GP explained the grounds for qualifying and emphasised they were very restrictive. She also explained grounds for accessing termination in the UK and provided contact details for the Abortion Support Network.

[The doctor doing the assessment] said that [the results] can take two weeks or more and it's even slower because of COVID. So that was the exact kind of pinnacle of where we were like, in our heads we were like "ok we either take the chance to go to the UK before the results come back or we wait for the results", which the results will show if it's, they would probably show if it's fatal abnormality or if it was actually just a severe foetal abnormality but that it wasn't going to be fatal. ... So the amniocentesis would have proved, hopefully, if it had, but [they] had said also that it's not always

efficient in the first round so that if [they] didn't find something in the first round of testing, [they'd] have to send, [they] had also taken a piece and frozen it so [they] said [they'd] send that off then again. So it may be like, a bit of time. ... Yeah so we phoned the Abortion Support Network and they were absolutely amazing .... they just gave me the [clinic] numbers. So then we rang them and they got back to us like within a day. And booked us in and everything.

Denise

Aware of time limits for guaranteed access to care in the UK and the uncertainty of being able to access care in Ireland, Denise arranged to attend a clinic in England. The couple tried to establish if they could qualify for care in Ireland and informed themselves more about methods of termination available.

[After booking an appointment in the UK] we rang the consultant on [their] mobile and just to speak to [them], ..., [the doctor] was still cagey about it. And [they were] basically, to us it seemed from [their] training and everything I'd say that [they] couldn't say too much until [the] results were back. (sigh) [The doctor] was like "look we can do a termination in our hospital, we don't use the method that's done in the clinics that you're mentioning," [they] said "you know you'd be induced and, well if it was found that your baby had a fatal problem, so you would be induced and you would go through labour kind of in the normal way."

Denise

Denise, like others, interpreted the doctor as highly cautious in what they are willing to discuss with patients. The uncertainty of accessing care in Ireland and the unavailability of the surgical method of termination within Ireland in the event of qualifying under Irish legislation prompted Denise to proceed to travel to England for a termination. They took account of the minimal information they had to date from the assessment consultations in their hospital to come to the best decision they could:

So the option that I had been offered ... in the UK was that I would be ... under general anaesthetic and it just appealed to me more. Yeah, I knew that, yeah, I think I knew that in mostly in Ireland, or in [the hospital I was attending] anyway, it was being done by, you'd be induced and then you'd give birth. But I was just really attracted by the prospect of being under anaesthetic, ... like what myself and my husband were doing was like, it was as if [the doctor was] almost like speaking in code to us and we were just reading through the lines everything [they] said. Like in the consultation in the foetal medicine unit [the doctor had described the anomaly they could see in the scans]. So like we were just taking it that things like that that [they] said, that when [myself and my husband] chatted afterwards we were like "yeah that baby would not survive because you know if it can't develop lungs and heart then what's it going to do?". But it was, yeah we kind of felt at times that we were like being our own kind of, it was like a DIY [Do it yourself] job kind of, like we were trying to piece together things that [they were] saying, information from the GP and then so much stuff we were looking up online, yeah.

**Denise** 

Two weeks after having a termination in the UK, Denise had the results of her amniocentesis which confirmed the anomaly that would have qualified for termination under Irish law.

Two weeks after the abortion and it was confirmed what we thought it was, that it's, I can't think of the name but it's ... it's a baby that's born and that it's going to die within days, usually within days of being born.

**Denise** 

The uncertain, indeterminate and protracted care pathway for qualifying for termination on grounds of FFA in Ireland, alongside the time pressure for accessing care in the UK up to 24 weeks' gestation, meant the couple felt they were on their own making sense of piecemeal information and trying to determine the best possible outcome of what was a devastating situation for them. Learning that surgical methods of termination are not available in Ireland also influenced Denise's decision to travel for care.

Natalie was pregnant following IVF, but at her 21-week scan structural anomalies were detected.

It was very much a planned pregnancy, we'd been trying to be pregnant for a long time and we had IVF in the end. ... our anomaly scan was at 21 weeks and we went into the anomaly scan just expecting to find out the gender and look at our baby, and you know baby was kicking away and we were super excited ... I noticed that [the sonographer] was being very thorough ... and then she said, she started talking us through the structures that she could see. And then she started mentioning the structures that weren't ok as far as she could tell. And she said that she needed to get somebody else in to have a look. So [a foetal midwife specialist] came in and took over the scan. And yeah, and there were [multiple anomalies]. And because I [had knowledge of child development], ... I stopped [the midwife] and I said "ok I need to tell you everything I think I know. And then it would be really helpful if you could tell me if I'm over-reacting." ... And I said "so I think this is what I know from what you're telling me." [And she said] "no you're not over-reacting, that's what we know." So at that point she gave us information on termination services in Ireland and in the UK. And she explained that in babies with multiple anomalies sometimes but not always they have chromosomal disorders such as trisomy 13 or 18 that would be considered fatal under the Irish legislation. And that the legislation in the UK was different and up to 24 weeks termination could be accessed for any reason, not for any reason but for any significant reason under the legislation. And then after 24 weeks the legislation around foetal anomaly was broader and covered severe and life-limiting as opposed to just fatal within 28 days. So that information was all given to us in the first scan. So that was a lot to take in. It was really helpful, it was, I'm really glad we got that information from the get-go. ... So we came home and that was a Friday, we were booked in for an amniocentesis on the Monday which was three days later.

Natalie

Natalie's own professional background meant she had the skills to interpret the information they were being given. The foetal midwife specialist attached to the hospital she was attending acted as an ongoing point of contact with her as the diagnostic process proceeded and Natalie worked through the best outcome. Natalie was referred for diagnostic testing within three days of anomalies being detected at the scan.

So the Monday we'd an appointment with the consultant and I suppose that was a much less open conversation. So at that point I was kind of armed with what I'd known initially plus the information I was starting to gather. And I was like "you know we're seriously concerned about the potential outcomes for our baby." And the consultant, understandably in a sense but I felt probably more than was necessary, took the stance of "we can't know, we need to do some more tests." ... . we started doing research into what our options were termination-wise. Because reading the research from what we could tell there was a high likelihood of trisomy 13 or 18, medium to high, not high. But outside of that there was a high likelihood of a life-limited and severe profound disability. And I've [known] children with severe profound life-limited disability and I believe that is, what we decided was that wasn't a life that we wanted for our child or for us. ... And we knew the most likely other anomaly that would be wrong [was] significant neurological problems. But if that did show up on scan it would likely not be until very late in pregnancy. And it might not ever show up on scan, it might just be a post-delivery kind of thing that you'd find out. So we didn't just make that decision and then not go back and forth. We went back and forth and back and forth .... So we started looking into things here

and I hadn't, I mean I voted for Repeal the Eighth, I lobbied for Repeal the Eighth. I don't think I'd ever realised quite how restrictive it was in terms of complex disability and complex anomaly. So we were hoping, and this was just the most awful thing, but we were hoping for a diagnosis of 13 or 18 because then we wouldn't have to decide. And we could do that here. And we could be cared for at home and we could, and it felt acceptable and all of the things that I heard about coming up to the abortion referendum, about feeling ashamed and feeling like you need to take your problems to another country because you're darkening the door of your own society. So at that point we started doing research into what our options were termination-wise.

Natalie

As the process progressed, Natalie formed the view that diagnostic clarity and certainty were required to qualify for termination under Irish law, but because complex and multiple anomalies were indicated in her case, this clarity may not be achieved. Natalie characterises the situation in Ireland as being one where diagnostic clarity of a fatal diagnosis makes the decision on qualification for termination on clinical grounds, but where complex anomalies feature and clinicians are uncertain of a diagnosis, there is strong reticence among clinicians to engage with parents about prognoses. Parents are then left assessing the information as they understand it and trying to determine the best outcome for themselves, their family and the child, without guidance. Uncertain of what the outcome might be in relation to accessing termination in Ireland, she explored her options for termination elsewhere. Accessing termination in the UK after 24 weeks' gestation was uncertain without genetic testing, which they could not secure in the short timeframe available. The only certainty for accessing termination was to qualify in the UK within 24 weeks' gestation. However, a key concern she had was for post-mortem genetic testing so as to fully understand the foetal anomalies, but this was difficult to access:

I rang [UK] hospitals that provide terminations to women from Ireland and when I emailed them my details, they got back to me to say that in order for them to review my case I had to have a full [diagnostic] result and I had to have seen a geneticist. And the hospitals were the only place where there would be an option for delivery. And they were also the only place where there'd be an option for a post-mortem and for the arrangement of post termination genetic testing or even just a sample to be sent back. So there was lots of phone calls back and forth between me and the foetal medicine nurses in [the hospital] and various other places for me to kind of get information of what I could get where. And the geneticist ... wouldn't meet with us until we had the results. Fair enough because, you know, arguably, what can he tell us? But he wouldn't meet with us. So we couldn't have a genetic consultation till we had the results [and the] results were going to come back when I was 23 weeks, but by the time I was 23 weeks [the geneticist] was on holidays and we knew he was going. So we couldn't see him. So the UK, because I really wanted to buy time and if we could have found out if we were eligible for a termination under section E of the UK legislation, then we had time. But in order to do that a UK doctor had to review the file. And a UK doctor wouldn't review the file because I had to have seen a geneticist. And I couldn't.

Natalie

#### When results came back from diagnostic testing at both the initial and final rounds, they were inconclusive:

In the meantime we got the results on day five, we went back in and we saw a different clinician and he told us that the results for the major trisomy chromosomal disorders ... were all clear. Which is really difficult, it was just really difficult [not to get clarity]. ... while we waited for the [next round of] results, sorry these things are hard to talk about, we proceeded with the planning around the termination but again this time not hoping for a fatal diagnosis that we could access care in Ireland but hoping that if we got diagnostic clarity and it was in the much milder end of the spectrum well

then we wouldn't have to, we wouldn't have the same concerns about our child having a severely life-limited disorder ... So we went back on the, when I was 23 weeks for the [final] results and we met the same consultant for a second time. And the [final] results, because at this point we just felt like we were jinxed because we couldn't get clarity in any direction, were also non-conclusive.

Natalie

Ultimately Natalie's tests all came back inconclusive and so she had to decide on how to proceed based on her understanding of the structural anomalies detected on the scans.

I mean we couldn't find that in the doctor's to have conversations with us. ... At 23 weeks we go back in, it's all unclear, [the doctor] did the exact same thing again, I was like "oh God if you tell me once more that you can't tell me what life would be like for my baby I [can't bear it]." And I repeated once again [what I understood] outcomes for babies with multiple foetal anomalies, but particularly with a similar profile to [our child], had. And I would have found it really helpful if someone could talk through that with me. And he just kept side-stepping it.

Natalie

Natalie travelled for termination immediately after that consultation and while she sought care in the UK under category C (see Section 1.2, Chapter 1) of the legislation there, the doctors reviewing her case categorised the termination under Category E (see Section 1.2, Chapter 1), which refers to a "substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped".

And at the time we were down, we scheduled the termination, we were in category C which is any termination up to 24 weeks in the UK is a category C termination. But actually on discharge I was given a copy of my file and the doctors who reviewed all of the reports we had before and reviewed the foetus, our baby when the termination happened, re-categorised it as category E.

Natalie

Natalie pursued genetic testing and found the outcome of that, while still inconclusive, more helpful as the clinician in that case was more forthcoming in discussing what the outcome for the child would be, given what they did know:

We saw [the geneticist] [six weeks post-termination ... I know it took three months to get the results so we saw him again after that] to discuss them. And when we went back in for that, so nothing showed up in any of the very extensive tests that were done. But when we went back in for that we did a really good discussion on everything that could likely have been. And it wasn't a prognostic discussion, it was just a discussion that we had always wanted to have about what life would likely look like. Knowing that there are exceptions and there are, it's a spectrum and there's people at either end but what it would likely look like. And that was really helpful. More to feel like we'd completed the circle for [the baby] than for planning for the future for ourselves. But also for planning for the future for ourselves. I don't want to sound ungrateful or negative but it was a bit like seeing the category E on the UK form. It was really good to have that conversation. It brought ease to a part of me that had felt really alone with a lot of information. And I think both of us had felt very alone with it. And it made us feel less alone. And it made the weight of what we knew feel shared. So that was incredibly helpful. And then it was really distressing that we were having it then. So it was both, yeah. And I think it might always be both, you know. And distressing and kind of infuriating, like why did we have to wait until then. But it was really helpful and it really, it did all the things I imagined it might do which is not give us a sense of "oh you're doing the absolute right thing" or "we know for sure" but just make us feel in community with the information and make us feel not like the people who are bringing the

bad thing into the room, which is what I had really felt with it before. So yeah it really helped in that respect. And I will always be grateful for him for that. But yeah you shouldn't have to wait so long.

Natalie

Summing up her experience of the care pathway in Ireland, Natalie was of the view that the legislation and regulations governing termination of pregnancy in Ireland heavily curtail openness in conversations between clinicians and parents where anomalies are detected but diagnostic testing is not clear cut. In the quote below Natalie depicts the effect of this as meaning they as parents *felt very alone with it*, that is with trying to assess the information they were getting and make a decision on the outcome for the pregnancy.

I suppose how I understand it is years of not being able to speak about prognosis. Years of it and fear of what that would mean in terms of culpability. And then adjusting to what is a really rigid set of legislation. Because the conversation that we had before we knew it wasn't [a clear diagnosis] was the freest conversation we had. So it felt like as soon as we weren't in the category that was eligible under current Irish legislation everyone was silenced because they didn't know how much to say or not say. Which is bizarre because there's freedom of travel and you know it's not, we weren't looking to have a conversation about whether or not we should terminate our child, we were looking to have a conversation about [what] outcomes for foetuses like our child is. But it feels like you can't have, separate them out because of historically maybe and culturally the way those conversations have been so heavily laden in this country. ... But my assessment of the situation here was as soon as we weren't in a clear diagnostic category that was fatal, everyone clammed up. That was my lived experience of it. ... I could see the shame and witness it and go "why am I internalising this because it's not how I feel I should be judged or want to judge myself." But there's something just very shameful about not being able to have these conversations with your care providers and not being able to access care in your own country.

Natalie

Natalie echoes other experiences highlighting the effect of legislation regulating termination on how clinicians relate to parents undergoing foetal anomaly assessment as closing down conversations when a qualifying diagnosis is not achieved, leaving the parent feeling alone and having to make very difficult decisions in time pressured conditions. Alongside feelings of being alone and unsupported, having to travel for termination raises feelings of shame when denied access to care in one's own country.

As noted above, the foetal midwife specialists had been a constant contact point for Natalie along the care pathway and their initiative to organise a post-abortion check-up a few weeks after she had the termination in England was appreciated by Natalie on a symbolic level in terms of continuity of care:

[The foetal midwife specialists] they were really good. They organised like a two to three week, after we returned scan just to check everything was healing ok uterus-wise. And that was just really, I mean the last thing I wanted to do was go back to [the hospital] but it felt like it was as much a way of welcoming me back as a way of checking physiologically on things. It felt more symbolic than anything else. And I'm really grateful for that. There was no medical care involved from a consultant point of view. It was all nurse led. And I don't know if that's an initiative they take or if it's a standard of medical care. But it was just really helpful. Just to feel like they still wanted to see you again.

Natalie

Finally, Cara was single and had become pregnant through donor conception. All scans including the 20-week anomaly scan had been fine until a scan at 25 weeks' gestation indicated multiple anomalies.

I'm single so I went down the donor conceived route. So I was very conscious, lots of hoop jumping

before to go through and that takes a lot of consideration and all of that. So I was very lucky to get pregnant first time, had the best pregnancy ever. Twenty weeks scan came and went and that was perfect that was great, and then it was, on week 25 I came back and in that particular scan they saw multiple abnormalities. So that was a huge shock and of course many, many questions why did they not see this at the 20-week scan. You know, did something happen in the interim. So that led to' so basically they couldn't tell me what was wrong, so that was, that scan happened in [the maternity department of the regional hospital I was attending] the 20-week scan and the 25 weeks. So like that when I went in for the 25-week scan I was by myself, I was having a little daydream as to where I was going to go for lunch and what coffee I was going to have. And then you know the radiographer said I think you might have a little bit of a cleft pallet or cleft lip. Oh okay, don't panic, don't panic, don't panic. So she comes back in with her colleague and says you know we just want to have a look and she said he does have a [congenital disorder] but it's the fluid on the brain now that we are worried about.' At which point I went "I'm sorry, what now? My God what?" And they said "no, no look we need you to see the consultant" and I said "look I have an appointment with the consultant this afternoon." So I said "we are talking hydrocephaly or what are we talking about?" They just wanted to get me out of the room, they just, for whatever reason they just seemed to find it difficult. And I'm going like, I'm kind of saying "no wait, wait hang on a second", "no, no we just need you to see the consultant." So that would I suppose be my first point of, you know, number one they knew I was on my own. They also knew that I had two hours to kill in between [the scan where the issue was detected] and seeing the consultant. So, my point, and I have gone back to [the hospital] and said this, at that point what I would have liked to have seen is to be, to have somewhere. Have a room, have somewhere that I could have gone to sit down, compose myself a little bit before, you know, and they did kind of say it to me "what are you going to do for the two hours?" And I said "I'm going to go for lunch somewhere."

Cara

Cara found the absence of any supports or offer of private space after the first initial indication of a problem with the pregnancy difficult, as she had to keep her composure in public spaces while highly anxious about her pregnancy between these two appointments. She returned to have a consultation with her obstetrician who referred her to a tertiary hospital for an amniocentesis. The hospital Cara was attending is a non-providing hospital of termination services.

She looked at it and she went "right, well we need you to go to [to another hospital], we need you to have amniocentesis. We need you to have..." I possibly made a face and she said "would you, do you want to continue on with this pregnancy?" ... I literally went "well is that what, is that what we are talking about? Like two hours ago I had a perfectly healthy pregnancy now you are asking me if I want to continue?" So she said "well look," she went on, she was quite good at giving the information about [what the scan showed]. "We need to find out more." But I was reeling for that going "well obviously it depends what's wrong. Like are we talking a fatal foetal abnormality?" She said "I don't know." And I went "but you," so yeah that was shock.

Cara

For Cara, termination of pregnancy being raised on the same day of the indication of an anomaly was a shock and she was relieved to receive an early contact from the tertiary hospital where she was being referred to for assessment.

So that was on a Thursday and [hospital I was referred to], in fairness to them, rang me that evening. So I wasn't left for any length of time. And they couldn't see me until [six days later] so that was a very long wait. ... And like that shut down the computer because I just, there was just, it could be so many

things. So I met with the team in [the maternity hospital in Dublin] and they did the, they saw me at eight in the morning and they obviously, in fairness to them, squeezed me in. And I had an ultrasound then and he did confirm that there was skeletal issues [and] several things wrong with the brain. So they said "look we are going to take an amniocentesis and we'll send it off and that should give us a bit more information." And at this stage I'm kind of going "yeah but again are we talking, you know", so at that stage I actually didn't know the definition of fatal foetal abnormality was that two doctors had to agree that they would, he would die after, or before 28 days. .... So I was, so that came back with you know "no, you are not for any of those [conditions tested for]. So we will wait another two weeks because they grow the chromosomes to give you know if there's any additions or deletions." And he said "now this might come back, you know, with nothing." So at this stage I was, you know, those five weeks were probably the toughest because I still did not know what the story was. How badly affected he was going to be or whether it was fatal. So it was a bit "what do I do?" You know and bearing in mind I'm quite late already [now approximately 26 weeks].

Cara

The foetal medicine specialist at the tertiary hospital told Cara they would discuss her case at the next multidisciplinary team meeting the following week and she was scheduled to return to the hospital for a foetal MRI in the interim.

Now in fairness they have a multidisciplinary meeting on a Tuesday morning or one of the mornings, Monday morning, and they said "look, we are going to discuss your case". So they brought me back for an MRI, foetal MRI and so that was on the Thursday, so that was a week after that. And they would have the results for me the next week, of course the Monday was a bank holiday so it was the Tuesday. But I knew by the radiographer as I was getting up, she said you know "when are you seeing the consultant again?" And I said "oh I've no appointment made, I think they are going to give me a call next week." "Well if they don't ring you on Tuesday I'd get on to them" and I thought "okay it's bad".

Cara

Another week later Cara attended the foetal medicine unit again to learn that while multiple anomalies had been detected and a severe LLC was determined, a diagnosis satisfying the criteria under Irish law had not been reached by any of the assessments carried out. This inconclusive diagnosis meant that the only option available to Cara was to travel to access termination in England under Category E of the legislation there, as by now she had reached 28 weeks' gestation.

They said "do you want to meet the neurologist?" and I said "absolutely yeah." So they did bring him in subsequently and we all had a chat and so the prognosis, again there was nothing definite. ... So you know they then discussed the option of, you know, "we could refer you to England to terminate the pregnancy" ... as he could not tell me, because that's a thing they could not tell me, how long he was likely to live. He could live a couple of months, he could live for a year, he could not, so I then, they did not in any way try and sway me. They were very good that way. It was "we will support you if you want to continue on with this pregnancy, but we will support you", he was also aware that I was single and he was saying "look, best case scenario you won't be working anymore." And I kind of went "how do you support a child, how 'o I pay the mortgage if I'm not", you know, so there was that to consider. But ... when the neurosurgeon came in I just said "look if this was your wife, sister, daughter, what would you recommend that they do?" And he said "you know I think you are making the right decision". So I kind of thought you know "okay I know everybody has to make the right decision for them." So they did, as I say it was the ambiguity that I found very difficult ... So I suppose the reassurance for me was that you know they had, I think it has to be because I was so far along,

it has to go in front of an ethics committee as well. So [the hospital in England] got back to me very quickly, that day I think it was the Thursday, got back to me that day and said that they would have an appointment for me in nine days ... So the procedure was that their consultant over there would do an ultrasound, obviously he had all the files from [the hospital carrying out the specialist assessment]. ... So by the time I got over to [England] yes they had all my files, they had all my scans and my MRIs and all of that. The consultant in [the English hospital] scanned me, now very quickly he came up with a working diagnosis [of a rare genetic disease] ... So I then proceeded to, he then terminated the pregnancy.

Cara

Cara and Natalie both received inconclusive diagnoses. Although specialist assessment clinicians could see there were multiple complex anomalies present with considerable life-limiting effects, a diagnosis was not reached in either case. The inconclusiveness and absence of clear-cut diagnosis meant their cases would not satisfy the criteria for termination under Irish law and both had to travel to Britain to access care under Category E of the British legislation.

Having portrayed women's care pathways in such a way as to allow an appreciation of the detailed experiential perspectives, we turn now to distil the key aspects and issues within those care pathways featured across the data set.



# Assessing Care Pathway for Women Seeking or Accessing Termination Under S.11 2018 Act

This chapter is a companion to Chapter 11 above, which sets out women's accounts of navigating the care pathway when seeking or accessing abortion care under s.11 of the 2018 Act on a case-by-case basis. This chapter integrates the analysis to set out key cross-cutting issues featuring in the data relating to women's views on their experiences of this care pathway.

### **12.1 Views on Pregnancy Assessment Process**

Women in this study group described how foetal anomalies were detected in their pregnancy either during routine scanning or indicated by early elective foetal screening. Women made aware of a potential issue with the development of their pregnancy during a routine scanning appointment recalled being deeply attuned to the verbal and non-verbal cues of sonographers, doctors or midwives, and being able to read when something was wrong. Where previous scans had been fine, this was a major shock. There was variance in terms of how this was managed. In some cases, staff involved in the assessments would not discuss next steps or what they observed, while in others the question of continuing or terminating the pregnancy was mooted:

And then I just remember [the sonographer] coming in the door and she was talking to the midwife and I could just tell by the face she made, and she just said, "look we're going to send you up after lunch to foetal assessment". I didn't even know what foetal assessment was at this stage, I just thought, you know, I've just gotten pregnant, I was relatively, what was I? I was [in my mid-thirties]. I was like what, "what's this?", we didn't understand, we were clueless.

Gabrielle

And then I had my 13-week scan here in the hospital and then the sonographer was just like, "it has a big, a lot of fluid around its head and that's not a good thing" anyway so she was just like, kind of straight away, now she was amazing, but the language as kind of like "whatever you decide to do" and like, it all happened so fast, like one minute you're getting scanned and the next thing you're like being told "you've to make a decision" and you're like "sorry what, what is going on here?"

Eavan

Both approaches were confusing for women who felt they were being catapulted into both terminology and potentially decisions they had not been prepared for. In settings where no specialist foetal medicine midwife was available – with a dedicated remit, skills and experience of supporting women receiving an indication of a foetal anomaly – women were left feeling particularly at a loss.

Once a potential issue had been identified, women were put onto a pathway of further scanning and foetal testing, often involving referral to another hospital. Where an anomaly was detected at an early gestation

either by scanning or NIPS, the realisation of needing to wait until a later gestation for further testing was difficult to cope with. These waiting periods were experienced as prolonged and highly distressing:

So, I didn't realise that you have to wait until almost 15 weeks for an amniocentesis. So that was the longest wait of my life, from 11 weeks to 15 weeks.

**Emily** 

And the amniocentesis is needed and you know I completely agree, you know, with that because it does give you 99% accuracy rate. But it's the fact that, I don't know, you have to wait for that till you're 15 weeks and then you have to wait for those, the first results and then you have to wait for the second results and then you have to. I know, like in hindsight, sorry when you think, it's about four weeks the whole, it lasted, but it might as well have been a year, like it's the longest four weeks of our lives, you know and the fact that it was under COVID, you know you're not doing anything else. You know, you're just waiting.

Martha

Those who had undergone NIPS were often surprised to learn that they could not act on the results and that the screening was not a diagnostic test. Women who had opted for early testing intended this would facilitate taking a decision regarding termination, should an anomaly be detected, as early as possible. However, the need to wait for more definitive testing to usually 16 weeks' gestation eliminated any potential benefit of the early testing, in their view. NIPS was often performed from 10 weeks onwards and results were usually not returned in time for women to access abortion care under 12 weeks' gestation.

But yeah there isn't enough time for anyone in my situation who needs to get results back from a test, 12 weeks is not long enough. It's as simple as that, it's just not long enough, it needs to be 16 weeks. Because a lot of people will get an amniocentesis, and you know the choice isn't there unless you have results of a test, I mean this was a wanted pregnancy you know.

**Emily** 

Early testing was sought by women so that in the event of a catastrophic diagnosis early termination could be availed of, but the later testing processes meant compassionate induction of labour was the only option left available.

But if I had to go through labour, you know to deliver, like it defeats the whole, to me mentally it defeats the whole purpose of why we got the Harmony test [NIPS] done in the first place. Why we tried to do this in advance, so we're not confronted with this decision so late in the pregnancy.

Martha

While the emphasis of the legislation is on a fatal anomaly, concerns about a severely life-limiting diagnosis were as high for participants in the study, who carefully evaluated what this would mean for the quality of life the child might have, and themselves as parents, and other children they had already. Severe, complex and multiple anomalies could often yield inconclusive diagnostic results, but initial assessment of the condition was sufficient to allow women and couples appreciate the impact of what was observed. As gestation advanced, women had to assess whether they would proceed through protracted testing procedures with a potentially inconclusive outcome achieved at an advanced gestational stage, or make the best decision they could based on what they did know at a gestational stage where access to termination was more certain if they travelled. The impact of this period of waiting and uncertainty was harrowing.

But then I suppose after the three weeks' waiting and thinking the worst and hoping for the best we had no further information and I suppose at this stage I was over 25 weeks pregnant. And we were told that we were going to have to wait for another two to three weeks for results of our tests. And you just feel like a bit of a caged bird in a way, if that makes sense. Just the gates are shutting in front

of you, you know. ... We had the fear, this unbelievable fear that our [second round] results in three weeks' time would come back inconclusive. Which at that stage there's nothing that could be done in Ireland or even if we had to travel at that stage then, I would have been over 28 weeks pregnant. Am I even allowed to fly at that stage and then throw COVID into the mix. And we had all these like just nightmare situations, just fear, just real hard fear.

Neasa

Faced with the prospect of a long, protracted wait for the outcome of testing to determine if the anomaly detected was fatal according to Irish law, in some cases parents opted to travel for termination before 24 weeks in the UK, for the certainty in access this provided them with.

That was really key actually, part of it that [they] said that they could take quite, like [they weren't] really being clear, [they were] like "they can take two weeks or more and it's even slower because of COVID". So that was the exact kind of pinnacle of where we were like, in our heads we were like "ok we either take the chance to go to the UK before the results come back or we wait for the results", which the results will show if it's, they would probably show if it's fatal abnormality or if it was actually just a severe foetal abnormality but that it wasn't going to be fatal.

Denise

There was a pervasive theme of "reading between the lines" as women went through all the various steps involved in having their pregnancy assessed. From the moment an issue was first detected, to being referred for further testing, waiting for results, being given diagnostic and/or prognostic information, women interpreted verbal and non-verbal cues as being "signs" from the health care professionals involved in their care as being potentially "good" or likely to mean something sinister. The caution exercised by clinicians in sharing results left women often piecing together any information they received with what they had researched themselves and/or already picked up. Denise recalls how having conducted research herself meant she could begin to put together a potential diagnosis with the sparse information she received from the hospital consultant she attended for further investigation:

I think I was lucky because I had looked up everything and researched everything myself, so we weren't really being told much information, you know about how profound this was or how serious it was. So it was only because I had that, you know research done that I knew when [they] said "ok it looks like there's ...", that I knew then in my head, I was like "ok I saw that that was a marker for most of the, like, foetal disorders" or you know different things like that.

Denise

While waiting to discover if they would qualify for termination in Ireland, women found themselves in what they depicted as the "bizarre situation" of hoping for the condition to be deemed "fatal enough". In this sense, "fatal enough" meant not having to travel, but even more importantly, it legitimised termination of the pregnancy and made women feel "taken care of" rather than denied care in Ireland, and having to resort to the unenviable situation of travelling for termination when the need for this was believed to have ended for Irish women:

And again that, at that stage it is bizarre waiting for results, and I'm saying please let it be fatal. Please let the diagnosis be fatal. So, I don't have to make this decision.

Cara

So you're like I don't know, my first feeling was relief because I was like this can, you know legally be ended now, we don't have to have that thought of do we need to go to England or do you know what I mean, like having the care. It just felt like someone had just taken care of us or something or like it was in someone else's hands.

The emphasis on diagnostic testing seems principally driven by the requirement for testing to a high level of clinical certainty, with the legal responsibility resting on the clinician as set out by the legislation regulating access to termination after 12 weeks' gestation. Women noted how their capacity to be involved in taking a decision informed by the results of screening or testing was removed. Furthermore, the highly restrictive legal regulations for accessing termination after 12 weeks' gestation, as only permissible if certified by clinicians based on a high level of clinical certainty, remove any capacity for the pregnant person to be a party to that decision.

### 12.2 Impact of Waiting for Assessment, Diagnosis and Care

Women were acutely aware of their developing pregnant body while they awaited test results or a decision as to whether they could access care in Ireland. Intuitively they knew that the longer the pregnancy continued, the more difficult it would be both physically and emotionally to terminate:

Ah it was awful, the waiting was the worst... Because I could feel the baby, that was, to me I didn't want to get to the point where I felt a presence of a being inside me, I couldn't even call it a baby because I was trying to completely emotionally detach from it and it was just, it was terrible, yeah, it was terrible...".

**Emily** 

Yeah so let me see that was the Friday, so then, again there was so much time and you're like, you're so aware that the baby is like growing and you're like if I terminate, when I terminate, it's going to be worse the bigger it is, like for yourself emotionally and also physically.

Eavan

Francesca questions the reasoning behind allowing her pregnancy to develop based on a negligible chance that the round one results of her CVS were incorrect:

And you're telling me for a 0.2% chance to continue going forward with my pregnancy week on week getting bigger, the baby getting bigger, I just don't really understand that at all.

Francesca

Being visibly pregnant was a pervasive concern for women - the waiting around was awful because I was starting to show (Maeve) and they described dreading meeting friends, neighbours and colleagues who would make well-meaning remarks on the pregnancy, not knowing what they were going through. The longer test results took to return, and the more tests that were required, the harder this became to avoid:

...it was the longest four weeks of my life, like it was so long, and I was lying to everybody bar my immediate, my parents and our immediate family, we were lying to everybody, continued at work, I still had a baby in me, I was having terrible thoughts, it was just not, like it was horrific, it was horrific.

Gabrielle

Women spoke about the lengths they went to to avoid these encounters – often ceasing to frequent locations they would have normally attended like shops or playgrounds:

Like I was looking pregnant, it was not my first pregnancy, I was hiding my bump, like I hadn't told anybody else. I was afraid to go to playgrounds with my kids in case of someone saying oh, you know. I was afraid to see people, like I was in this horrible way, like I was so scared.

Lily

But like it was just so awkward to, like to leave the house because I would see people at the local shops or we'd go to like you know whatever, go to do things in the local town and even just shopping and I met people and like they're just talking to you about the pregnancy and everything and you know I was like, I couldn't, I don't know how somebody could know that they were going to lose a child and decide to wait out the pregnancy. Or even I couldn't imagine what it would be like if I had been given a termination date like a month after that in Ireland. Would I just hide for a month, you know and just?

Denise

All the while as the pregnancy developed and women tried to manage their interactions with others while assessments continued, they were engaging in an ongoing process of coming to a decision on what the best outcome for this pregnancy could be.

### 12.2.i Deciding on Best Pregnancy Outcome

In anticipating pregnancy, prospective parents may have engaged in some anticipation of how they would respond if during that pregnancy they received a diagnosis of a foetal anomaly. Accounts of considering potential hypothetical situations of foetal anomaly featured in the data.

We had already decided ourselves if there was anything wrong that we would be going for a termination so we already knew that.... we've talked for a long time about having a baby and do we even want children, like this wasn't a light decision to even go for it [to get pregnant], so we knew if there wasn't anything, not that I'm like "oh I must have a perfect baby", if the baby's life is going to be in any way compromised and compromised our life as well then we wouldn't, we didn't want that. ... We already knew that.

Maeve

The fact that we'd already taken the Harmony test [NIPS] on our first [child] and had taken it again, I mean there's a reason why you take these tests. And we had spoken before about the, what it would mean to our family to have a baby with chromosomal abnormalities.

Francesca

When faced with a foetal anomaly people considered wider concerns for their family and other children they had already, and in particular quality of life issues for a child born with the anomalies indicated.

And you know we did plan this pregnancy and we did want the baby but we thought about everything, we thought about our kids, we thought about the child itself and for us it made more sense not to go ahead with the pregnancy. ... you're not just making, it wasn't just for me, I'm thinking of my ... kids, you're turning your children into carers, you know and you have to consider that you know and the plans you have for them and your future life together completely changes. So that's, you know and then for them as well. ... So you know when we made an educated decision, it wasn't just "oh no we don't want that", you know we thought it all out and I've experience of it and you know, not as a parent but I've dealt with a lot of people who have children with special needs. And like that it's, it's not easy.

**Emily** 

You know, so all these things were going through our mind. I think we both had kind of decided that if our baby's diagnosis is non-fatal but if quality of life is so poor, we don't really have an option but to terminate our pregnancy, which is the hardest decision in the world because [the pregnancy] was always wanted you know.

Neasa

Those receiving a diagnosis on much-wanted pregnancies weighed up all the information they had regarding their own and their family's capacities, and drew on insights about supports provided for families raising children with profound needs, in trying to make the best decision in their situation.

And you know I actually have done a lot of work in the area of special needs through my job and they say "oh you know there's supports for them", there's not supports for them. I've worked specifically with children with [the same condition indicated] and oh my God their parents are so stressed, the majority of them are depressed and just they get like six sessions of speech and language therapy a year. You know six sessions of OT [Occupational Therapy], it's not enough and then you know what happens after school? They're just constantly stressed out and that's just the parents of any kind of special needs but just, there aren't the supports there.

**Emily** 

And I've [known] children with severe profound life-limiting disability and I believe that is, what we decided was that wasn't a life that we wanted for our child or for us. And I absolutely think that's a life of value and that can be a life of pure meaning. But it's also a life of so much suffering for everyone involved. And can have a major impact on day-to-day quality of life. And we knew the most likely other anomaly that would be wrong with our baby [was] significant neurological problems. But if that did show up on scan it would likely not be until very late in pregnancy. And it might not ever show up on scan, it might just be a post-delivery kind of thing that you'd find out.

Natalie

Reflecting on the decision they made, Natalie challenges notions of the "right" decision in the context of such a difficult decision:

I don't think we made the right decision, I think there were just shit decisions and we made one of them. And it's never been a comfort for me to think one was right and one was wrong, there's just difficult decisions and that's parenting and that's what you sign up for. And we made the best difficult decisions we could think of at the time. But part of the follow through on that was honouring and respecting their legacy and getting genetic testing done and making sure that there was nothing else that we could have foreseen.

Natalie

The weight of the decision facing women receiving a diagnosis was a recurring feature in the data. While clinicians provide and administer testing and interpret results for women, women receiving the results felt the heavy onus of having to take the decision on the consequences of receiving the diagnosis themselves, without guidance from their clinician. The situation women portrayed was that where there was an inconclusive diagnosis or one that did not satisfy the criteria to qualify for care under Irish law, there was reticence among many clinicians to engage in open and detailed discussion on quality-of-life prospects for the child. There is an indication that again the law is having a chilling effect on these clinical setting encounters that leaves a lot of frustration and gaps for women and parents.

And you're like, you can't leave it up to someone in that situation to make a rational decision.... You can barely make dinner, like you can't decide, not maybe decide but like you're not informed basically, like you're not and, because no one told you really, they kind of assume that you know and you're like "I do not know what the alternative is." So I don't know, it was like probably the lowest point, I was like, oh it was awful.

Eavan

Exhausting the testing process and getting genetic test results offered certainty that the basis of the decision to be taken was as well-founded as possible, and that any hope of an alternative diagnosis might emerge.

We wanted to wait until we had the [genetic test] results on the off chance that [we would get a diagnosis] or some miracle, that it was like a [milder diagnosis]. And then we could be more confident that it would be ok to go ahead with the pregnancy. So we wanted to wait until [a diagnosis].

Natalie

A conclusive diagnosis of a fatal anomaly had the effect of women feeling that any decision-making process was taken out of their hands. The distress of learning conclusively that a catastrophic anomaly on a much-wanted pregnancy was fatal had the effect of relieving women and parents of the onus of taking a decision to terminate.

But in a way [baby] took that decision away from us you know. So really I suppose when we found out [baby's] condition, there came a huge relief but there also came a massive sadness. Because our baby wasn't going to survive. Where do you go from there, do you know? So we had to make the decision then, well not then but like [the doctor] let us go and we were allowed kind of think about what we want to do.

Neasa

Meanwhile Neasa acknowledges that if the outcome of the assessment of her pregnancy was severe life-limiting conditions that did not adhere to the criterion of "fatal", required to qualify under Irish law, that quality of life considerations would have placed the decision back on her without the option of accessing care locally.

So I suppose selfishly there came a massive relief when we heard that our baby wasn't going to have a life-altering disability, you know that our baby won't have to spend its time in a wheelchair and have brain damage or, you know. It's not that we didn't want our baby, we wanted a baby that had some sort of a quality of life. ... But if our baby was to be [severely disabled] you have to consider that, because that's life-altering for everybody, that's life-altering for [baby], for our [eldest child], who would always depend on [their older sibling]. [The older child] would have to go through that their whole life. And then for us as a family, for my husband and his, you know everything. ... Everything pointed towards [fatal foetal anomaly] which is what [baby] had. But if our doctor went "well no actually maybe, maybe it is [a non-fatal condition]", you know our roads would have been completely different. And not only that because, or would have been completely different because then we would have thought "ok maybe now we have to travel."

Neasa

Karla portrays a care pathway where she did feel there was shared, collaborative engagement between the clinical team and herself and her partner, from the point where at 21 weeks' gestation a structural anomaly was detected to its ongoing assessment using echography or imaging. During each assessment echography, Karla felt the team explained well to them how the condition for their child was evolving. Clinicians were willing to share diagnostic information with a specialist clinician outside Ireland the couple had contacted for a second opinion and potential treatment options.

Yeah, we were very involved, we wanted to be involved, we wanted to see for ourselves, we were able to see for ourselves, we were able to .... Yeah when, on the day that we knew that we were going to have a stillborn child.... And for us it was much better to be able to end, well I would say psychologically it was the best thing and at the right time. If we had to carry this pregnancy to term for a stillborn baby to come, it just wouldn't, it was already really hard. ... Yeah, we definitely felt like we had the control of the time. Because of course we wouldn't do it before they felt they were ready but if we needed more time, [the medical team] would give us more time.

It seems like, you know, you've given us a lot of detail there about the importance of that really

#### involving parents in getting every opportunity to hear the diagnosis as fully as possible.

One hundred percent yes. I think it's really important to be part of what is going on. But at the same time being able to go through the process at the time that it should be done and not wait longer than, procrastinating the pain.

Karla

However, when a qualifying diagnosis was not achieved women felt clinicians opted out from making any recommendation on how they would proceed, and an onus of responsibility reverted fully back on women's shoulders and left them feeling unsupported:

Just the entire decision is on your shoulders. ... And there really is no, I would say there was no clinical, like you said a clinical, I wouldn't say support, but they don't give you any feedback as to what you should do, you know?

Francesca

Clinicians being unwilling to discuss with parents possible prognosis for a child with multiple, complex anomalies but an inconclusive diagnosis means the experience of care is considerably different and diminished.

And for the parents like us there should be a fucking geneticist and medics who are willing to talk about the [information] and you know open the discussion about the fact that this is, life is complicated, there aren't easy decisions. And this is one of them. But I really struggled with that and that's why I think this research is so important because not every pregnancy [gets a diagnosis].

Natalie

The data demonstrates that regulating access to termination of pregnancy on the basis of a high threshold of clinical certainty of imminent fatality has the effect of closing down conversations about likely prognosis between clinicians and people they are caring for, and closing pregnant people and their partners and families out of the decision-making process based on considerations relating to quality of life and capacity to care. While Martha did receive a diagnosis and qualified for care in Ireland, the experience of going through the assessment process highlighted for her how pregnant people are positioned within the process and she questioned that:

We're the people who really wanted these babies, we're the people who have really thought through the decisions that we're making. And I'd say as well, I don't know, the vast majority as well could be on second, third, subsequent kids. And then, you have to factor in the family that you have as well in the decisions that you make. ... For us once we found out, like it wasn't an option to continue on with the pregnancy, do you know. It wasn't the fact – it was when we were still hopeful but once we knew, you know, that things weren't, you know that this was definitely, that there was no, we knew in our heart that we weren't going to be able to continue. ... And I think women should be trusted to know what's right for them, what's right for their families. And I don't think they are, which is the unfortunate thing. ... Which is why you have the multidisciplinary hearing that meets and discusses what's best for this woman and her family. ... And they don't consider that if they, you know if they tell this couple that you know they have to continue with the pregnancy, with the child that has life limited, how are they going to be able to support this child. Will one of the parents have to give up their job, how will they care for their other children, do you know. Somebody else is making that decision for them.

Martha

Alongside this changed and diminished clinical support and engagement regarding prognosis and outcome for those who did not receive a qualifying diagnosis, being denied access to termination care in Ireland was very difficult at the end of what had been a devastating and arduous process.

I don't think I'll ever regret the decision but I'll regret, having to travel was a real thorn in the side now on top of, you know, the long wait to get the definitive answer was the worst period of my life so far. But yeah it was, yeah not having your country there for you. ... in your time of real need was really hard.

**Emily** 

The impact of having to travel is discussed further below.

### 12.3 Having to Travel to Access Termination

Within our data set, seven women travelled to access termination of pregnancy care for the various reasons outlined at Section 11.2 above, "Overview of Data Set of Women Seeking Abortion Care After 12 Weeks' Gestation", namely not receiving a qualifying diagnosis (n=4), time constraints (n=2), and choice of method (n=1).

The hospitals women attended took a range of positions on their role in relation to women travelling to the UK to access termination following denial of care under Irish law. Some women described being simply handed a piece of paper with the details of an English-based care provider to contact themselves. In other settings staff used the term "refer" when telling women about providers they could attend in England for termination, and provided diagnostic scans and materials either directly to facilities women were attending in England or directly to women to bring with them.

Emily, Francesca and Maeve all had anomalies detected in the first trimester and, following assessment, learned they did not qualify for care in Ireland. All received contact details of care providers and varying levels of information about the procedure, but there was no liaison between the Irish hospital and the care provider in England.

I mean you get a piece of paper with their contact information on it, that's it. ... And you know [the foetal medicine midwife] was very good as well in saying that anyone she knows who had gone to BPAS had a very positive experience and that they were all lovely and you know that they'd be concerned for our care and all that kind of stuff. But you get a piece of paper with a phone number on it.

Francesca

Emily asked for diagnostic reports to bring herself to give care providers in England.

So, our only option was to go to England. And they can't book anything for us. They gave us the information, you know on paper, and that this is what we can give you about England and you know they told us a few bits and pieces but that was as much as they could do to help us. ... contact details and what it would involve and that kind of thing, the websites and people to get in touch with in England. ... So you were just, unfortunately it was very hard, you're just on your own then and you have to go and make a phone call. ... That was really hard, here you go, there's the information, we can't help you. ... I brought reports with me from like say the amniocentesis report, I got [the hospital] to, did they send that to me, I think they posted it to me.

**Emily** 

When it became evident for Neasa that a complex foetal anomaly had been detected in her case but the outcome of assessment as to whether she would qualify for a termination under Irish law was indeterminate and would take some time, she explored the possibility of travelling for termination with the clinician

carrying out the assessment. In her case the doctor gave her details of care providers' websites in England and an Irish pregnancy counselling service that were helpful in informing her as to options for accessing termination outside of Ireland.

And then the doctor gave us email addresses, well websites pretty much, because you see I suppose the way things are in Ireland he can intervene if there is a fatal foetal abnormality but up until that stage he can't, nor can he be seen to guide us in any which way. So he just gave us websites for a hospital in England and for a link towards a hospital in England. And [a pregnancy counselling service] was kind of the next email we had and then we had another. So we rang the UK first ... it was after the results had come back inconclusive. So it was three weeks after we had heard that there was a problem. And so it was three weeks after we heard there was a problem but it was that we didn't have any answers. So he was like ok, I said I need to, just I need to know what our options are you know. So he just gave us the websites of the organisation in the UK, the [pregnancy counselling organisation] and I actually don't know what the last one was because I stopped at [the pregnancy counsellor] then.

Neasa

Martha did qualify for termination under Irish law but wanted to have a surgical procedure as opposed to a medical termination of pregnancy. The hospital she attended in Ireland provided Martha with information on the diagnostic scanning and tests she had undergone to bring with her, and also contacted her with results that had returned after she had travelled to the UK. She also returned there for post-termination assessment.

So in fairness to the foetal medicine... the midwives, they did ring me on the Wednesday, so I was already in the UK at that stage, to tell me that the karyotype, the full results came back too. So, they told me that on Wednesday and wished me luck obviously and hoped that everything went well. So, then when I came back to Ireland the following week, they touched base with me again...

Martha

Martha commented on the impact on staff of not being able to provide women with the care they were seeking. Francesca also noted this and described particular efforts the specialist foetal medicine midwifery team at the hospital she attended took to support her, particularly offering a scan directly prior to travelling in case the pregnancy had ended in an undetected miscarriage by that point. She perceived this as the hospital staff desperately attempting to offer care within the context of highly restrictive legislation.

They're literally clutching at straws, they're clutching at straws to try and help us. Because they know that they can't, it's really obvious that they want to be able to give a better level of care and they can't. So, they're doing everything that they can to try and help you.

Francesca

Denise consulted with her GP after a foetal anomaly was detected at her 20-22-week scan and was advised that to be secure about accessing care she should travel to England. Her GP connected her with a support group who the GP's colleague recommended when the GP sought advice on Denise's behalf:

[My GP] said "ok there's a route for you to go, you have to go through the Abortion Support Network. So my [colleague] has said that you can contact this number and they support Irish women who are going to go abroad for abortions if they want to. Or they could even kind of chat through a bit more about, you know, what's available to you and that". But she said "you have to go through the Abortion Support Network". ... we phoned the Abortion Support Network and they were absolutely amazing .... they just gave me the [clinic] numbers. So then we rang them and they got back to us like within a day. And booked us in and everything ...

Denise

Finally, Cara travelled to the UK for termination of pregnancy after complex anomalies detected after 25 weeks' gestation yielded an inconclusive assessment, meaning she did not qualify under legislation in Ireland. In this case, the hospital in Ireland liaised with the care provider in England to transfer diagnostic materials between the hospitals.

So you know they then discussed the option of, you know, we could refer you to England to terminate the pregnancy. ... The procedure was that their consultant over there would do an ultrasound, obviously he had all the files from [the hospital carrying out the specialist assessment]. ... By the time I got over to [the hospital in England] they had all my files, they had all my scans and my MRIs and all of that. ... the process of referring me to [the hospital in England], that was seamless enough. [The midwife] emailed all my scans and reports over and that was cc'd to me as well. So I could see them, so there was that sharing of information.

Cara

There is variance in the information women receive about accessing termination through a care provider in the UK and linkages between Irish hospitals and English care providers. In cases of later gestation and more complex anomalies that are indeterminate, direct transfer of diagnostic information was provided by the Irish hospital to the English care provider, but not in the case of earlier assessment and more conclusive diagnosis. In these instances women were bringing copies of diagnostic reports they requested from the hospital with them themselves. There was also variance in terms of information women were given about what care in England would entail, ranging from just receiving printed information to consultants or midwives discussing care protocols in more detail. Support services including pregnancy counselling services in Ireland and volunteer support networks in England did provide more detailed information and support for women. In settings where specialist foetal medicine midwives were in place, and would have had greater specialisation and involvement in cases where women opted to travel, specific efforts were noted to support women and lessen the impact of having to travel for care. Women did detect regret among some care providers in Irish settings for not being able to provide the care they needed due to legislative restriction, and felt supported by this.

Beyond variation in referral pathways (where they existed at all), having to travel to access termination also meant not being in familiar and comforting spaces:

I suppose in some senses, familiarity aspect, would have been nicer to do it in our hospital than have to go to England.

**Emily** 

Yeah, I could have come home to my own bed, I've a very strong desire to sleep in my own bed. ... my house is set up and everything I want like. I want my pets, I want, it would have just been nice to come back here ... Be in my own space instead of being in a hotel room. Like it's not even like your, so yeah it's not even like you're in, I wasn't even in a friend's house, we had to go back to a hotel room, there's no space, there's no privacy or comfort.

Maeve

Across the data set among both women who received care in Ireland and those who had to travel, the symbolic significance of being cared for in Ireland or not was emphasised. Not qualifying for care in Ireland signified being unsupported, denied care and cast out, and was associated with shame, stigma, and judgement.

And I just didn't want to go to the UK, so you know, I know so many women have had to do that. But that was something I did not want to do. It was horrible even thinking about ending the pregnancy,

that I'd wanted for so long and then you know it was being taken, I had to take, end it, that decision was horrible, but hopping on a plane over to the UK to do it would have just absolutely killed me, like you know, so.

Gabrielle

it's just like the past, you feel like you're a criminal getting on a plane and not telling a soul and sneaking off to England like, I mean that's what they had to do 50 years ago like and we're still having to do it.

**Emily** 

Travelling involved attending an unfamiliar health care provider in another country with whom women had no prior care relationship or prospect of continuity of care, at a time of high vulnerability. It involved practical logistics of travelling, arranging leave from work, absence from home and possible childcare, and considerable cost at short notice as time was always of the essence. It meant leaving the clinic after a traumatic procedure to return to a hotel or home of a family or friend, but not one's own home and the familiarity and comfort of home. Women felt a strong sense of injustice that legal change in Ireland providing for termination of pregnancy did not extend to include them, given that support for the Repeal referendum preceding the legislative change had been heavily influenced by compassion towards pregnancies ending for reasons of foetal anomaly.

I could have come home to my own bed, I've a very strong desire to sleep in my own bed. My house is set up and everything I want like. I want my [pets], I want, it would have just been nice to come back here. Be in my own space instead of being in a hotel room. Like it's not even like your, so yeah it's not even like you're in, I wasn't even in a friend's house, we had to go back to a hotel room, there's no space, there's no privacy or comfort. You need comfort, you need proper tea-making facilities. Just you need to be in a house with a bit of space and space to be either with your partner or someone or a bit of space to be on your own. The dignity of your own bathroom when your body is going through all this stuff. ... I would ask that the restrictions be widened. So that you could terminate for a range of foetal anomalies. Like you scan for, you scan for something and then you tell me it, like you know you're delivering bad news but then you tell me you can't do anything about it, that's mad. Why would you scan for something and tell me it was a problem with my baby and present it in a way that, like, you know you're breaking bad news but then you're telling me you can't do anything about it.

Maeve

The legality around it and because of the fact that abortion is not available after 12 weeks for people like me (upset) because the baby isn't going to die with a month of being born. You feel like you're doing something wrong, you feel like you're totally on your own. ... you feel like you're doing something wrong. I think that everybody is different, but like you know if people choose to continue with these pregnancies and I think they're amazing, but you know you have to factor in your current family situation, you know what it means for your future, what it means for your kids' futures, what it means for their kids' futures. And I think at the end of the day we all should be allowed make the decision that works for us. And it shouldn't be mandated on us that we have to continue with a pregnancy or travel to the UK, it's crazy.

Francesca

Travelling for termination diminishes women's capacity to memorialise the loss of their pregnancies and leaves harrowing memories instead, as Natalie and Francesca describe.

But there's just no system, or if we'd been able to access a termination in a hospital there's a system

organised for how the baby's remains are managed. But there just isn't for this situation. And because ... we didn't want to leave [them] behind, we didn't want to go down the cremation route. But there's nothing more horrifically surreal than being in Halfords buying a plug-in fridge for your car, while your baby is kicking in your belly. Because [they were] kicking away. And it was just insanely horrific.

Natalie

We had to leave our baby in England and that's closure that we will never get.... And we will never be able to bury our baby because our baby is in England. (upset)

Francesca

The section below will discuss the impact of this in relation to accounts across the data set of acknowledging the loss.

### 12.4 Impact of Care Pathway on Women's Capacity to Acknowledge their Pregnancy Loss

Women seeking termination of pregnancy following diagnosis of a foetal anomaly had a range of expectations of how their loss of this wanted pregnancy would be acknowledged that varied depending on gestational stage. A range of experiences regarding this were reported by women, demonstrating protocols operating in care settings and a diverse capacity to acknowledge the loss depending on the care pathway, and in particular whether termination was accessed in Ireland or women had to travel.

Women who had a foetal anomaly detected in earlier gestational stages tended to view this as a loss of a pregnancy rather than the loss of a child. However, data demonstrated how care pathway protocols in place in hospital settings situated it within a perinatal bereavement and palliative care framework. Eavan, who had a foetal anomaly detected at 13 weeks' gestation and a termination at 16 weeks, framed the loss as the loss of a pregnancy. When staff at the hospital she attended raised the idea of burial and memorialising with her, Eavan found this at odds with her own framing of the loss:

The nurse came in and she's like, oh God she was so kind of sympathetic and she just, and I don't know why, started to talk about like the burial options or like "is it hospital or will we take it" and, oh my God, like I was in an awful state and then to kind of be like told "how do you want to bury it" and like I was just like "get me out of here."

Eavan

Towards the end of her inpatient care for the termination she was told by the midwife caring for her that bereavement specialist practitioners would be coming in as part of her care pathway before leaving the hospital. Eavan describes it as follows:

[Two nurses] carry in the box and you might know this ... it's like a kind of a memory box and it's like, you know the little teddies and stuff. And next thing they're like, I'm just in complete shock that this is happening. And it's like, they're just explaining how it works and how the teddy, like, stays with the baby and this, and the coffin and the burial and I'm literally just like "get out of this room, like what are you doing to me." And they're, like they're trying not to cry and it's like they were trying to make me cry. And they were like "did you know that it was a boy" and I was like "yeah I read it on the piece of paper." And like just this kind of stuff. And it's again not what you want at that moment in time, if ever, like you don't want to be thinking of this as like an actual, you know newborn or stillbirth or something, you're just like "stop doing this." [They] say they have a little kind of a made-up birth certificate, that was blank, a kind of a birth certificate thing and I'm just like "this is not my baby", like

this is, do you know, a failed pregnancy, I'm not considering this as my baby that's not, you know delivered and do you know named or anything. I was like this to me isn't a baby, like it's just, it's not, I know it is technically but you're like, you don't think it's going to need a teddy in the coffin in the ground or the grave, like you don't think like that. You mentally can't do that. So that was just like "get out of this room."

Eavan

Eavan had been managing her loss by not considering it as the loss of a new or stillborn baby but rather "a failed pregnancy". Being subjected to the hospital's bereavement care policy for perinatal death cut across this and foisted a particular framing of the pregnancy that did not align with Eavan's perspective on her pregnancy loss. While internally and intuitively Eavan reacted strongly against this initiative, she questioned her own stance and felt obliged to go along with it to align with what "other mothers do".

I just had to go with them because you're kind of like "is this what other mothers do?" Like so you're just a bit like nodding along thinking "why don't I want this", like you know. There was no like "would you like this?" it was just like "here it is" and I'm like "oh my God a memory box". Oh yeah and I'm like maybe the Monday or Tuesday previously [during a consultation] they were like "once it's delivered like you can get the chance to hold it" and I was just like "I don't want to hold this", like this, again you're completely in survivor mode and you're like this is really shocking, this just has to get out of me for health reasons. So just kind of the language, I was, again maybe some mothers do appreciate this kind of, I don't want this, stop kind of insinuating that I want all this, all this suffering, I don't, I just want to go home. So that was probably the worst part in terms of like the emotional, like this insane side of things.

Eavan

Gabrielle also had a termination at 16 weeks' gestation in an Irish hospital, and also experienced the protocol in relation to perinatal palliative care and bereavement being invoked by midwives caring for her. This included the suggestion that she could see the foetus after delivery. Gabrielle went with the suggestion but found no comfort from the experience and regrets the decision.

...they said that "you know, you can look at your baby if you want to" and I said "no" straight away, I was like "no, no, no, no", and then I don't know, something came over me and I said "ok I will". And I kind of regret that now because, and it was done so lovely and really nice and you know they put the baby in a box and, but I can't get that image out of my head either. I felt that if I didn't see it would I regret it and you know, but I should have stuck with my first instincts to not to. So now I have that horrible room, giving birth and then just seeing the foetus, it just, you know it's not what a baby looks like. ... Some women do [find it comforting], but I really regret, at the time I was kind of like "ok no that's fine" but thinking and the more I think about it I just, yeah, I kind of regret looking and seeing yeah.

Gabrielle

Care pathway guidelines specify a palliative care approach should be taken in cases of abortion for cases of FFA, and this is implemented by following guidelines on bereavement for perinatal death and pregnancy loss. However, our findings suggest that this should be carefully negotiated with women terminating pregnancy during the second trimester.

Lily had endured a four-week process during which a scheduled termination was cancelled three times due to ongoing contestation among clinicians as to whether she qualified for termination. On two of those occasions the midwife specialists had discussed bereavement supports with her, but when it became apparent that the termination was not agreed this was rescinded.

And meanwhile one of the bereavement counsellors had come in and she just said "oh you know about taking the tablet", she gave me all the forms and she gave me forms about like information leaflets and she gave me information leaflets about compassionate induction of labour, what they called it. ... so she was in with me talking through everything and I was getting upset. So she was like "ah look, you know this is the hardest part, just getting to this point" and I was like "yeah". So, she left the room and then [the doctor] came back in and was like, I just knew by the look in his eyes, he was like "we can't do it" ... it was just really like a mess. And then the bereavement counsellor came back in and was like, started back-pedalling and was like "oh I'm sorry that I said all this, I thought that everything was organised and obviously it's not and I didn't realise this case was this way" and like everybody started backing down from saying that like, that you know the baby was this unwell, she was like "I didn't realise, I didn't realise, I hadn't spoken to [your doctor]".

Lily

Lily explained that the protracted contestation about her care left her angry and exhausted and unable to engage with the loss aspect of her experience by the time the pregnancy was finally resolved by termination:

Yeah and it is one of those things as well that I just spent so much of the time being angry that I literally had no room left for grief, like I was just so incredibly angry for those six weeks. Not the six weeks, for the four weeks I was just so angry. Like because I just felt like I was just being, like nothing was, I just felt like, I just knew that it wasn't the way it should be, like I wasn't being treated the way I should be treated. So, I spent so much of the time being so angry that then by the time I had my baby girl I was just like oh my God, like it was just like the anger had just taken over everything, I had no capacity left to even grieve or be sad, it just really, really, like the anger was just so draining. That like there was just no need for it, like I could have been supported and been allowed to grieve through the process as opposed to being like just fighting every stage of it and being so angry, you know the way, it was just like it took away from everything, it made the grieving process, at the end so much harder because nothing had hit me because I'd just been so angry you know.

Lily

By contrast Karla, who qualified for care in Ireland at 25 weeks' gestation and depicted her care pathway as a collaborative process, described how the hospital facilitated her and her partner and their family spending time with their baby and having a memorial service, which both herself and her partner were very grateful for:

When we had [James], it was in the evening and my husband's family ... were able to travel to see the baby as well and so they, yeah, [the hospital] allowed them to come and visit us even though it wasn't the right time for visiting hours. That was really nice because it was [quite late into the night by the time they arrived]. But it was really nice that [baby] stayed in our room and they could see, and you know pick him up ... so he stayed in the hospital, I think it was Tuesday when we had him, wasn't it? And then Friday was the cremation so we went there and we, [the hospital] had the chapel set up for us and we could park the car on the side, so it was, you know away from everyone else in the hospital as well. And we were able to spend a bit more time with him before putting him in the car to bring to the cremation. And we had a service there.

Karla

As Karla's case illustrates, implementation of the perinatal and pregnancy loss protocol is very much valued and appropriate for women within this care pathway once they feel it aligns with their framing of the loss.

Women in the study who did not qualify for care under Irish legislation had to travel to England, and in these

circumstances attending to the loss aspect of the pregnancy was very challenging. Francesca described how organising termination in England after being told she would not qualify for a termination in Ireland was so stressful, particularly given COVID-19 times, that she had no opportunity to consider what she wanted to do about the foetal remains. It was only when being booked into the clinic in England for the termination that she realised the full import of this:

The nurse [when booking me in to the clinic in England] asked if we wanted to bring the baby home. And I had read up just a tiny bit before we left in their online booklet about it, but I guess with everything that was going on we really didn't have time to think about it and that's something else then that you have to organise. You have to organise, like she said that we would, it would be put in a container and we would have had to put it in our check-in bags which we didn't have. But I would have checked in a bag but then I was like "what do we do then? Like do we have to call a funeral director?" We had to leave our baby in England and that's closure that we will never get. .... And we will never be able to bury our baby because our baby is in England. (upset). ... Yeah that is something that, as well that I wish we could have spoken about. Again, I don't know if [staff at the hospital] know these things. But the piece that BPAS had on their booklet, you know it didn't tell you exactly what you had to do, like it didn't say, like I know that if the remains are not kept on ice they don't last very long. And so that was something else, like I panicked in the waiting room after she said it to me, I was like "what do we do?" like. ... Yeah. I still don't, it wasn't even set out, it was just like "we can put it in a container, and you'll have to bring it back in check-in, you can't bring it in hand luggage". But then after that it's like then what do we do? We had no idea do you have to call a funeral parlour, can you bury it yourself? Like is that even legal, like and that's why we panicked and just said no. Because we didn't know what to do.

Francesca

Natalie travelled to England to access termination just within the 24-week timeframe, after a complex and detailed process of determining that she would need to travel to access termination. It was Natalie's wish that if a diagnosis could not be reached during foetal assessment, post-mortem pathology testing would be carried out as she wished to honour her baby by attempting to achieve a diagnosis through all means possible. This was only possible when the termination took place in England if Natalie was willing to leave the baby's remains with the English hospital for a number of weeks, but she wanted to bring them home with her. Like Francesca, Natalie described having very little time to attend to the matter of bringing the remains home. She had been advised by somebody knowledgeable to travel by car and get a car fridge to transport them home. Self-managing the logistics of this was a process she describes as *horrific*.

But part of the follow through [for us] was honouring and respecting [our baby's] legacy and getting genetic testing done and making sure that there was nothing else that we could have foreseen.... you have all of the issues of how do you access a post-mortem, how do you access tissue sampling to bring home for genetic testing. How do you bring your baby's remains home, how do you get there and get back .... And we decided to bring [our baby's] remains home with us, we had a conversation, at the 11th hour, ... So we were in frickin' Halfords buying a plug-in fridge for the car to have the baby's remains cold on the way home, just stuff you should never have to do. But there's just no system, or if we'd been able to access a termination in a hospital there's a system organised for how the baby's remains are managed. But there just isn't for this situation. And because ... we didn't want to leave [them] behind, we didn't want to go down the cremation route. But there's nothing more horrifically surreal than being in Halfords buying a plug-in fridge for your car, while your baby is kicking in your belly. Because [they were] kicking away. And it was just insanely horrific.

Natalie

Cara travelled to England for a late gestation termination and did opt to have the post-mortem carried out there, involving leaving the baby's remains behind and returning to collect them following cremation a fortnight later. The dedicated bereavement team and facilities in the clinic she attended were comforting for her but leaving her baby's remains to return home was *horrendous*:

They have their dedicated bereavement team [and] they have a dedicated little nursery room so after I delivered I left on the Thursday, I had a friend with me and she has small children so I knew she needed to go back. And at some point you have to leave. He was going for post-mortem but leaving a child over in England is possibly one of the, the second most horrendous things. Yeah, so what made it better was they have this room which is the most beautiful room ever, it's a nursery with a little lullaby playing. And so they have this, I think they have raised funds to do this. So it's so beautiful and that, you know, when I left him there I thought you know look he's, it's beautiful you know. And they were very, like because he had to go for another, to another hospital for a post-mortem. ... it was being treated with such dignity and respect both myself and [my baby] that's just huge. Like there is no detail that they haven't thought of, ... then you know I came back and then I went back two weeks later for the cremation and I brought the ashes back and that. So that was nice.

Cara

When she contacted the tertiary hospital for follow-up care after the termination, she learned they had a bereavement midwife that she would have liked to have been referred to but hadn't.

So it was actually the first time that I was there for the retained placenta that one of the nurses on the ward said, "would you like us to get the bereavement midwife to speak to you?" and I went, "you have a bereavement midwife"? And I said, "yes I'd love to see her", and I'm thinking "hang on a second now I've been going through this for two months, why is this the first time that I've heard that you have a bereavement midwife?"

Cara

The data here suggests that acknowledging the loss of pregnancies terminated following diagnosis of foetal anomalies is complex relating to gestational stage, how protracted and contested or straightforward determination of qualification for termination under Irish law is, and whether or not the person has to travel to access termination or their preferred method of termination. Implementation of perinatal palliative care and bereavement protocols need to be handled carefully so that women have space to consider what feels right for them rather than feeling compelled to engage in rituals that do not fit with their own framing of their loss and experience. Women who do relate to the loss as the loss of a baby they wish to memorialise, do value the perinatal palliative care and bereavement protocols and dedicated facilities and services being made available to them and their families.

## **12.5 Views on Navigating Care Pathway Through Irish Hospital Settings**

As this chapter has shown, foetal anomalies are detected at diverse stages in pregnancy and in diverse settings. Within our study participants were attending the full spectrum of settings for maternity care, ranging from regional maternity units without foetal medicine departments to tertiary hospitals when anomalies were detected. As the guidelines indicate, if the setting where an anomaly is detected does not have diagnostic or assessment specialist facilities women are referred to the closest regional or tertiary setting that does. This section sets out findings from the data about people's experiences of going through foetal assessment for anomalies within the termination of pregnancy framework, some of whom ultimately qualify for care under Irish law, while others do not and instead travel to access termination care in England.

Women referred to hospitals with specialist assessment facilities were generally contacted by the hospital they were referred to promptly on referral, and scheduled to attend the next available clinic usually within one week, which women were happy with:

So that was on a Thursday and [the hospital], in fairness to them, rang me that evening. So I wasn't left for any length of time. And they couldn't see me until [six days later].

Cara

So the next thing we knew was like we had to go to [another hospital for assessment] the following Tuesday, that was the Friday so we were going up on the Tuesday. So it wasn't a long wait.

Eavan

Women were attuned to the presence *or* absence of hospital protocols for managing situations where a foetal anomaly was detected, and especially whether private spaces were available where women could have an opportunity to process the information they were receiving. The absence of a dedicated or private space while waiting for appointments between foetal medicine assessments was keenly felt:

So that would I suppose be my first point of, you know, number one they knew I was on my own. They also knew that I had two hours to kill in between [the scan where the issue was detected] and seeing the consultant. So, my point, and I have gone back to [the hospital] and said this, at that point what I would have liked to have seen is to be, to have somewhere. Have a room, have somewhere that I could have gone to sit down, compose myself a little bit before, you know, and they did kind of say it to me "what are you going to do 'or the two hours?" And I said "I'm going to go for lunch somewhere". And I did, I went to a café, I cried into my cappuccino.

Cara

Those attending a tertiary hospital noted there was a specific room, and this was appreciated:

...obviously something comes up on the screen, you're sent to a completely different area so at least you're not sitting in the waiting room with the pregnant people. You go into the place, "the bad news room" I call it.

**Emily** 

[The hospital], you know they have the sign, they give you a little card with the sign that people know that you're going, what you're going through, and they made sure that, you know even my consultant, she was making sure that I didn't stay too long on the waiting room with other pregnant women beside me. And you know, they really thought of everything they could. Whenever we had to go through a scan, even on the public side, they would put us in a different room to wait and you know, that side I think it was really good.

Karla

For those attending hospitals that did not offer a private waiting space, many felt upset at encountering pregnant women:

So that was a Friday and then on the Tuesday I was booked into the maternity hospital. So up to the, I think it was the ultrasound department and I guess first things first, I was sat in a room with a lot of heavily pregnant women, which is not ideal.

Francesca

like I was in the sort of corridor, waiting area with the rest of the pregnant women and given the circumstances I would have preferred to have been ushered straight in ... and not had to sit around and hear everyone saying "oh yeah it's my third and I'm like just one please, just one". That was one of the worst bits of it, like all these normal happy pregnant women around.

Maeve

On the other hand, another woman reflected that she was so focused on her own situation, it did not phase her to be around pregnant women:

So you're just going into the waiting room and like I didn't mind that it was with all the other, we'll say heavily pregnant mothers, just because I think at that stage you're like, you don't know what people are going through so you're like, you just want to get this day to be over. So that was kind of that.

Eavan

The data demonstrates how protocols applied in some hospitals that flagged to hospital staff that foetal anomalies had been detected could be employed more extensively. Maeve was referred for foetal assessment following her booking-in scan but was required to attend the full booking-in appointment at her local hospital to get a pregnancy chart. No awareness of her referral for foetal assessment featured during this appointment, which was distressing:

Then they sort of, everyone in [the hospital I was referred to for assessment], the first question they asked me was like "have you got your chart" and I was like "no", so it turns out there's this really important chart that you're supposed to have and it sent everyone into a flap that I didn't have it and I was like "I don't really care because there is a problem here". So after that first appointment [in the hospital carrying out the foetal assessment] I had to go for my booking appointment in [the referring hospital]. So I could get this mythical chart. And at that appointment they treated me like a normal pregnancy, I don't think they knew what was going on. Which was really upsetting because the midwife I was in with, she started going through all these questions and I think she asked me "ok well this will happen at this point", I just started crying, I was like "but we're not going to get that far." Like they just didn't know.

Maeve

Like this, other women also experienced a lack of continuity of care throughout the process, feeling as though they were continuously having to explain themselves:

And one of the times I rang to cancel the appointment, and this had happened three or four times so the secretary, like that, she knew I was attending the maternity hospital in Dublin so she knew there was an issue. And she said "oh you've a glucose tolerance test on Friday", I said "I'll cancel that too." "Well are you getting that done somewhere else?" I said "no, no I'm not". And she said "well that's very important now, you need to do that", I said "look, it's looking like the pregnancy is not viable." "Oh right, do you need to make another appointment?" And like that, I thought I have just told you some life changing, and I don't want a song and dance made about it, just for her to say "I'm so sorry to hear that. Do you need to see us again?"

Cara

By contrast, where systems were in place signalling to all staff that a pregnancy was undergoing foetal assessment or had a diagnosis, women felt continuity of care:

They also made sure that we kind of had the same people looking after us every time that we went

in, through all the weeks. That's also very important because we don't want to have to explain what is going on to, you know, different people every time you're going into the hospital.

Karla

Having to end a pregnancy in a maternity setting was jarring for many women, with many considering being placed on a labour ward to be unacceptable for such care. One woman felt so strongly about this, it partially influenced her decision to travel to the UK despite qualifying in Ireland. She explained that she didn't think anybody in their right mind would presume that [termination] is done in the maternity hospital on labour ward in a private room if you're lucky (Martha). Gabrielle explains how despite having had a private room assigned for the termination procedure, it was in the middle of a labour ward and herself and her husband could clearly overhear what was happening for people having happier pregnancy outcomes than the loss they sadly grieved:

The only thing I would say about the whole ordeal was, and I don't know about other hospitals, but we were in the, when we were ending the pregnancy, so we were put into a room on our own with a toilet and it was on the labour ward. So, I had to give birth and then like obviously I was, it was horrible, horrific, like my husband, now [the staff] were so good, they let my husband stay in the room the whole time obviously. And he, like we could hear everything going on outside. And like you could hear men coming out, like I remember one man and he was like "it's a girl, we're delighted" and oh it was just, that was the part that killed me.

Gabrielle

In some hospitals, facilities did not allow staff guarantee women a private room when going through the termination, and again women felt this fell short of the facilities they needed:

...they were kind of like, I know they have to, but were like the possibility of not having a private room. So then you're like, can you imagine being in, like you're having this abortion and then in the bed next to you there's like a fully pregnant woman, you know picturing that scenario, so you're like God I hope that doesn't happen.

Eavan

Notably, a few women who travelled to the UK commented on their preference to attend a dedicated clinic rather than a maternity hospital for such care, considering such clinics to be more appropriate spaces:

The other thing, so when I went to the UK they were really helpful and supportive and really for, it's unfortunate circumstances I had to go over there but the service itself all went really well. It's done in a clinic where women are there to access similar services. So I'm not looking at, you know people walking out, like I think people have to bear in mind that I had to go in, so after I found out something was wrong with my baby, I still had to go into the hospital on numerous occasions, you're walking past people bringing, you know, car seats out with their baby, you know.

Martha

And here I don't know how it happens here, it just happens in the maternity hospitals here which is terrible really. I don't know if there are specific clinics, but it would be terrible to have to go into a maternity hospital to do it, especially if you've been through our situation, in that sense...

**Emily** 

Having to return to a maternity setting for follow-up care was something women also found difficult:

And even having to go back into the maternity hospital to have that scan after the abortion, I had to go back into the same waiting room that I was in when we went in there the first time, it's tough.

Francesca

For Emily, the hospital setting had become so associated with bad memories, she declined bereavement counselling because it was offered in that environment:

They were offering me counselling in the hospital, you don't want to go back into the hospital for anything. They offered it and I said, they said "we've a new counsellor especially for this" and I said "I do not want to go back in there again." ... I can't imagine anyone wanting to go in there for bereavement counselling. It would have to be off site somewhere.

**Emily** 

### 12.6 Acceptability of Method of Termination Offered in Ireland under s.11 2018 Act

As discussed above, Martha travelled to England to access a second trimester surgical abortion, having learned what the medical method of termination offered under the Irish care pathway entailed. A medical method, involving women collecting the products of conception as they passed them during the procedure for inspection taking place within a hospital setting, was unacceptable for Martha compared with the option of a surgical method.

For me it was a really big thing that it was over, so I went to sleep, you know this awful nightmare that you know I wouldn't wish upon anybody else, but I was able to, somebody was able to look after it for me. I had done so much at that stage to try to make, you know I've done it and I don't think I had any more strength, there was nothing else I could do and I needed somebody to take care of me and you know I woke up and it was over. Well in a sense the physical aspect of it was over.

Martha

Limiting the method of abortion in Irish settings to just medical abortion methods, and locating all terminations within maternity hospitals or units, raise issues of acceptability of care for all women. Women described having it explained to them that only the medical method of termination was offered after 12 weeks' gestation; many equated this with giving birth and expressed a preference for a surgical method.

In my head I had decided that I wanted a D&C, so I said that then, I said like "when the CVS results come back, like how do I decide what I want to do? Like can I have a D&C or?" and he said "oh no you're way too late for a D&C now". So, I was like "ok why?" and he said "because you're 13 weeks now" and I was like "... I have to basically give birth", which just terrified me. So, he said, you know, he was just matter of fact, he was like "this is what needs to be done, it's too late, it's 13 weeks, ... we don't have the specialists for that here". So, I said "ok".

Lily

[They] said like, [they were] like "look, we can do a termination in our hospital, we don't use the method that's done in the clinics that you're mentioning, [they] said you know you'd be inducing and, well if it was found that your baby had a fatal problem, so you would be induced and you would go through labour kind of in the normal way". So the option that I had been offered, and that they said was the only one for me with BPAS in the UK, was that I would be under anaesthetic, under general anaesthetic and it just appealed to me more. Yeah, I knew that, yeah, I think I knew that in mostly in Ireland, ... it was being done by, you'd be induced and then you'd give birth. But I was just really attracted by the prospect of being under anaesthetic, yeah.

Denise

When I was being told all the information of you know "you'll have to end the pregnancy" and all that, I didn't realise I had to give birth until the day before. I was like "so how does this happen?" and they

explained it to me and I was like "what?" they were like "oh, we give you a tablet" and I was like "oh my God, I have to give birth", like you know these are horror stories. Yeah, and it was, it was a horrific, I will never get that room and doing that out of my head.

Gabrielle

Eavan described the process of undergoing a second trimester medical abortion in an Irish hospital in detail, providing an insight into what the experience of the process is like:

I knew it was going to be a medical one, so just take your tablet and then you kind of start cramping and bleeding. So I was like "oh that sounds fine, like I can just do that at home like", you know just picturing say like, again like my miscarriage, like just back to what it was, just cramping and just bleed it out, like you don't see it or anything, you know, and then it's done. So I was like that's obviously what it will be and they were like "no, you'll have to go into hospital" so I was a bit like "oh God, you know I'd rather just do it at home". ... [The midwife] gave me the first tablet to kind of induce the cramps so that was fine. And then I had to relieve myself into a commode so that was fine. And then, you'll think I'm mental by the end of this study so, but that was fine anyway for maybe an hour and a half or two hours later I was cramping badly and then, but also quite nauseous, so I ended up, oh God, like I had to get sick and I was like, you don't know where to get sick, like do I get sick into the commode, like because it's in the way of the toilet ... So I buzzed [the midwife] to come in and by the time she had come in I had got sick into it but was still getting sick a lot. So she was kind of like "ok I'll just swap out the commode". But what should happen is she would have a spare one to put in, but she leaves with the commode, right so next thing I have awful bad cramps, this is like within seconds. So she just leaves and next thing what I can only describe as like waters breaking, like it was literally like my trousers, were just soaked and I was like what do you do then, like you have no commode, like you're not going to get up on the, like what do you do. Oh my God so I just honestly pushed whatever wheelchair out of the way and I sat on the toilet because I was like honestly it's too early for anything you know to happen. And it's just like not much comes out but you had to let it go somewhere like. Anyway she comes back in and the toilet is flushing and she's like, ... "ok anymore just go into the commode. ... we have to look through whatever comes out" and I was like "that's fine but I need one here basically to go in" ... the next few hours then, it's kind of the same thing, like was like "buzz me every time you use the commode" but like you're constantly using it so you're kind of just buzzing every maybe half an hour or so. But she'd take it out and next thing you won't have one so you're there cramping up, knowing that you need to basically have a commode there but there's none there. So she should always have a spare one and you know, just kind of swap it out. ... Yeah, why would you not have one, it's insane that you'd have to wait, and it could be gone for half an hour, like it was crazy stuff, or else you just had to use the toilet, you had to like hold back and it was mad. And then, so then I think the doctor, the consultant had come in at this stage and put something in my arm and you know that sort of stuff was going on and that was fine. And then, ... so next thing at about 1 o'clock or so the midwife comes in and I think at this stage my cramps had stopped and I was kind of fine, I was a bit like "did I pass it or not?" But like compared to how bad I was cramping, like there was no cramp but then I had painkillers so I wasn't sure if it was just the painkillers. So then I just asked the midwife like "when do I go down to the labour ward?" and she was just like "oh I don't think you're going to have to now, I think it looks like you've passed, kind of, some of it or some tissue", I can't remember what word she was saying. But she was like "I don't think you're going to have to go down now". So I was like "that's just amazing news, like you know thanks for telling me". So that was fine ... And then I just wanted to go home at this stage so then the doctor comes in and she is like, she was like "I don't think you've passed it yet" and I was like "what?" So she kind of does another scan and like a manual exam, we'll say, and she was like "ah yeah there's nothing there". So just like get me out of the hospital at that stage. So she is talking about next day and how it's easier to

do tests and stuff and to have the actual foetus but they had, I don't know the placenta or something to test. So that was kind of it then.

Eavan

The emphasis in the care pathway depicted by Eavan was on ensuring the collection of materials from the termination for testing, which dominated the experience.

Overall the limitation of termination method over 12 weeks' gestation to the medical method of abortion only was queried by women for acceptability. Four of the five women in the study who qualified for termination in Ireland would have preferred an alternative method of termination to the medical method offered. One woman ultimately opted to travel to access abortion care in England in order to be able to have a surgical method of abortion. As highlighted in accounts of women undergoing repeat medical abortion in hospital under 12 weeks' gestation, the management of the procedure involving detailed emphasis on collection and inspection of materials was queried by Eavan, who portrayed this as dominating her experience of the process.

### 12.7 Receiving Counselling or Bereavement Support

For the most part, women in this group did express a strong desire for some form of support, and most recalled being referred to a support service or a counsellor at some point. However, some felt that the timing of the referrals they received was inappropriate. For some of those who were faced with uncertainty regarding eligibility for care in Ireland, immediate offers of counselling felt incongruent with their own priorities:

So my GP rang me and she was like sympathising with me as if I'd had a death, a death in the family, and she was like "I'm so sorry", you know like "how are you guys doing?", you know really being so sympathetic and was saying you know "do you want me to like, you know, will you need counselling, do you want me to arrange, you know, supports like this?" and... because obviously, I think the baby is still alive at this stage, you know? And I was like "ok maybe this means that definitely that we're losing the baby" or whatever. And then she, I don't know from where, but I just had the idea, I was kind of like, a bit like not really into her, you know like "do you need help or?" I was like "I don't need counselling right now anyway, that's not what I need."

Denise

You know, initially they offer [counselling] kind of straight away but you're so in shock like, you just, you know "do I actually have to go to England" and all that, you know you're processing it all. If you go to counselling kind of at that point you're just going to cry for the hour, you won't actually, you know talk, you know. So you kind of need to let things settle and then you know, well everyone does it differently you know but yeah.

**Emily** 

Women considered that counselling supports would have benefitted them from the outset of the detection of the anomaly, while awaiting referral for assessment, and during the early stages of assessment when they felt there was an information gap from care providers but extensive worry and concerns for them.

Yeah but you certainly found during these four days that there was, you'd a need for information and kind of emotional and psychological support, is it all of those things?

Yeah absolutely yeah. Even more so the support to be honest. You just, I suppose how I describe it is like you feel like you're the only person ever to go through this, even though you know you're not

but you feel no one you know has ever gone through this, no one understands. And like just to have someone to talk to and like make you feel that you're not completely alone would be, would have been so good.

Eavan

I was quite surprised actually because we didn't, we weren't given any counselling until we had our diagnosis. And our diagnosis was quite late in the day, like our diagnosis was after 28 weeks. So, there was a long time between like, before 23 weeks. So, what is that even, nearly six weeks, of not kind of knowing and that's actually when you're at your worst because that's when you're like, thinking the worst.

Cara

Neasa noted that hospitals withheld referring women to be reavement supports until there was a conclusion to their assessment, and considered that this was an effect of regulations inhibiting any reference to fatality until a definitive assessment had been arrived at.

I suppose in a way in the hospitals they're not, because they're not really allowed maybe. Like do you know, as I said like, we didn't meet our bereavement counsellor until I was around 30 weeks so I had gone through all those weeks at that stage. And really around 30 weeks was nearly too late.

Neasa

Participants recalled their efforts to find appropriate support services. The importance of finding a counsellor with the right expertise was highlighted by Gabrielle, who although she had been given *leaflets* for contact organisations for people who have received similar diagnoses from the maternity hospital she attended, decided to self-refer to a counsellor some time after the abortion:

I ended up going to a counsellor in work, one of the work counsellors because it was actually just handy, she works across in the building from where I was working, and she was lovely. But she, like she even said to me herself, she said "look, do you feel comfortable speaking to me about it because I'm not, I don't have much knowledge of, you know, the whole diagnosis?" And I said I actually did feel comfortable with her. But then I felt after a few sessions, you know what, I've spoken about it and I've cried, and I think I'm ok....

..

So, like during the pandemic I looked up somebody and I did an online counselling. But I just didn't find that lady great either, so I find it hard to find the right person. So maybe I should be looking at somebody that deals with the diagnosis, you know with those kinds of incidents.

Gabrielle

Maeve was referred from a non-providing hospital to a foetal medicine department of a regional maternity unit for assessment but deemed not to qualify for termination in Ireland. She left the regional maternity unit with information about services providing termination in England. She had expected a follow-up support call but did not receive one:

Yeah someone was supposed to phone me on, a couple of days afterwards. I don't know if she was a pregnancy loss specialist or something but that phone call never came.

Maeve

Referrals to specialist pregnancy counselling at women's health clinics seemed to be especially infrequent and sporadic, with women themselves not necessarily associating them as a place for someone in their circumstances to seek support:

I fumbled across the pregnancy counsellor, you know.

Neasa

And the hospital, you know they did always say "look it, if you need us for anything get back in touch and this is our number, and this is our email." So that's why I did get back to them about the counselling. .... I wouldn't have thought of [the women's health clinic] in a million years... it's not easy to necessarily get that information about [counselling], they I think sent a leaflet in to the hospital and that's how they were able to tell me about it, you know there was a small link there, you know, somebody thankfully saw the leaflet.

**Emily** 

Consequently, women often felt there needed to be a more proactive approach taken by health care providers to ensure that people had access to, and were aware of, appropriate supports:

I mean some people wouldn't be maybe, like I'm happy to go to counselling and I would, you know, follow up on it and I know it's good to talk about these things because it's only going to get worse, but for someone who is really struggling and needs a little push and can't find the information, they probably won't get help, you know, and they could go down a very dark road and it's a very dark time, very dark time and you know, you do need to talk to someone. And if you can't find the information, you know, I'd be worried about someone who won't, you know doesn't have someone to help them find the information or won't keep pushing to find it.

**Emily** 

I suppose they could be a lot more proactive in terms of, I know they're really busy and like it's easy to say they should do this and this, but like if say the bereavement counsellor had just called you before it happened because you're like, no one has to like, like no one wants to end their pregnancy so you're like, you're grieving before you even decide and you're like, once it happens it's over and you nearly don't need it now, whereas to have to make that decision and you're also grieving as you're doing it, but like you're just in hell so you're like, if someone reached out in that, you're obviously going through hell at the moment, you know like, do you want to talk about it.

Eavan

Some women who considered attending dedicated support groups like Féileacáin spoke of fearing stigma or judgement, particularly if they had terminated a pregnancy that had not been deemed as having a FFA within Irish law. They worried about how they would be perceived by people attending who had had a fatal anomaly confirmed:

I remember contacting the nurses who were linked to the team in hospital in Dublin saying, because they had given me the details of, oh I can't remember the name of the website now. But it seemed to be for people who, it was kind of more fatal foetal abnormalities. Butterfly or something.

#### Oh Féileacáin?

That was it, and I was reading all the testimonies and they were all people who had fatal foetal abnormalities, which in some ways made me feel worse because I thought "no this is not fatal." And you know "I can't contact them because they'll judge me too because this baby will survive most likely", and I just went "ok."

**Emily** 

So you know, and I did find that too when I did go to the likes of, you know, the meetings that were for any baby loss or through stillbirth or afterwards or that, I did feel slightly fraudulent being there

because I was saying like this was my choice to end my child's life. So you know I could have had him here if I'd wanted and I'm thinking these people are probably thinking they had no choice, my child died.

Cara

Some were concerned about the judgement of others who might discover they were engaging with such support organisations or specialist pregnancy counselling:

I went to that group and there was one woman there who was fairly recently bereaved, the same as myself, and it hadn't occurred to me, she was very, very worried about the level of judgement even coming to the meeting. She thought that oh my God, there would be people here that would be protesting or that they would be, you know whatever, and I kind of went oh gosh, that didn't occur to me, you know. And she was kind of saying oh you know, only that the psychotherapist assured her it was a genuine group.

Cara

I fundraised for support organisation when I was trying to get the word out there. I wanted to fundraise for the pregnancy counselling services and their work but I was afraid because I was like "what will people think?" Which is wrong, isn't it wrong that I was thinking like that?

Neasa

Overall, women who engaged with support services, be it counselling, a support group/organisation, or received support from a foetal medicine midwife (FMM), felt their needs were well met by the service. Some expressed a sense of stigma that termination of a wanted pregnancy was a subject they were unable to talk about with anyone else, with one woman noting in the interview *it's* soothing to me able to talk [with you] as well but it's not that many people that you can talk to about (Gabrielle). In the context of a stigmatised aspect of health care, support services provided a much-needed emotional outlet:

So, I just went for one session because like that I couldn't talk to anyone about it. And I'm a talker, I'm happy to talk about my feelings. But I couldn't just because of the situation and the circumstances. So, I had one session literally the day before I went over, and I don't know if it helped but you know it was good to talk for that one hour about it. I felt as if I was cracking up, I needed to talk to someone.

Emily

I would highly recommend that service as being one of the, and especially the first few months but even still now it's like one of the kind of saving graces because it is, it's such a lonely time for people, I think especially because of COVID, well I don't know, it's kind of conflicting whether, in some cases I felt it was good because people didn't know and then in other, you know it's kind of a mix of the two. But people find it really difficult to talk to you, even people in my own family, it's not an easy conversation for people to have. And I think for the women that have gone through it, myself included, it's really comforting to have that space where you can talk to somebody freely about it.

Martha

The expertise of such services was also recognised and valued. When Neasa was faced with the situation of possibly needing to travel to an European Union (EU) country to access termination, the specialist pregnancy counsellor she engaged with was able to offer practical support and guidance relevant to her situation.

So then we rang the pregnancy counselling services and we spoke with a girl there and like I couldn't even speak, like my husband spoke for the first I'd say three calls because I literally couldn't talk

on the phone. So, the girl took my details and then [she] rang us back. And [she] was amazing, absolutely amazing. And in a way like I obviously needed counselling, 100%, but at that moment in time I needed support and I needed to know what our options were. Because we had no idea of what to do, what we were facing. ... But she was great as well, like I suppose like she really came into like proper, being able to provide 100% counselling support after we had the diagnosis. But up until that stage she was amazing because she was kind of saying, she would give me counselling, 100% but she would always say "ok and now where are we with things, have you gotten the file from the doctor, have you been able to get your European health card? Do we know what we'll do with [baby] if you do have to go to Belgium?" you know. So it was, she was providing 100% support for either situation and completely non-judgemental you know.

Neasa

For Martha, who attended counselling at a maternity hospital, her counsellor's medical background and understanding of her situation was especially important in helping her to feel supported:

I found [counselling] really helpful. Yeah extremely helpful. The other thing was that, you know you'd probably be able to access something yourself but because, I mean the counsellor does have that, she's aware of the topic, you know there's other therapists there but because this is a very specific issue, do you know. And to go to somebody that has an understanding of, and then the counsellor does come from a medical background so she does, she gets it, you know.

Martha

This contrasted with the experience of Gabrielle, who self-referred to a non-specialist service:

So, like during the pandemic I looked up somebody and I did an online counselling. But I just didn't find that lady great either, so I find it hard to find the right person. So maybe I should be looking at somebody that deals with the diagnosis, you know with those kinds of incidents.

Gabrielle

The holistic approach to acknowledging loss taken by support groups was valued by those who attended them and had reached the gestational stage where they framed the loss as a bereavement. Here Cara and Neasa (who chose to continue her pregnancy) speak about the wide range of support offered by the organisations they engaged with, beyond standard therapeutic support:

And one of the [groups], they run support meetings [attached to the service I attended in England] and I've actually flown across there a couple of times to two support meetings because there's such a, such a support network there. Absolutely, and I went across for their memorial service and they say like, you know we, obviously they said we thought it would be too difficult for our population in Ireland to come across but then we thought hell why do we make the decision, we will tell you what's there if you want to come, you can come, and kind of like leave it up to you. And like that over Christmas, I'm part of their Facebook group and they kind of you know, we are saying I didn't go to the meeting in December but it was all, it's a very useful meeting as well. In that they generally will have one or two people speaking on how to deal with Christmas and New Year or how men and women deal differently with grief. And then they have an area for crafts if you want to, or you know, they sit around and they would have pictures, cards and you can pick one that resonates with you and if you want to talk about it and say whatever it is you know, so it is very, very useful, very, very useful.

Cara

I was absolutely overwhelmed by the support that I received from the support organisation. And their support is amazing. Like they were amazing. Like they have offered me counselling and they

provide a memory box in the hospital to every parent that has lost a baby. So, in that memory box you have a blanket to wrap your baby in and you have a box to keep a lock of their hair, you can take their handprints and their footprints. And you can also get a cast of their footprints and handprints. Which is amazing, absolutely amazing. And then a big leaflet filled with all the support that's available. And that goes out all over the country to families that have lost a baby in whatever stage and, be it a termination or not, you know.

Neasa

A further key source of support, information and continuity of care were FMMs. Women talked of being in ongoing contact with FMMs and valuing that ongoing care. The FMM acted as a continuous point of contact for women:

The midwife was kind of like "here is my card, here is my number, contact me if you have any questions" or kind of "I'll be in touch with you with the results". So I was like, you know the midwife was kind of taking over my care in a way in terms of like information and stuff. So yeah we were, I won't say happy but a bit calmer once we had that over and I knew like it was going to be tough anyway having to go up there and having whatever procedure done so once that was over I was like, it was just out of our hands then and it was just a matter of getting the results.

**Eavan** 

Specific, tailored efforts taken by FMMs to support women who had to travel to access termination, as attempts to minimise the strain and impact of that, were noted and appreciated. Francesca explains the efforts made to support her:

[The foetal medicine midwife] had really kindly offered was the day that we were due to fly, she said to come in on the off chance that I had a missed miscarriage and the heart had stopped beating because then we wouldn't have had to travel. But you know unfortunately that didn't happen. ... we flew on a Thursday and I had a scan just before I went to the airport.

Francesca

Initiatives of FMMs to organise post-abortion check-ups for women a few weeks after they returned following termination in England were also appreciated by women, both for the reassurance it provided but also on a symbolic level as an effort to offer continuity of care.

[The foetal midwife specialists] they were really good. They organised like a two to three week, after we returned scan just to check everything was healing ok uterus-wise. And that was just really, I mean the last thing I wanted to do was go back to [the hospital] but it felt like it was as much a way of welcoming me back as a way of checking physiologically on things. It felt more symbolic than anything else. And I'm really grateful for that. There was no medical care involved from a consultant point of view. It was all nurse led. And I don't know if that's an initiative they take or if it's a standard of medical care. But it was just really helpful. Just to feel like they still wanted to see you again.

Natalie

Guidelines specify a designated contact person should be assigned to a woman going through this care pathway. In settings with FMMs this was most developed and the information, support and continuity of care provided after termination were valued. In settings without FMMs there were gaps in information, support and continuity of care. Women had variable experiences in connecting with counselling support services. The data demonstrated a need for support like counselling at an early stage of the assessment process for qualification for abortion care, possibly at the point when foetal anomalies have been initially detected. Crucially, in the case of women who do not qualify for care in Ireland, this should be *before* 

they are at the stage of having to organise travel to the UK. There was also reluctance among women to return to the setting where the diagnosis and/or termination had taken place for ongoing counselling and supports. There is scope for specialist pregnancy counselling currently attached to community settings to be integrated into this care pathway, particularly given findings about emphasis of the clinical team on diagnostic testing.

### 12.8 Overview of Analysis of Women's Experiences of Care Pathway Relating to s.11 2018 Act

The care pathway in relation to termination for FFA begins with detecting an anomaly either in scanning or through screening testing. The data shows there was a variance in how the initial indication of a diagnosis was conveyed to women. In turn, women's concerns when this was intimated left them highly attuned to any cues, verbal and non-verbal. Women's concern is for timely diagnosis, an open and full communication process, and continuity of access to care within the Irish health system.

Referral for assessment and testing was prompt, but assessment was protracted with no certainty of outcomes, and this takes a heavy toll on women. Where FMMs were in place, communication, information and support was optimum but where they were not, there were deficits. Even when FMMs were in place, concerns not to breach clinical protocols about what could be discussed or stated conclusively left women with questions and anxieties, not knowing where they could turn. The integration of specialist pregnancy counselling supports into this care pathway could provide women with a resource where they could explore emotions, questions and concerns with professional facilitation, to help alleviate anxieties and distress during protracted assessment. Given the expertise of these counsellors, women could also be prepared for the decisions that lay ahead for them, whatever the outcome of assessment.

The data indicated concerns about a diagnosis of a severely life-limiting condition were as high for participants in the study as for a diagnosis of a fatal anomaly – what this would mean for the quality of life of the child, for themselves as parents, and for other children they had. The current restrictions on legal access to termination in cases of foetal anomaly fell short of women's needs, as evident in decisions women took to travel to the UK to access termination. Power et al. (2020) noted that diagnosing conditions as fatal in accordance with the Irish legislation is complex, as many anomalies in isolation may not be considered fatal foetal anomalies, but when combined are potentially fatal. Uncertainty of qualifying under Irish law meant that where an anomaly was detected late in the second trimester, taking account of the usual assessment timeframe, women were weighing up waiting for the outcome of that assessment against taking the decision to travel for certainty of access to the UK before the 24-week time-limit.

Qualifying criteria were portrayed in the data as highly restrictive, resting legal responsibility with clinicians and rendering the pregnant person with no capacity to be involved. Women portrayed finding themselves hoping for a "fatal enough" diagnosis rather than being denied care and faced with travelling. Legislation, and particularly the criminal penalties the law contains, had a distinct chilling effect on interaction and openness between clinicians and women during the assessment process. Where diagnosis was inconclusive and/or did not satisfy the criteria to qualify for care under Irish law, women noted reticence among clinicians to engage in open and detailed discussion on quality-of-life prospects for the foetus. There is an indication that again the law is having a chilling effect on these clinical setting encounters, leaving considerable frustration and gaps for women and parents.

Not qualifying for care in Ireland signified being denied care, being unsupported and cast out, and travelling to access termination was associated with shame, stigma and judgement. It involved attending

an unfamiliar provider, complex logistics and cost, being away from the comfort and dignity of home, and travelling after a traumatic procedure, especially during COVID-19. In particular it created harrowing situations for parent(s) who were either not able to bring their baby's remains home or had to transport remains independently. The opportunity for a post-mortem to achieve greater diagnostic clarity was also affected, as to do so required leaving the baby's remains, which some parents did not want to do.

The integration of termination of pregnancy care into maternity settings raises issues of acceptability, where no dedicated separate spaces are available either during the assessment process or when attending as an outpatient for scans or consultations. Facilities where termination of pregnancy was performed were often in the same area as delivery suites, and women described overhearing relieved and jubilant parents announcing safe arrival of babies as they were undergoing a termination of pregnancy. In addition, confining method of termination of pregnancy to the medical method only raises issues of acceptability. In this study group, one woman travelled to the UK to access the surgical method of abortion after qualifying for care in Ireland, and others expressed shock upon learning they would be required to "give birth" as they considered it.

In addition, implementation of perinatal palliative care protocols needs careful management. Women with second trimester terminations will not always relate to the bereavement of losing a child but rather frame their loss as the loss of a pregnancy. Those who do relate to their loss on these terms, however, do value and welcome bereavement supports and should continue to have those offered.

Finally, while a review mechanism is available, this was not referred to or invoked by any women in this study. The data would indicate that time is one factor precluding this measure having any practical value. The review entails entering into another process of clinical review with an indeterminate timeframe and outcome in the context of a developing pregnancy, and the time limitations that imposes. There is consensus among women that time really matters in this process. They want to strike the optimum balance between taking enough time to fully assess the foetal health and prognosis, and the pregnancy progressing no further than is necessary if termination is the outcome. These factors combined considerably question the practical value of the review mechanism within the legislation.



### Analysis of Women on Web Data

### 13.1 Introduction

This section explores continued requests from women and people in Ireland to online telemedicine abortion provider WoW following legalisation. WoW is a non-profit organisation providing safe online telemedicine abortion care to regions with limited access. People contact WoW by filling out an online consultation form. If clinical criteria are met, a physician prescribes according to the World Health Organization (WHO) recommended regimen for EMA up to 13 completed weeks' gestation. WoW provides guidance on taking medication, monitoring the process, possible adverse effects and how to respond if these occur. A trained help desk team provide help throughout the abortion process (Women on Web, 2021). Here, patterns of WoW consultations by people from Ireland are reported using data for the full years of 2019 and 2020.

#### 13.2 Results

#### 13.2.i Analysis of Quantitative Data

There were 764 requests from Ireland to WoW in 2019 and 2020, of which 225 (29.5%) were completed (Table 13.1). A request entails a person from Ireland contacting WoW seeking telemedicine abortion care. Requests are automatically replied to with an email explaining that abortion is now lawfully available in Ireland and signposting people to My Options. People who still need to access the service through WoW can continue to communicate with the help desk team by email. A doctor will review their request and, if clinical criteria are met, will prescribe care following a WHO-recommended regimen. Medication and a care pack will then be sent to the person by post.

Requests declined by 21% between 2019 and 2020, while the proportion of completed requests declined by 11.3% (p<0.01).

Regarding the effect of COVID-19 restrictions, the proportion of completed requests decreased by about one-fifth during the March-June 2020 period of restrictions compared to the equivalent months of 2019 (-21.3%, p<0.001), but did not significantly change during the latter period of restrictions (October-December 2020 versus October-December 2019; Table 13.1). There were no annual differences in the characteristics of the women who contacted WoW in 2019 (n=427) and 2020 (n=337), except for a slightly higher proportion of pregnancies more than seven weeks' gestation in 2020 compared to 2019 (8.9% versus 5.3%, p<0.05).

Table 13.1. Requests for abortion pills from Irish women to Women on Web

Time period		2019	2020	Difference in proportion	p-value <sup>1</sup>
Jan-Dec	Total number of requests	427	337		
	Completed requests n (%)	147 (34.4)	78 (23.1)	-11.3%	0.001
Jan-Feb	Total number of requests	101	80		
	Completed requests n (%)	34 (33.7)	21 (26.3)	-7.4%	0.242
Mar-Jun	Total number of requests	126	137		
	Completed requests n (%)	48 (38.1)	23 (16.8)	-21.3%	<0.001
Oct-Dec	Total number of requests	103	63		
	Completed requests n (%)	34 (33.0)	16 (25.4)	-7.6%	0.300

<sup>&</sup>lt;sup>1</sup>Chi-square test for difference in proportion of completed requests in 2019 versus 2020, values bolded are significant at p<0.05.

Table 13.2 compares reasons for contact with WoW according to year (2020 versus 2019), and before COVID-19 restrictions in 2020 (January and February) compared to the equivalent months of 2019. Unsurprisingly, "Coronavirus" was one of the most frequently selected options (34%) in 2020 (Table 13.2) but there were also other periodic changes in reasons for contacting WoW. "Legal restrictions", and "cost" reduced in frequency as reasons for requesting online telemedicine while "childcare", "school or work commitments", and "I would rather have my partner or friend with me during the process" increased in frequency when compared with the equivalent months of 2019 (all p<0.05; Table 13.2). Notably, privacy concerns and perceived greater comfort afforded by home-based EMA remained consistently common reasons for contacting WoW, selected by >30% of women across all four time periods (Table 13.2).

**Table 13.2.** Reasons for contact with Women on Web during 2020 (compared to 2019) and in January and February 2020 (compared to January and February 2019)

	Reason	Jan-Dec 2019 (%)	Jan-Dec 2020 (%)	Difference in proportion	p- valueª	Jan-Feb 2019 (%)	Jan-Feb 2020 (%)	Difference in proportion	p- valueª
	Total n	427 (100)	337 (100)			101 (100)	80 (100)		
	Coronavirus	-	114 (33.8)	-	-	-	-	-	-
	Legal restrictions	99 (23.2)	50 (14.8)	-8.4%	0.004	40 (39.6)	14 (17.5)	-22.1%	0.001
	Stigma	107 (25.1)	89 (26.4)	+1.3%	0.671	23 (22.8)	20 (25.0)	+2.2%	0.727
	Cost	132 (30.9)	77 (22.8)	-8.1%	0.013	33 (32.7)	17 (21.3)	-11.4%	0.088
lt in hard	Distance	75 (17.6)	48 (14.2)	-3.4%	0.215	17 (16.8)	12 (15.0)	-1.8%	0.739
It is hard for me to	Childcare	60 (14.1)	45 (13.4)	-0.7%	0.781	7 (6.9)	14 (17.5)	+10.6%	0.027
access abortion because	School or work commitments	103 (24.1)	73 (21.7)	-2.4%	0.423	19 (18.8)	28 (35.0)	+16.2%	0.014
(of):	I need to keep my abortion a secret from my partner or family	137 (32.1)	121 (35.9)	+3.8%	0.268	26 (25.7)	26 (32.5)	+6.8%	0.318
	My partner is abusive	21 (4.9)	16 (4.7)	-0.2%	0.913	6 (5.9)	_ b		
	I do not want to deal with protestors	48 (11.2)	45 (13.4)	+2.2%	0.375	10 (9.9)	11 (13.8)	+3.9%	0.422
I prefer to access abortion through WoW because:	I would rather take care of my own abortion	133 (31.1)	117 (34.7)	+3.6%	0.296	28 (27.7)	32 (40.0)	+12.3%	0.081
	Abortion pills are not available in my country	41 (9.6)	21 (6.2)	-3.4%	0.090	15 (14.9)	8 (10.0)	-4.9%	0.330
	I would be more comfortable at home	138 (32.3)	125 (37.1)	+4.8%	0.168	31 (30.7)	36 (45.0)	+14.3%	0.048
	I would rather have my partner or friend with me during the process	70 (16.4)	64 (19.0)	+2.6%	0.349	18 (17.8)	25 (31.3)	+13.5%	0.035
	I would rather keep my abortion private	153 (35.8)	133 (39.5)	+3.7%	0.303	36 (35.6)	30 (37.5)	+1.9%	0.797
	I find it empowering	27 (6.3)	23 (6.8)	+0.5%	0.781	_ b	6 (7.5)		
	I am an undocumented immigrant	8 (1.9)	7 (2.1)	+0.2%	0.840	_ b	_ b		
	Other reason	17 (4.0)	17 (5.0)	+1.0%	0.479	_ b	_ b		

Participants could choose more than one response option

Table 13.3 compares reasons for contacting WoW during COVID-19 restrictions in 2020 (March to June and October to December) with the same months of 2019. "Coronavirus" was selected by almost half (47.5%) while the proportion selecting "I need to keep my abortion a secret from my partner or family" and "I would rather keep my abortion private" were both over 10% higher during the first lockdown period compared to the same months of 2019. During this time the proportion concerned about legal restrictions decreased (-16.5%, p<0.001). The only discernible change in reasons for contacting WoW during the second COVID-19 lockdown was an increase in the proportion selecting "my partner is abusive" (+7.6%, p<0.05).

 $<sup>^{\</sup>mathrm{a}}$ Chi-square test for difference in proportion, p-values significant at p<0.05 are bolded.

<sup>&</sup>lt;sup>b</sup>Cells of less than 5 are suppressed to protect anonymity.

Comparison of reasons provided by those completing requests with those who did not reveal stigma (+12.1%, p<0.001), an abusive partner (+3.9%, p<0.05), fear of protestors (+5.4%, p<0.05), and being an undocumented immigrant (+2.3%, p<0.05) featuring as particular barriers to local access (Table 13.4).

**Table 13.3.** Reasons for contact with Women on Web during the periods of COVID-19 restrictions in 2020 (March to June and October to December) compared to the equivalent months of 2019

	Reason	Mar-Jun 2019 n (%)	Mar-Jun 2020 n (%)	Difference in proportion	p- value <sup>a</sup>	Oct-Dec 2019 n (%)	Oct-Dec 2020 n (%)	Difference in proportion	p-value
	Total	126 (100)	137 (100)			103 (100)	63 (100)		
	Coronavirus	-	67 (48.9)	-	-	-	28 (44.4)	-	-
	Legal restrictions	35 (27.8)	11 (8.0)	-19.8%	<0.001	10 (9.7)	11 (17.5)	+7.8%	0.145
	Stigma	31 (24.6)	36 (26.3)	+1.7%	0.756	23 (22.3)	18 (28.6)	+6.3%	0.366
	Cost	41 (32.5)	33 (24.1)	-8.4%	0.128	28 (27.2)	10 (15.9)	-11.3%	0.092
It is hard for	Distance	14 (11.1)	19 (13.9)	+2.8%	0.399	15 (14.6)	9 (14.3)	-0.3%	0.961
me to access abortion because (of):	Childcare	14 (11.1)	14 (10.2)	-0.9%	0.815	19 (18.4)	10 (15.9)	-2.5%	0.672
	School or work commitments	21 (16.7)	25 (18.2)	+1.5%	0.736	28 (27.2)	9 (14.3)	-12.9%	0.053
	I need to keep my abortion a secret from my partner or family	32 (25.4)	56 (40.9)	+15.5%	0.008	35 (34.0)	25 (39.7)	+5.7%	0.458
	My partner is abusive	9 (7.1)	6 (4.4)	-2.7%	0.334	_ b	6 (9.5)		
	I do not want to deal with protestors	9 (7.1)	19 (13.9)	+6.8%	0.077	10 (9.7)	7 (11.1)	+1.4%	0.772
	I would rather take care of my own abortion	34 (27.0)	47 (34.3)	+7.3%	0.199	38 (36.9)	18 (28.6)	-8.3%	0.271
	Abortion pills are not available in my country	9 (7.1)	5 (3.6)	-3.5%	0.207	10 (9.7)	_ b		
I prefer to access abortion through WoW because:	I would be more comfortable at home	33 (26.2)	49 (35.8)	+9.6%	0.094	39 (37.9)	21 (33.3)	-4.6%	0.555
	I would rather have my partner or friend with me during the process	17 (13.5)	22 (16.1)	+2.6%	0.559	19 (18.4)	7 (11.1)	-7.3%	0.207
	I would rather keep my abortion private	37 (29.4)	55 (40.1)	+10.7%	0.067	38 (36.9)	26 (41.3)	+4.4%	0.574
	I find it empowering	11 (8.7)	10 (7.3)	-1.4%	0.669	5 (4.9)	_ b		
	I am an undocumented immigrant	_ b	_ b			_ b	_ b		
	Other reason	6 (4.8)	8 (5.8)	+1.0%	0.697	_ b	_ b		

Participants could choose more than one response option

<sup>&</sup>lt;sup>a</sup> Chi-square test for difference in proportion, p-values significant at p<0.05 are bolded.

<sup>&</sup>lt;sup>b</sup> Cell suppressed to protect anonymity

**Table 13.4.** Reasons for contact with Women on Web in 2019 and 2020 according to request status (non-completed)

	Reason	Non- completed requests (n=539) n (%)	Completed requests	Difference in proportion	p-value <sup>a</sup>
	Total	539 (100)	225 (100)		
	Coronavirus	97 (18.0)	17 (7.6)	-10.4%	<0.001
	Legal restrictions	105 (19.5)	44 (19.6)	+0.1%	0.981
	Stigma	119 (22.1)	77 (34.2)	+12.1%	<0.001
It is hard	Cost	157 (29.1)	52 (23.1)	-6.0%	0.089
for me to	Distance	79 (14.7)	44 (19.6)	+4.9%	0.093
access abortion	Childcare	73 (13.5)	32 (14.2)	+0.7%	0.804
because (of):	School or work commitments	123 (22.8)	53 (23.6)	+0.8%	0.826
	I need to keep my abortion a secret from my partner or family	178 (33.0)	80 (35.6)	+2.6%	0.500
	My partner is abusive	20 (3.7)	17 (7.6)	+3.9%	0.024
	I do not want to deal with protestors	57 (10.6)	36 (16.0)	+5.4%	0.037
	I would rather take care of my own abortion	174 (32.3)	76 (33.8)	+1.5%	0.688
	Abortion pills are not available in my country	47 (8.7)	15 (6.7)	-2.0%	0.343
I prefer	I would be more comfortable at home	178 (33.0)	85 (37.8)	+4.8%	0.207
to access abortion	I would rather have my partner or friend with me during the process	86 (16.0)	48 (21.3)	+5.3%	0.075
through WoW	I would rather keep my abortion private	190 (35.3)	96 (42.7)	+7.4%	0.054
because:	I find it empowering	31 (5.8)	19 (8.4)	+2.6%	0.170
	I am an undocumented immigrant	7 (1.3)	8 (3.6)	+2.3%	0.040
	Other reason	25 (4.6)	9 (4.0)	-0.6%	0.697

Participants could choose more than one response option.

aChi-square test for difference in proportion, p-values significant at p<0.05 are bolded.

#### 13.2.ii Qualitative Email Data Analysis

The codebook relating to the analysis of this qualitative email data is set out in Appendix 6. Analysis of email correspondence by 188 of the 225 people who received abortion pills from WoW in 2019 and 2020 showed multiple barriers to accessing locally provided abortion: I live in a rural town. There is still massive stigma attached to having an abortion in Ireland. In my area, no doctor provides abortion pills and my GP is a family friend. I would have to travel to Dublin to avail of this procedure. I am unable to do this because of childcare, work and cost issues.

Scarcity of local services was a primary issue: *I am finding it tough to get an appointment. Everyone I try to call is full for at least a month.* Accessing services would involve travel incurring time and expense: *The nearest hospital in which they have this service is over 100 kilometres from my village.* Many believed their registered GP was their only point to access services, but were reluctant about this: *I know my GP really well,* I don't feel comfortable talking about abortion with him. Concerns a doctor would not be impartial or would attempt to dissuade against abortion featured. People wanted to avoid being *questioned by others about my decision* or feared GPs opposing abortion would be judgemental: *my GP is not supportive of abortion and would judge me.* Stigma was also cited *due to the stigma and my situation with how my* 

pregnancy came about I don't want to go to a doctor and explain or even talk to them about what happened to me I am embarrassed.

Abortion is universally free for people with a Personal Public Service (PPS) number in Ireland, but misunderstandings were prevalent: it is not free as the GP requires €450 for the 3 visits. I simply cannot afford this. Requirement to have a PPS number left some migrants unable to access care: I am on a Working Holiday. I do not have a medical card nor a PPS number. I do not have access to free medical care here, and for those of undocumented migrant status: I am not legal here nor I don't have a GP.

Abusive relationships were a key factor for some seeking online telemedicine, considered easier to conceal: *I cannot get an abortion over here as my partner is abusive. He always wants to know where I am and there's no way I'd get away with getting one over here.* The local remote model relied on phone consultations, which were difficult when in controlling relationships: I am in an abusive relationship I can't go to my GP without [partner] knowing. ... The abortion service here is by phone consultation I'm not gonna be on my own long enough without him knowing what's going on.

Finally, although the revised model of care allowed for remote consultations, many assumed they still needed to visit a health facility during the COVID-19 pandemic, considered difficult as movement during lockdown was curtailed and fears of exposure to risk of transmission persisted: *Due to COVID-19 I have no way of travelling a distance to go to a clinic to receive the medical abortion pill. I am a single mother and I would be putting myself and my child at risk making the journey to do so.*"

#### 13.3 Overview of Analysis of Women on Web Data

Our analysis of contacts by people from Ireland to WoW in 2019 and 2020 shows that after receiving an automated response highlighting local availability of abortion, most did not progress their request. Nonetheless, reasons for contacting WoW highlight ongoing barriers to local access, while in 2020 COVID-19 represented an additional obstacle. Those who received abortion pills from WoW cited access issues, particularly no providers in their area, lack of choice in where to access care, and fear of stigma. There were widespread concerns about accessing services through local GPs. Many were unaware that services are provided free of charge. Being of migrant status or in an abusive relationship posed particular barriers.

The proportion of completed requests from people in Ireland decreased significantly between 2019 and 2020. This may reflect increased awareness of legal availability of abortion in Ireland by March-June 2020, compared with a year earlier when the service was within six months of implementation. Lending support to this, "legal restrictions" significantly decreased as a reason for contacting WoW during March-June 2020 compared to the equivalent months of 2019.

Across all time periods studied, relatively high proportions of people contacting WoW demonstrated a preference for the perceived privacy and comfort afforded by telemedicine services. This suggests a role for continued provision of remote services locally, as has been temporarily implemented during the COVID-19 pandemic. Sparse data collection regarding abortion care services in Ireland precludes an analysis of the efficacy and safety outcomes of the remote model, but in England a large-scale study of electronic records and incident databases (n=52,142) reported that the British comparable remote model of care was as safe and effective as in-person provision. It also improved accessibility to care and was considered widely acceptable by women (Aiken et al., 2021). Similar results were also reported in a study of a smaller cohort in Scotland (Reynolds-Wright et al., 2021).

Analysis of emails by pregnant women and people who received abortion pills from WoW revealed multiple barriers to local access including sparse coverage of providers, especially in rural areas, and some continued reticence discussing abortion with a GP due to concerns about stigma and confidentiality. Continued remote provision of abortion care within the Irish service, as well as increased awareness of how to access abortion care from GPs other than one's own registered provider or WHCs, and that abortion is provided free of charge for those with a PPS number, could alleviate these barriers. Comparing reasons for contacting WoW given by those who received the service versus those who did not revealed that despite legalisation of abortion in Ireland, stigma remained a prevalent concern for those needing to access it. As noted by Bras et al. (2021, initiatives to promote normalisation of abortion in Ireland are needed for this to dissipate.

These analyses also highlighted groups for whom local access is particularly challenging – recent and/or undocumented migrants and those experiencing domestic violence. Tailored changes to the model of care are required to avoid people in these circumstances continuing to seek care via telemedicine providers such as WoW.

A key strength of this component of the study is the use of unstructured emails, which allowed more nuanced understanding of why people sought access to telemedicine services after legalisation of services in Ireland, and which were triangulated with the quantitative data. Regarding limitations, while every effort was made to clean the data, there is potential that some women resident in Northern Ireland selected "Ireland" rather than the "United Kingdom" as their home country, although these numbers are anticipated to be low and steps were taken to address this. Finally, the onset of the COVID-19 pandemic means that a true comparison of contact with WoW during what would have been "normal" service provision in 2019 and 2020 was virtually impossible, but the analysis did facilitate consideration of the impact of a remote model of care.

This chapter explored changing patterns in and reasons for contacting and receiving online telemedicine abortion services by pregnant women and people from Ireland after legalisation of abortion. The majority of those in Ireland who contacted WoW in 2019 and 2020 did not go on to receive abortion pills from the service, but our findings indicate support for retaining provision of remote abortion care in Ireland, as has been temporarily implemented in response to COVID-19. Policy measures to increase public understanding of the model of care, specifically highlighting access pathways, confidentiality and free cost, as well as ongoing efforts at normalisation, could further reduce reliance by pregnant women and people in Ireland on telemedicine providers of abortion care like WoW.



# Synthesis of Findings of Unplanned Pregnancy and Abortion Care (UnPAC) Study

This chapter provides a synthesis of the findings of the Unplanned Pregnancy and Abortion Care (UnPAC) Study. To aid the reader it begins with a brief reminder of the study background and methodology. It then outlines the summary of study data and analysis pertaining to each of the findings chapters (Chapters 5-13), followed by an overall distillation and overview of the findings of the UnPAC Study as a whole.

#### 14.1 Background to the Study

The Health Service Executive (HSE) Sexual Health and Crisis Pregnancy Programme (SHCPP) is a national policy priority programme situated within the Health and Wellbeing function of the HSE, and is responsible for implementing the National Sexual Health Strategy 2015-202 (Department of Health, 2015). The aims of the strategy are to improve sexual health and wellbeing and to reduce negative sexual health outcomes. A key focus of the strategy is the development and use of knowledge to support decision-making to improve the health of the population. A key recommendation in the strategy is to build on the existing evidence base to understand emerging trends relating to crisis pregnancy and sexual health, and to undertake new research initiatives to address knowledge gaps.

The Health (Regulation of Termination of Pregnancy) Act 2018 ("the Act of 2018") was passed by the Houses of the Oireachtas on 13 December 2018 and signed into law by the President on 20 December 2018. The new Act repealed the Protection of Life During Pregnancy Act 2013 and the Regulation of Information (Services Outside the State for Termination of Pregnancies) Act 1995. The Act came into effect on 1 January 2019, permitting termination of pregnancy where there is a risk to the life, or of serious harm to the health, of the pregnant woman; where the pregnancy is likely to lead to the death of the foetus either before or within 28 days of birth because of a problem with its development; and without restriction up to 12 weeks of pregnancy<sup>18</sup>.

Under the Health (Regulation of Termination of Pregnancy) Act 2018, abortion services can be provided by way of medical abortion by general practitioners (GPs) or medical doctors in women's health clinics (WHCs) up to nine completed weeks' gestation. Between 10 and 12 weeks' gestation, GPs and WHCs should refer patients to hospital settings to access abortion services. People can also be referred to hospital settings to access abortion services if clinically indicated at any stage up to 12 weeks' gestation. Medical or surgical abortions can take place in hospitals up to 12 weeks' gestation. Abortion services beyond 12 weeks' gestation are restricted and can only be provided in hospital settings. The Act allows for conscientious objection to facilitate health professionals in settings where the service is provided to opt out of providing the service. People seeking abortion services under 12 weeks are required to attend a GP, WHC or hospital setting for two separate appointments, with a three-day wait required between the first and the second appointment before the abortion can be provided.

The HSE funds unplanned pregnancy and post-abortion counselling services delivered through the Sexual Health and Crisis Pregnancy Programme. The services are intended to support people through an unplanned pregnancy. The services provide the opportunity to talk to a trained pregnancy counsellor about the pregnancy and how it affects their personal circumstances; and to access factual information on available services and supports, including continued pregnancy supports and abortion services. The HSE-funded support services include face-to-face pregnancy counselling services and telephone counselling and support. Face-to-face counselling is available in over 20 locations across the country and is free of charge to pregnant people, their partners or a family member. Telephone counselling provides free and confidential information and counselling to support women six days a week, and since April 2020 runs from 9am to 8pm Monday to Friday and 10am to 2pm Saturday. From January 2019 to April 2020 it operated from 9am to 9pm Monday to Friday and 10am to 2pm Saturday. The My Options 24-hour nurse helpline is also available for people who are going through or have gone through an abortion procedure. The My Options service is legally entitled to provide information to women about GPs and WHCs who will provide abortion services in Ireland.

The unplanned pregnancy and abortion care support services provided by the HSE SHCPP relate to all people seeking termination of pregnancy, both within and outside the jurisdiction. During 2019, the first year of implementation of abortion care in Ireland, 6,666 terminations were notified by Irish care providers and in 2020, 6,577 terminations were notified. Outside of the jurisdiction, statistics from England and Wales for those years show that 442 people from Ireland under 12 weeks' gestation continued to access abortion care, and a further 127 over 12 weeks accessed abortion care there since the implementation of the 2018 Act on 1 January 2019.

The HSE SHCPP commissioned this study pursuant to the programme's remit to build on the existing evidence base to understand emerging trends relating to crisis pregnancy and sexual health, and to undertake new research initiatives to address knowledge gaps. The aim set out by the HSE SHCPP for the research study was to develop an in-depth understanding of the experiences of women who have accessed unplanned pregnancy support services and abortion services since the enactment of the legislation on 1 January 2019. The study objectives were:

- 1. To gather in-depth information from people who have availed of unplanned pregnancy support services and clinical abortion services in Ireland;
- 2. To provide a comprehensive description of the experiences of people who have availed of these services in Ireland, taking account of differing backgrounds, ages and locations;
- 3. To provide a comprehensive description of the trajectories of people who have accessed abortion care in Ireland, including linking with unplanned pregnancy support services and health care services.

The project began in December 2019 and is reporting in July 2022.

The following section describes the methods employed in work package three, the in-depth qualitative study of users' experiences. Section 14.3 provides a summary of findings from both work package three and four.

#### 14.2 Research Methodology

The UnPAC research study comprised four work packages:

i) Work package one: A policy case study of the implementation of the Act (Chapters 1 & 2);

- ii) Work package two: A literature review which collated evidence on abortion provision in the Irish context since the implementation of abortion services in Ireland in January 2019 (Chapter 4).
- iii) Work package three: An in-depth qualitative study of service users' experiences of unplanned pregnancy support services and abortion care (Chapters 5-12); and
- iv) Work package four: A quantitative and qualitative analysis of WoW data, an online telemedicine abortion care provider to regions with limited access (Chapter 13).

Qualitative methods were employed in this study of experiences of accessing and using unplanned pregnancy and abortion care services. The research approach taken was premised on the constructivist grounded theory (Charmaz, 2014) method and data generated following principles of purposive and theoretical sampling (Conlon et al., 2020). The qualitative research approach followed in the study was premised on the grounded theory (GT) method (Flick, 2018; Timonen et al., 2018), specifically the constructivist iteration of grounded theory (Charmaz, 2014; Conlon, 2020). The method is designed to generate understandings and meanings grounded in data generated through empirical observation and indepth engagement with the phenomenon of interest.

As this study was concerned with a novel process and context from the perspective of key actors – women using abortion services – the GT approach facilitated insights emerging from this novel context. GT was a good fit for a study inquiring into an area of health provision – unplanned pregnancy and abortion care services – that has been in place and the focus of research in the context at hand and other contexts for some time. It also allowed for specific insights into how this area of health provision is being engaged with and experienced by service users given the particular socio-political/cultural context, regulatory framework and implementation model in the setting of interest.

The research design for this GT study allowed the examination of people's experiences of unplanned pregnancy supports and abortion care services in the context of a radical change in abortion care at legislative, policy and service delivery levels. While the method privileges empirical data over existing theories or frameworks, within this study the constructivist method was chosen and adapted. The constructivist iteration of GT acknowledges pre-existing knowledge and frameworks and facilitates their application. This is best aligned with research carried out for applied policy purposes, where some specified parameters (e.g. pre-existing model of care and care pathways), as well as frameworks, are of interest to those charged with policy implementation. The principles of GT employed primarily within the project research design then emphasised two key principles of:

- · A maximally open approach to generating empirical data; and
- Privileging the empirical data in constructing an analytical framework over existing theories or frameworks.

While a synthesis of literature and key existing frameworks was referred to, an emphasis on openness in the design of data generation and analysis facilitated new, context-specific insights emerging.

The requirement of the method to be maximally open meant collecting data early on using lightly structured data generation methods, e.g. interview guides. Critically, it meant starting analysis as soon as data was available, to identify concepts and processes emerging early from the data as empirically observed. Emergent insights informed generation of further data following theoretical sampling principles (Conlon et al., 2020) designed to deepen and test these insights, and regarding the processes, conditions and contexts relating to the phenomenon of interest on the ground. Theoretical sampling allows diverse or multiple

conditions and contexts to be attended to, as the researcher notes not just patterns suggestive of emergent explanations but also gaps and anomalies, and seeks out data to fill gaps and illuminate anomalies. A key focus involves seeking out anomalous and contrasting contexts and perspectives to check continuously if the accounts and explanations emerging from analysis are rigorous and a good fit.

Semi-structured, in-depth interviews with people accessing unplanned pregnancy and abortion care services were considered the optimal format of data collection for this project. This interviewing format allows for maximally open and flexible data generation aligned with the grounded and emergent premises driving the study (Timonen et al., 2018). One-to-one interviews were also a format that best acknowledged the sensitivity of the topic and the centrality of women's accounts driving the project.

The target sample population was people using unplanned pregnancy support services and abortion care. The data was collected in a range of settings, and fieldwork sites were selected having regard to the different care pathways available to people accessing unplanned pregnancy and abortion care supports, including the following:

- People attending unplanned pregnancy counselling services who may decide to continue the pregnancy or not:
- People under 12 weeks' gestation seeking abortion care whose care pathway was confined completely to community/primary care settings;
- People under 12 weeks' gestation seeking abortion care who were referred to hospital settings for abortion care because of clinical indicators or reaching 9-12 weeks' gestation for abortion care;
- People under 12 weeks' gestation who had abortion care provided in community/primary or hospital settings who were referred to hospital for care relating to post-abortion symptoms;
- People over 12 weeks' gestation who seek and/or qualify for abortion care under the 2018 Act;
- People accessing abortion care outside the jurisdiction since the implementation of the 2018 Act.

Purposive sampling was employed to recruit participants from across each of these categories as set out below. Within each category, theoretical sampling principles were followed to achieve an overall data set compiled with rigorous attention to diversity and depth.

#### 14.2.i Participants

Recruitment of participants took place in a range of community, primary care and hospital or tertiary care settings, reflecting the service delivery settings relevant to the focus of interest of the study. A total of 58 participants were interviewed for the study across various sites, as outlined in Table 14.1.

**Table 14.1.** Initial recruitment sites of study participants (n=58)

Recruitment site	n (%)
GP	21 (36.2)
Women's health clinic	11 (19.0)
Hospital	13 (22.5)
Pregnancy counselling	7 (12.1)
Self	3 (5.2)
British Pregnancy Advisory Service	2 (3.4)
Termination for Medical Reasons	1 (1.7)
Total	58

Thirteen study participants accessed HSE-funded unplanned pregnancy supports (n=10) and/or post-abortion counselling (n=6).

#### 14.3 Summary of Study Data and Analysis

#### 14.3.i Analysis of Data Relating to My Options Service and Nurse Helpline

Chapter 5 documented service users' experiences of using the My Options service and nurse helpline. The key functions of My Options within the unplanned pregnancy and abortion care pathways are to provide people seeking care with names and contact details of doctors providing termination of pregnancy; to provide them with information about all options regarding pregnancy including termination of pregnancy, adoption and/or parenthood; to provide listening support; and to offer telephone counselling if requested and/or details of community-based pregnancy counselling services. In addition, the care pathway for EMA in community settings includes provision of the My Options 24-hour nurse helpline as a support to providers and service users.

My Options is serving people well in being a responsive, accessible, caring and continuous element of the care pathway for women and pregnant people. In particular, being able to readily talk with someone knowledgeable about access to and eligibility for abortion services, questions on confirming pregnancy, what the abortion procedure will involve, getting contact details of providers and reassurance that these are GPs who will readily provide the care, and supporting people in making appointments for abortion care. My Options can assist people in identifying if their own GP is or is not a provider, avoiding people approaching their own GP to find they are not a provider and the shame, embarrassment or judgement they consider that would entail. However, My Options can only identify GPs on the "open list", while information on GPs on the "closed list" is not available to them. An initiative is underway of a "grey list" identifying GPs providing to their own patients only, who can be confirmed as providers to callers. My Options also offers people the option of sourcing a local GP or one outside their own area if this is their preference for privacy reasons. These are all facets of My Options that are valued by the study participants. Moreover, they all contribute to My Options operating as a responsive and supportive gateway for people to access care. While My Options was very positively evaluated by many research participants, there were participants who recalled their engagement with the service in a minimal or perfunctory way.

However, the model of care positions My Options as the sole source of information on GP providers. The practical effect of this seems to be to remove any onus or responsibility on actors across wider services to be knowledgeable about, willing to discuss, and willing to refer women seeking abortion into the care pathway for abortion services. People who contacted hospital or GP services expecting to be provided with care or referred to a provider but were not, reflected on the stress involved in trying to access a service when service providers are not openly acknowledged. People know the service is legal and expect to either be cared for by the hospital or GP they approach, or at least be referred to a provider by them, but this frequently does not happen. Instead participants reported being turned away by other GPs or hospital staff, either with no information or details of the My Options helpline. Some see My Options as a conduit and an additional step that should not be necessary for them to access legally regulated and provided-for services, and actively avoid the service for that reason. Ultimately they have to contact My Options when efforts to directly access the service themselves are unsuccessful, and this is a source of frustration and delay. The My Options 24-hour nurse helpline was assessed positively by study participants for being easily accessible, especially out of hours. In particular the service was reassuring to people given the onus of selfmanaging abortion care. Staff were assessed as understanding and knowledgeable. The service supported people to determine if they needed to take a second round of the second medication, if symptoms they were experiencing indicated they should present to their doctor or hospital, or simply if symptoms they reported were normal/could be self-managed.

## 14.3.ii Analysis of Data Relating to Experiences of Community/Primary Care Provided Abortion Care Under s.12

Chapter 6 documented people's experience of receiving community-based abortion care under s.12 of the Act. While the experiences of participants who attended GPs and WHCs were analysed separately, it was observed that once people had accessed a provider, be they a GP or WHC doctor, their experiences were largely comparable. Thus, the experiences of women attending either a GP or WHC were integrated in this section, with points of difference highlighted where they arose.

Overall, people were satisfied with the care they received from their provider. Many commended them for their non-judgemental and empathetic approach, with participants attending GPs sometimes giving specific examples of how this was demonstrated. While these practices were appreciated, there is a risk of some of the more unusual ones, such as personal mobile numbers being given out for management of complications, being unsustainable in the long term. Such practices may need to be reviewed if abortion care is to be successfully integrated into primary health care on a greater scale.

People generally received clear and detailed information from their provider regarding various aspects of the abortion, including on legal requirements for accessing it and what to physically expect during a medical abortion. However, there appeared to be less focus on hormonal changes to be expected after abortion. This information may also be valuable to include in standard consults to facilitate a more holistic approach to care.

It was not the norm for participants who did not experience post-abortion complications to attend a third appointment, and while a few did attend such an appointment, others were unaware it even existed in the care pathway. Communication via phone/text was appreciated as a means of checking in after the abortion, with some of those who did not receive any form of follow-up expressing a sense of incomplete care. Crucially, timely management of post-abortion complications when experienced is vital for mitigation of people's anxiety around such complications. Fortunately this was generally the case, with most women recalling their provider responding in a prompt and thorough manner and making appropriate referrals where necessary. On the other hand, the cases where this did not happen illustrate how poor management of post-abortion complications can serve to substantially increase a service user's stress and decrease their satisfaction with the care received.

Regarding GP-led care, although people were generally very positive about their experience of receiving care from their providing GP, many described the major challenge of accessing a provider in a context where such appointments are not universally and transparently provided by GPs. Pathways may differ in terms of their starting points – some people contact GPs directly while others are referred to GPs by My Options – although both may require multiple attempts before an appointment is secured. It also seems that few non-providing GP practices are referring women to My Options, an issue that needs to be addressed. Furthermore, not all people are aware of the role of My Options, with some assuming that they will be able to access abortion from their own GP. This leaves people vulnerable to delay in access to care, most concerningly exemplified by Grace's story. In fact, the accounts of several people indicates that conscientious objection is being applied in a manner that appears to contravene that permitted by the Irish Medical Council's Guide to Professional Conduct and Ethics for Registered Medical Professionals. Beyond this, the lack of transparency regarding provision of the service means that some people (especially those who do not contact My Options in advance) rely on cues from previous interactions with their GP to try to pre-empt their provider status – mental calculations that would not likely be required to access other aspects of primary health.

Our data also show that people hold mixed views about the appropriateness of GPs as providers of abortion care. This suggests that there is a role for other pathways within the model of care such as WHCs, which were generally portrayed as appropriate providers of abortion care with the specialised knowledge to do so. On the other hand, there is limited provision of abortion care by WHCs, with these services being mostly concentrated in Dublin. Unsurprisingly with these limited resources, there were several participants who reported having difficulty with securing a timely appointment at a WHC, and this was the case pre-COVID-19 as well as during it. Therefore, while WHCs are an acceptable – and for some, preferable – alternative to GP-led care, they cannot be solely relied on as an alternative to adequate nationwide provision by GPs.

While GP provision of abortion care has been steadily increasing since the service was first implemented in January 2019, the accounts of some women highlight how sparse coverage, particularly in rural areas, remains a significant barrier to access. Notably rural participants used the word "shock" in relation to their discovery of the limited availability of providers in their area. Some women were required to travel long distances to access a providing GP, a particular barrier for those who do not have access to their own vehicle. Nonetheless, there remains ongoing debate regarding the need for more GP providers versus the need for committed GP providers, and within our data set people generally were wary of encountering noncommitted providers. Therefore, there remains the need to increase GP provision of abortion care, with a special focus on increasing uptake in areas of sparse coverage by those who are currently not providing for reasons other than conscientious objection.

Finally, it appears that the remote model of care has increased accessibility of the abortion care service, particularly benefitting people in areas where GP or WHC providers were limited. Overall, people described the remote visit as convenient and facilitating early access to consultations, consistent with people's strong concerns for timeliness in seeking abortion care. For those who needed referral to hospital, the remote consultation seemed to speed up that process of the apparently faster initial point of contact with the community provider. Remote consultations from the comfort of one's own home and space were valued by participants and considered comforting, and overall had high levels of acceptability as a format of care. Meanwhile there was no indication of lower quality of consultation, with women attending care remotely not feeling any less informed, confident about or supported in the care process. The data here supports making remote provision a permanent feature of the model of care. However, providers, particularly WHCs, need to assess carefully how the information session/process call introduced during remote provision is working in relation to counselling provision, to avoid people engaging without counselling without fully informed consent.

## 14.3.iii Analysis of Data Relating to Experiences of Hospital-Provided Abortion Care Under s.11

Chapter 7 presents analysis of data relating to women seeking abortion care under s.11 of the 2018 Act, which specifies that women will attend hospital for abortion care under 12 weeks' gestation at any gestational stage if clinically indicated, and in all cases after they reach a gestational stage of nine weeks.

Overall, participants described hospital-based care providers in administrative and clinical roles as non-judgemental, highly professional and maintaining good communication, who made women feel cared for. The location of services within maternity settings was considered disconcerting by some people because of the opportunity it presented for encountering pregnant women and babies. It was perceived by some as the "nether regions" of the hospital, indicating it as in some way marginal, and this diminished acceptability of the setting to people overall.

Within hospitals the absence of separate waiting areas for scanning and assessment and separate inpatient beds from maternity care facilities were also queried. The integration of abortion service users with maternity care service users within the hospital raised the possibility of encountering staff not connected with the service, who may not have been a sensitive or committed provider of abortion care. It also raises the possibility for human error and women being assigned to incorrect wards or areas. The case of Pippa self-presenting at a non-providing hospital requesting termination and encountering obstructed access raises the need for a protocol for non-providing hospitals to refer anyone requesting termination to a provider and/or My Options at the first opportunity.

## 14.3.iv Analysis of Data Relating to Views and Experiences of Mandatory Three-Day Wait

In order to access abortion under Section 12 of the Health (Regulation of Termination of Pregnancy) Act 2018, three full days must elapse following certification of the pregnancy as being under 12 weeks' gestation by a medical practitioner. Chapter 8 outlined participants' views on and experiences of this mandatory three-day wait.

Participants expressed different opinions on the three-day wait. Some viewed it simply as a legal requirement to be overcome, while others viewed it as a deterrent to care. Very few considered the three-day wait to be of any personal benefit to them in their decision-making process, while some wondered whether it may be useful for "other" people who might be less decided. For some, the three-day wait was experienced as a time of heightened anxiety and distress, especially during an already time-sensitive period. People portrayed themselves as making careful decisions. They feel the wait shouldn't be mandatory – but were conscious that it might be useful for another person, even if it wasn't for them. The data indicates the mandatory three-day wait should be removed from legislation. Instead, the model of care should retain a second consultation as optional for women to attend within a timeframe agreed by them and their provider, while allowing the service to be delivered within one consultation if preferred.

#### 14.3.v Analysis of Data Relating to Self-Managing Abortion

Experiences of the process of self-managing abortion, reflecting the specific model of care implemented in the Irish context, were described in Chapter 9. Data gathered from service users demonstrates rich descriptions and embodied experiences of the early medical abortion (EMA) process.

The self-management of the abortion entails careful management of both the logistical aspects and physical processes of the EMA. Logistical aspects include the scheduling of abortion care appointments with care providers around work, care and study responsibilities; and travel to and from both appointments, though the introduction of the teleconsultant under the remote model of care alleviates having to travel on two separate occasions. Managing post-abortion complications depends on the individual situation, though it

might mean multiple visits to the GP or WHC for monitoring of hCG levels or a referral to hospital for followon care. In particular, we heard that people with childcare commitments not only had to consider how their children would be minded during their abortion care appointments but also had to carefully consider the timing of the self-administration of the medical abortion. Participants made practical preparations regarding how they set up the primary space where they would manage the abortion and the provision of hot water bottles, sanitary towels, painkillers and extra sheets they had to hand. Data demonstrates that people had various personal supports in place during this process.

In terms of the administration of the medication, the first medication was generally taken with the care provider, while the second medication was carefully timed in consultation with their care provider to be taken at home at a time most convenient to the service user. Participants readily discussed bodily experiences of the medical abortion, including reading the signs to know the pregnancy had successfully been terminated. The data also show that people were conscious of practising self-care as the medical abortion was happening. Overall people valued having privacy, support and personal spaces in which to manage the abortion. Furthermore, the data demonstrated that self-management of the EMA could be difficult for those who lived in shared accommodation. Participants also reflected that for those without personal supports in place, or for those who have experienced sexual assault or living in a domestic abuse situation, there should be an alternative offered to the home-based medical abortion.

## 14.3.vi Analysis of Data Relating to Views and Experiences of Pregnancy Counselling Services

The HSE SHCPP funds unplanned pregnancy and post-abortion counselling services intended to support people through an unplanned pregnancy, provide the opportunity to talk to a trained counsellor, and give access to factual information on available services and supports, including continued pregnancy supports and abortion services. The HSE-funded support services include face-to-face crisis pregnancy counselling services and telephone counselling and support. Chapter 10 outlined data relating to the views and experiences of such pregnancy counselling services by those who accessed abortion care under s.12 of the Health (Regulation of Termination of Pregnancy) Act 2018.

Overall, those who chose to access counselling considered it valuable and supportive for a range of reasons: reassurance, affirmation, validation, information, or as an opportunity to discuss their decision. Notably, abortion stigma has not become extinct with the advent of the new abortion legislation; despite abortion care now being a legal right, some women continue to experience guilt and shame. For these reasons, counselling services should continue to be available for those who wish to access them. Additionally, the availability of such services to partners may need greater highlighting. The importance of counselling remaining free was especially highlighted in the talk of women who already had a private counsellor or therapist (and were therefore cognisant of the potential for cost to be a barrier) and Anna, who reported that she would have been unable to attend counselling were it not freely available. It is also sadly the case that for some women, counselling was required to support them with the fall-out of a difficult care pathway. For these women, counselling was needed to paper over cracks imposed by the model of care itself and every effort should be made to ensure that this is not the norm.

On the other hand, many participants did not see counselling as having any relevance in their abortion care pathway. Again, this was for a range of reasons, although largely related to them simply not considering it as necessary or having sufficient personal supports in place. Many perceived the role of pre-abortion counselling as related to decision-making, suggesting a potential mismatch between these understandings and those of service providers. The views and wishes of these women should continue to be respected, with counselling continuing to be a voluntary process engaged by the service user, not the reverse.

## 14.3.vii Summary of Data Relating to Abortion Care Experiences After 12 Weeks' Gestation (s.9, 10 and 11 of 2018 Act)

In the study, the 12 people seeking or accessing abortion care over 12 weeks' gestation (one of whom continued to give birth) had all received a diagnosis of foetal anomaly on a wanted pregnancy that had prompted them to consider termination. The legislation and guidelines for termination of pregnancy care following diagnosis of FFA/LLC were detailed in Chapter 2, but by way of reminder, the pathway set out in the Interim Clinical Guidelines provided by the IOG recommends referral to a foetal medicine specialist within a 24-72-hour window of suspecting an anomaly. The foetal medicine specialist is expected to be involved in the full care pathway for a woman considering termination of pregnancy. The guidance anticipates that the majority of women will be referred to a tertiary hospital for review, specialist assessment and possibly investigative testing. A multidisciplinary team at the tertiary site will discuss the case to reach a consensus about diagnosis and prognosis, and to consider the option of termination of pregnancy being discussed with the parents. Results will be communicated to local units and ongoing care is managed with the local obstetricians and neonatologists/paediatricians, supported as needed by the tertiary site.

Our analysis of the experiences of the 12 participants undergoing this care pathway was set out in Chapters 11 and 12, with Chapter 11 providing case-by-case accounts of experiences of navigating individual care pathways, followed by presentation of key themes highlighted across the data set in Chapter 12. Care pathways described were complex and crossed several different services and care providers in the care landscape. They often begin with the detection of a possible concern, identified during routine scanning and/or in conjunction with NIPS towards end of the first trimester, or during an anomaly scan at around 20 weeks' gestation in the second trimester.

It is important to note that while the study group comprising 12 participants may seem small, the principles of theoretical sampling as set out in the methodology chapter (Chapter 4) above were adhered to in generating this sample and data set. The fine-grained diversity within the study sample set testifies to the careful attention and rigour given to purposive and theoretical sampling during this study, and in particular in relation to this study sub-group, in the interests of achieving overall rigour and validity in the analysis. In presenting the study data relating to this group, we first portrayed women's care pathways in turn to allow an appreciation of the detailed experiential perspective achieved in the study. We then distilled down how key aspects and issues within those care pathways featured across the data set.

Presenting detailed case studies of the care pathways of the people interviewed who sought or accessed abortion care in Ireland over 12 weeks' gestation depicted the complex care pathways followed, including gestation at initial detection of a foetal anomaly, diagnostic testing received, whether they qualified for care in Ireland, and the outcome of the pregnancy. The following care pathways were represented in our data set:

- Anomaly detected at booking-in scan, qualified for care in Ireland and had TOP under 20 weeks' gestation (n=3): Lily, Gabrielle, Eavan
- Anomaly detected at booking-in scan, qualified for care in Ireland, travelled to England to access preferred surgical TOP under 20 weeks' gestation (n=1): Martha
- Anomaly detected at booking-in scan, did not qualify for care in Ireland following assessment, travelled to England for TOP under 20 weeks' gestation (n=3): Emily, Francesca, Maeve
- Anomaly detected at anomaly scan 20-22 weeks' gestation, qualified for care in Ireland and had TOP after 20 weeks' gestation (n=1): Karla
- Anomaly detected at anomaly scan 20-22 weeks' gestation, qualified for care in Ireland, decided to continue to delivery (n=1): Neasa

- Anomaly detected at anomaly scan 20-22 weeks' gestation, travelled to England for TOP before UK 24week limit, before determination on qualification in Ireland (n=2): Natalie, Denise
- Anomaly detected at anomaly scan 24 weeks' gestation, did not qualify for care in Ireland, travelled to England for TOP after 24 weeks (n=1): Cara

## 14.3.viii Analysis of Data Relating to Women's Experiences of Care Pathways Relating to s.11 2018 Act

The care pathway in relation to termination for FFA begins with detecting an anomaly either in scanning or through screening testing. The data shows there was a variance in how the initial indication of a diagnosis was conveyed to people. In turn, people's concerns when this was intimated left them highly attuned to any cues, verbal and non-verbal. Women's concern is for timely diagnosis, an open and full communication process, and continuity of access to care within the Irish health system.

Referral for assessment and testing was prompt, but assessment was protracted with no certainty of outcomes, and this takes a heavy toll on women. Where foetal medicine midwives (FMMs) were in place, communication, information and support was optimum but where they were not, there were deficits. Even when FMMs were in place, concerns not to breach clinical protocols about what could be discussed or stated conclusively left women with questions and anxieties, not knowing where they could turn. The integration of specialist pregnancy counselling supports into this care pathway could provide women with a resource where they could explore emotions, questions and concerns with professional facilitation to help alleviate anxieties and distress during protracted assessment. Given the expertise of these counsellors, people could also be prepared for the decisions that lay ahead for them, whatever the outcome of assessment.

The data indicated concerns about a diagnosis of a severely life-limiting condition were as high for participants in the study as for a diagnosis of a fatal anomaly – what this would mean for the quality of life of the child, for themselves as parents, and for other children they had. The current restrictions on legal access to termination in cases of foetal anomaly fell short of people's needs, as evident in decisions women took to travel to the UK to access termination. Power et al. (2020) noted that diagnosing conditions as fatal in accordance with the Irish legislation is complex, as many anomalies in isolation may not be considered fatal foetal anomalies, but when combined are potentially fatal. Uncertainty of qualifying under Irish law meant that where an anomaly was detected late in the second trimester, taking account of the usual assessment timeframe, people were weighing up waiting for the outcome of that assessment against taking the decision to travel for certainty of access to the UK before the 24-week time-limit.

Qualifying criteria were portrayed in the data as highly restrictive, resting legal responsibility with clinicians and rendering the pregnant person with no capacity to be involved. People portrayed finding themselves hoping for a "fatal enough" diagnosis rather than being denied care and faced with travelling. Legislation, and particularly the criminal penalties the law contains, had a distinct chilling effect on interaction and openness between clinicians and women during the assessment process. Where diagnosis was inconclusive and/or did not satisfy the criteria to qualify for care under Irish law, participants noted reticence among clinicians to engage in open and detailed discussion on quality-of-life prospects for the foetus. This may in part have been due to clinicians' uncertainty regarding the diagnosis/prognosis for the foetus, but nonetheless, there is an indication that again the law is having a chilling effect on these clinical setting encounters leaving considerable frustration and gaps for women and parents.

Not qualifying for care in Ireland signified being denied care, being unsupported and cast out, and travelling to access termination was associated with shame, stigma and judgement. It involved attending

an unfamiliar provider, complex logistics and cost, being away from the comfort and dignity of home, and travelling after a traumatic procedure, especially during COVID-19. In particular it created harrowing situations for parent(s) who were either not able to bring their baby's remains home or had to transport remains independently. The opportunity for a post-mortem to achieve greater diagnostic clarity was also affected, as to do so required leaving the baby's remains, which some parents did not want to do.

The integration of termination of pregnancy care into maternity settings raises issues of acceptability, where no dedicated separate spaces are available either during the assessment process or when attending as an outpatient for scans or consultations. Facilities where termination of pregnancy was performed were often in the same area as delivery suites, and participants described overhearing relieved and jubilant parents announcing safe arrival of babies as they were undergoing a termination of pregnancy. In addition, confining method of termination of pregnancy to the medical method only raises issues of acceptability. In this study group, one person travelled to the UK to access the surgical method of abortion after qualifying for care in Ireland, and others expressed shock upon learning they would be required to "give birth" as they considered it.

In addition, implementation of perinatal palliative care protocols needs careful management. People with second trimester terminations will not always relate to the bereavement of losing a child, but rather frame their loss as the loss of a pregnancy. Those who do relate to their loss on these terms, however, do value and welcome bereavement supports and should continue to have those offered.

Finally, while a review mechanism is available, this was not referred to or invoked by any women in this study. The data would indicate that time is one factor precluding this measure having any practical value. The review entails entering into another process of clinical review with an indeterminate timeframe and outcome in the context of a developing pregnancy, and the time limitations that imposes. There is consensus among women that time really matters in this process. They want to strike the optimum balance between taking enough time to fully assess the foetal health and prognosis, and the pregnancy progressing no further than is necessary if termination is the outcome. These factors combined considerably question the practical value of the review mechanism within the legislation.

#### 14.3.ix Analysis of Data Relating to Women on Web

Chapter 13 examined continued requests by people from Ireland to online telemedicine abortion provider WoW following legalisation. WoW is a non-profit organisation providing safe online telemedicine abortion care to regions with limited access (Aiken et al., 2018).

Our analysis of contacts by people from Ireland to WoW in 2019 and 2020 showed that after receiving an automated response highlighting local availability of abortion, most did not progress their request. Nonetheless, reasons for contacting WoW highlight ongoing barriers to local access, while in 2020 COVID-19 represented an additional obstacle. Those who received abortion pills from WoW cited access issues, particularly no providers in their area, lack of choice in where to access care, and fear of stigma. There were widespread concerns about accessing services through local GPs. Many were unaware that services are provided free of charge. Being of migrant status or in an abusive relationship posed particular barriers.

The proportion of completed requests from people in Ireland decreased significantly between 2019 and 2020. This may reflect increased awareness of legal availability of abortion in Ireland by March-June 2020, compared with a year earlier when the service was within six months of implementation. Lending support to this, "legal restrictions" significantly decreased as a reason for contacting WoW during March-June 2020 compared to the equivalent months of 2019.

Across all time periods studied, relatively high proportions of people contacting WoW demonstrated a preference for the perceived privacy and comfort afforded by telemedicine services. This suggests a role for continued provision of remote services locally, as has been temporarily implemented during the COVID-19 pandemic. Sparse data collection regarding abortion care services in Ireland precludes an analysis of the efficacy and safety outcomes of the remote model, but in England a large-scale study of electronic records and incident databases (n=52,142) reported that the British comparable remote model of care was as safe and effective as in-person provision. It also improved accessibility to care and was considered widely acceptable by women (Aiken et al., 2021). Similar results were also reported in a study of a smaller cohort in Scotland (Reynolds-Wright et al., 2021).

Analysis of emails by women who received abortion pills from WoW revealed multiple barriers to local access including sparse coverage of providers, especially in rural areas, and some continued reticence discussing abortion with a GP due to concerns about stigma and confidentiality. Continued remote provision of abortion care within the Irish service, as well as increased awareness of how to access abortion care from GPs other than one's own registered provider or WHCs, and that abortion is provided free of charge for those with a PPS number, could alleviate these barriers. Comparing reasons for contacting WoW given by those who received the service versus those who did not revealed that despite legalisation of abortion in Ireland, stigma remained a prevalent concern for those needing to access it. As noted by Bras et al. (2021), initiatives to promote normalisation of abortion in Ireland are needed for this to dissipate.

These analyses also highlighted groups for whom local access is particularly challenging – recent and/or undocumented migrants and those experiencing domestic violence. Tailored changes to the model of care are required to avoid people in these circumstances continuing to seek care via telemedicine providers such as WoW.

A key strength of this element of the study is the use of unstructured emails, which allowed more nuanced understanding of why people sought access to telemedicine services after legalisation of services in Ireland, and which were triangulated with the quantitative data. Regarding limitations, while every effort was made to clean the data, there is potential that some women resident in Northern Ireland selected "Ireland" rather than the "United Kingdom" as their home country, although these numbers are anticipated to be low and steps were taken to address this. Finally, the onset of the COVID-19 pandemic means that a true comparison of contact with WoW during what would have been "normal" service provision in 2019 and 2020 was virtually impossible, but the analysis did facilitate consideration of the impact of a remote model of care.

This chapter explored changing patterns in and reasons for contacting and receiving online telemedicine abortion services by women from Ireland after legalisation of abortion. The majority of women in Ireland who contacted WoW in 2019 and 2020 did not go on to receive abortion pills from the service, but our findings indicate support for retaining provision of remote abortion care in Ireland, as has been temporarily implemented in response to COVID-19. Policy measures to increase public understanding of the model of care, specifically highlighting access pathways, confidentiality and free cost, as well as ongoing efforts at normalisation, could further reduce reliance by women in Ireland on telemedicine providers of abortion care like WoW.

## 14.4 Distillation of Findings Relating to Impact of Legalisation of Abortion in Ireland on Participants' Sense of Reproductive Autonomy

The impact of the legalisation of abortion in Ireland and the preceding referendum is invoked by women in the data as establishing a right to a quality, accessible service – across community care, hospital and

over 12 weeks' care pathways. Even a woman who had not known about legalisation and would not have travelled to access abortion outside of the jurisdiction, or even outside her own locality, integrated it into her reproductive health options when it came to her attention as she came to terms with an unintended pregnancy. The provision of abortion care at local community level had an important symbolic effect, signifying it as a legitimate, social and legally endorsed component of reproductive health care.

The data indicates that the impact of legalisation notwithstanding, the legacy of the Eighth Amendment and the contestation of legalisation of abortion in Ireland has left a residue of symbolic effect that presented in the data as considerable levels of insecurity among women in the certainty of the provision of and access to abortion. It also featured in the form of concerns about judgement and stigma, including potential for protests, that affected accessibility of the service. The data illustrated that people were keenly aware that while the service is now legally provided, ways in which broader social discourse around abortion will take further time to shift and for its effects to dissipate. This all points to the need for particular attention to cultivating normalisation of abortion through care provision practices, evolving discourse and tailored policy initiatives such as legislating for safe access zones.

A sense of insecurity around the provision of abortion was a resounding feature of the study data. Many expressed an initial fear or worry that they would not be able to access abortion care for a multitude of reasons, but including that the service was new, it might be difficult to connect with a provider, or uncertainty of gestational age and awareness of looming gestational cut-off. Women understood the momentous change that legalisation of abortion represents and that it is a new service. This features in complex ways as a legacy of non-provision of abortion and contestation over abortion. The outcome of the referendum to repeal the Eighth Amendment was invoked by women as underpinning their right to abortion care. Local, open and accessible services reinforced those rights while encountering delays, obstruction or refusal to provide undermined a fragile confidence in provision.

## 14.5 Overview of Findings Relating to Model of Unplanned Pregnancy and Abortion Care in Ireland 2019-2021

The model of abortion care implemented in the Irish context is innovative for its community-based provision for those seeking care under nine weeks' gestation, and the data indicates that this model has inherent potential to normalise abortion care with attendant capacity to enhance accessibility. The data indicates strong evidence of high quality conscientious commitment by dedicated providers across the full spectrum of the care pathway. There is an expectation that non-providers will show a duty of care and refer on if they are not in a position to provide. We found that this was an exception and not the norm. In the over 12 weeks category, confining access to reasons of fatal foetal anomaly is not meeting women's needs.

The data demonstrates how the model of care places a high burden and onus on the person accessing care to navigate what can be a complex, fragmented care pathway. In particular, self-management of the early medical abortion is onerous for the person, yet we heard how women welcomed the method facilitating them being in control of their own care and the opportunity afforded to them to put in place comforts and supports. Some highly personalised accounts of ways women marked the ending of the pregnancy demonstrate the value of such self-management that achieves a particular form of acceptability of care.

Meanwhile the data demonstrated, at the same time, particular burdens and challenges. The model of care positions My Options as the primary source of information on abortion providers for those under 12 weeks' gestation. The practical effect of this seems to be to remove any onus or responsibility on actors across wider services to be knowledgeable about, willing to discuss, and willing to refer women seeking abortion

into the care pathway for abortion services. Women who contacted hospital or GP services expecting to be provided with care or referred to a provider but were not, reflected on the stress involved in trying to access a service when service providers are not openly acknowledged. Women know the service is legal and expect to either be cared for by the hospital or GP they approach, or at least be referred to a provider by them, but this frequently does not happen. Instead women reported being turned away by other GPs or hospital staff, either with no information or details of the My Options helpline. Furthermore, the necessity of having an appropriate and private space where the EMA could be carried out was not available in all cases. Women plan the management and logistics of self-administered medical abortion very carefully alongside childcare, work and study commitments. Timeliness is a key concern for people (and we know also for clinicians). Indications from accounts of the service more broadly are that people are identifying the need for and seeking abortion care early in gestation, and data was resounding in participants emphasising wanting access to care as soon as possible. The data indicated some capacity issues among providers that an increased number of GPs opting into the service, and increased capacity within the WHC sector, could resolve. The experiences of the remote model of care, particularly in the GP setting, indicated its potential to enhance timely accessibility to care. Meanwhile the emphasis on timely accessibility is at odds with the mandatory three-day wait within the legislation. The data indicates this mechanism had no role to play in improving conditions for people to make a decision regarding pregnancy outcome. In the absence of any clinical role for this mechanism it seems to have no value in enhancing abortion care, but rather runs contrary to aspects of accessibility and acceptability.

Data relating to seeking or accessing termination of pregnancy under section 11 of the 2018 Act, referring to fatal foetal anomaly grounds, showed the effects of the legislative regulations and how they are being implemented. In particular the data demonstrated how people in this care pathway, who are already coping with the loss of a wanted pregnancy, experience protracted assessment, are impacted by the inherent potential for contestation among clinicians, note a chilling effect on interaction within the care encounter, and are dealing with high levels of uncertainty about accessing care at all. All the while people emphasise the symbolic as well as practical importance of accessing care within their own health care setting and jurisdiction. Current legislation does not accommodate complex multiple anomalies indicating severe lifelimiting conditions, yet our data demonstrated that such diagnoses are of as high a level of concern for women as a diagnosis of a fatal anomaly, and prompted women to travel seeking termination, some before the protracted assessment process completed to ensure certainty of access in the UK. Limited availability of surgical abortion across both care pathways featured in the study was criticised by women on grounds of acceptability. There is an absence of surgical abortion after 12 weeks and our data shows that women who access for reasons of FFA over 12 weeks would like to have the surgical option. Factors such as a willing providers, trained providers and difficulties in accessing necessary facilities in all hospital sites have been cited as reasons for this limitation in the model of care. Multi-level strategies are necessary to address this.

#### 14.5.i Model of Care – Systems Perspective

The data in this study demonstrates some of the effects of the Irish model of abortion care, wherein the abortion service was "grafted on" to existing primary, secondary and tertiary services. The potential for this model to promote normalisation, acceptability and access was evident. However, there were also "wrinkles" evident in the data. Accessing services in areas where there is sparse or no coverage by providers in either community or hospital settings featured. This is an effect of uneven uptake at hospital and primary care level, with uptake known to be interdependent. Meanwhile it is well-established that there are stretched resources in both community and hospital health care settings, and so from the outset development of dedicated infrastructure was challenged, while the service was launched into a context of competing for existing scarce high-value facilities such as theatres. The abortion care pathway is a complex and fragmented care pathway and there is the potential for service users to encounter a diverse range of

personnel with diverse views along the way. The fragmented nature of care pathways also highlights that it is challenging to ensure consistency in a quality response. Implementing values clarification exercises comprehensively across the spectrum of the broad care landscape is highly challenging but represents a critical tool to advance normalisation and accessibility of services.

Considerations arising from the study findings are detailed in the final chapter below.



### Concluding Chapter

In this final chapter the study PI begins with a reflective section drawing together overarching insights from the process of carrying out this research across the four work packages of this study. This is followed by a discussion of the study's strengths and weaknesses. Matters for consideration by a range of stakeholders are then proposed having regard to the designation by the Department of Health of this study as informing the service user strand of the review of the operation of the Health (Regulation of Termination of Pregnancy) Act 2018.

#### 15.1 PI's Reflective Account

Starting out on this research journey following a GT method, it quickly became apparent to me as PI that the research focus, service user experiences, needed to be situated in context when interpreting meanings in the data. Researching a component – the service user perspective – of a new strand of health care during its implementation phase involves collecting and interpreting data in a continuously evolving context. While not striving to systematically document or analyse the context itself, I wanted to get a "handle on" the overall care landscape the service users were navigating. Thus, alongside the core activity of this research project of generating and interpreting interviews with service users, I engaged in supplementary activities to help the research team understand the context from which this data was emerging. The contextual work involved reading any publicly available policy and service documents, conducting formal interviews and focus groups with key informants, and learning from informal observations throughout the overall research process to glean this contextual overview. This component of the study was not systematic in the way the core research activity of generating and analysing qualitative data with service users was. Notwithstanding, I would contend that this work provided an informed vantage point of the evolving landscape of abortion care.

A number of features of the abortion care landscape struck me as salient to understanding service user accounts. The fragmentation of the model of care, wherein components are dispersed across different settings including the My Options helpline, GP surgeries, women's health clinics, private scanning facilities, and hospital units/clinics, wards and theatres, made for a complex landscape for service users to navigate. The implementation of the abortion care service presented as a process of "grafting" onto a complex primary and secondary health care model/setting; one that is acknowledged for being under-resourced and overstretched, meaning the service joins the fray of competition for scarce resources alongside all other elements of health care. Grafting the service on and integrating it with pre-existing care settings also entails a diverse and broad range of health service staff engaging with and providing the service. Some opt in to be centrally involved in this component of care, while others encounter it as part of the care provided in the setting where they work. Abortion care is acknowledged as a contested area of health care, and in the Irish health, social and cultural contexts, abortion was a continually contested legal, policy and rights issue over the past half century. A range of positions then can be expected to be held by those working in settings where abortion care is being implemented following legal change that significantly expanded provision and access.

In carrying out this research, I was principally guided by the grounded theory maxim of "remaining open" to seeing and understanding multiple vantage points and perspectives. As noted throughout the study, the findings and analysis set out in this report are centrally grounded in the data generated with women who used the service between December 2019 and August 2021, a time of considerable change in the service landscape itself. We were privileged to sit with women as they recounted this time in their lives when they sought abortion care from the Irish health service and are grateful to every person we met for the contribution they made to this study. We witnessed in this research a multiplicity of health professionals caring for women seeking abortion care, working hard and with commitment to ensure that care was responsive, compassionate and timely. While our data does not provide the robust evidence needed to allow us draw conclusions from a service provider perspective, we did note how aspects of the legislation negatively affected how health professionals could respond to service users. Criminalisation of doctors under the law did feature as having a chilling effect on the interaction between health professionals providing abortion care and people seeking abortion care. The absence of safe zones surrounding health care settings providing abortion care impacted health professionals themselves and decisions they made about how and if they could provide abortion as a service within their health setting. That said, our findings and conclusions set out in this report arise out of rigorous and systematic research with service users whose perspective is centrally placed in the analysis.

#### 15.2 Study Strengths and Limitations

This study has a number of strengths and limitations. This large qualitative research study sampled a diverse range of service users and settings, capturing the variety of people and places affected by the new legislation and changes in clinical practice. Qualitative sampling methodology is guided by the principle of "data saturation", one achieved through the iterative sampling and analytic process within this study. Service users were not paid to participate, so their participation was most likely driven by a desire to contribute to research and to share their personal experiences. The majority of participants were recruited through the health care system itself, either through their GP or their hospital, minimising a self-selection bias. Three participants referred themselves to researchers on learning about the study, but constitute a small component of the overall study sample so as not to skew the data.

This study used a semi-structured approach to interviews allowing for comparability between interview responses, but also the flexibility for a further level of depth to be explored within interviews, where specific topics were pertinent to individuals. Interviews took place either in person or remotely from participants' own homes or in settings of their choice, ensuring a safe and comfortable environment for the interview to take place, important given the potentially sensitive subject matter. A strength of this research is its novelty and timeliness. Interviews took place relatively shortly after enactment of the legislation and close to the time of accessing care, reducing the risk of retrospective bias and capturing in real time the variety of experiences in response to implementation of the new services.

There are a number of limitations worth noting. It is commonplace in qualitative research to involve the participants in the data analytic process. However, the research team decided not to ask participants to be involved in data analysis given the potentially sensitive nature of the qualitative interviews. Interviews often took place proximate to accessing care but researchers were aware that analysis and write-up would continue for some time. It was decided not to involve participants in data analysis so as not to potentially burden participants with continued involvement in the study. Instead participants were invited to contact the team for any reason after their involvement had ended.

Secondly, we do not know the socio-demographic details of people who did not wish to participate in this study, therefore we cannot know whether those who chose to take part in the research hold different views or have different experiences to those who did not. It is likely some difference exists, a problem in research with all human participants. Every effort was made, however, to have as inclusive a study sample as possible and the only exclusion criteria applied were based on age and capacity to consent. Indeed, this research sought a time extension to accommodate the inclusion of a higher-than-expected number of participants willing to take part.

Thirdly, the authors of this study are experts in qualitative research methods and applied social science. As private citizens, they have also been involved in abortion rights campaigns and the Irish Repeal campaign. Inherent within qualitative study design is the acknowledgement that those carrying out the research are an integral part of the research process. To separate the researcher from the final research product is neither possible nor desirable; rather, the researchers should strive to be transparent and critically self-reflexive (Galdas, 2017). The reflexive discussion in this chapter aims to account for the study Pl's own perspective on completion of this research.

The conclusions and implications from findings outlined below are drawn directly from service users' experiences of navigating often complex care pathways. These should be considered in conjunction with other strands informing the review of the operation of the 2018 Act including service provider research, the public consultation and wider policy and legislative analysis which will all inform conclusions reached by the Independent Chair. As regards implementation, some issues highlighted in our conclusions require further scoping alongside conclusions from other strands of the review to identify appropriate responses with reference to factors including feasibility, acceptability, infrastructure and cost. However, the conclusions reached here arise from the service user perspective and we would argue this is the central vantage point that should drive steps taken to practically address issues highlighted in this early implementation phase of the service affecting availability, accessibility, acceptability and quality of care.

#### 15.3 Study Conclusions

The overall experience of many service users was frequently described positively, with service users describing how abortions were attained following contact with My Options and referral to GPs, hospitals and other settings. We acknowledge that abortion care provision is relatively new and service establishment and delivery occurred within a relatively short time period. This research study collected data between December 2019 and August 2021, so it captured the service in the early stages of implementation. Abortion care in Ireland involves a number of different providers, each playing differing roles, and experiences of accessing abortions were affected by the degree of service provision fragmentation.

The conclusions set out below highlight issues for consideration within the review of the operation of the Act relevant to a range of stakeholders including the HSE and the Department of Health. Wider social and cultural factors feature as well as the context for the delivery of care.

#### 15.3.i Issues Addressed to the HSE

#### 15.3.i.i The Sexual Health and Crisis Pregnancy Programme (SHCPP)

The UnPAC study contributes to the emerging empirical evidence base for informing ongoing implementation of policy and delivery of care in this area. The range of findings in this study indicate a need for a knowledge translation framework that would harness the insights generated from the study data in a structured way to enhance the investment made by the HSE SHCPP in the UnPAC study.

The HSE Research and Development office<sup>19</sup> have developed a knowledge translation framework model that could be applied to the findings from the study to allow them receive full consideration by the full range of relevant stakeholders.

Specific issues arising in relation to crisis pregnancy counselling (CPC) and My Options come within the remit of the SHCPP.

#### 15.3.i.i.i Crisis Pregnancy Counselling

The SHCPP have lead responsibility for CPC services. Overall, those who chose to access counselling considered it valuable and supportive for a range of reasons, including providing reassurance, affirmation, validation, information, or as an opportunity to discuss their decision.

The study findings however highlight a broad misunderstanding amongst service users, whereby CPC is associated with decision-making regarding pregnancy outcome, possibly due to a legacy effect of the service provision and service type prior to legislative change. Many participants did not view counselling as relevant to their abortion care pathway or as necessary, as they had sufficient personal supports in place. We noted a potential mismatch between these understandings and those of service providers. Provision of CPC is currently attached to community-based services (although not GP services) as another legacy of how services were organised prior to legalisation of abortion in Ireland, and not to hospital settings where service users receive abortions after 12 weeks. Finally, in relation to remote counselling provision, providers, particularly WHCs, need to assess carefully how the information session/process call is introduced to avoid people potentially engaging with counselling without fully informed consent.

The place of counselling in the model of care should be reviewed to identify opportunities and pathways for counselling to best meet needs across the range of services. Data in this study regarding experiences of counselling and the My Options service should inform this review. This would help inform future funding of these services to ensure they are addressing need.

#### 15.3.i.i.ii My Options

My Options is serving people well in being a responsive, accessible, caring and continuous element of the care pathway for women and pregnant people. The My Options service is a component of the CPC that was adapted as part of implementing abortion services to act as a source of information on GPs providing care. In a future review of this element of CPC particular attention should be paid to:

- Clearly communicating the remit of the service and in particular its role as a source of information on providing GPs;
- · Using terminology accessible to all;
- Demand for this information service beyond current operating hours; and
- Whether the service could extend to operating as a central booking service, which would reduce the number of contacts needed for people to access care.

The data indicated interest by service users in a peer support initiative, whereby people in Ireland seeking abortion care services could consult a resource where other people in Ireland share their insights and experiences of using abortion services in Ireland. The SHCPP should consider whether such an initiative could be implemented as part of the crisis pregnancy counselling and support services.

## 15.3.i.ii Issues relating to s.12 Terminations for Consideration by HSE Primary Care Services and The National Women and Infants Health Programme (NWIHP)

NWIHP, under the governance of the Chief Clinical Officer, provides strategic direction and leadership for ToP services. The Programme convenes a Clinical Advisory Forum (CAF) and appointed a Clinical Lead for Termination of Pregnancy Services in 2020. The conclusions highlighted below raise issues for consideration principally by NWIHP in conjunction with other divisions of the HSE represented on the CAF, including Primary Care.

#### 15.3.i.ii.i Duty of Care for Non-Providing Doctors to Refer to My Options or other Provider

Our findings show that people seeking care who presented to non-providing doctors or hospitals were not always referred on to a service where they could access the care they wanted. Medical Council guidelines<sup>20</sup> updated in light of the 2018 Act specify that even where a person holds a conscientious objection to a treatment, they must inform the patient that they have a right to seek treatment from another doctor, and give the patient enough information to enable them to transfer to another doctor to get the treatment they want. A joint initiative by NWIHP and HSE Primary Care should be considered to ensure health care providers in primary and maternity care settings are aware of their duty of care to provide information and refer people seeking abortion services on to a setting where they can access care. My Options is an appropriate point of referral to transfer people seeking care.

#### 15.3.i.ii.ii Provision in Community Settings

Overall, an important insight from the data was the greater acceptability of locally based services. Overall, people were satisfied with the care they received from their provider. Many commended them on their non-judgemental and empathetic approach.

Findings show the symbolic importance of having care available locally that promotes accessibility and acceptability. Local provision of care counteracts a perception of termination of pregnancy as culturally unfamiliar and has the effect of people integrating it into their reproductive health choices where they had previously considered it culturally anathema. Local level provision of care enhanced people's capacity to engage with comprehensive reproductive health care. Notwithstanding, some avoided attending their own GP or a local GP to avoid being identified, and so the current model that allows GPs to provide for people not registered to their practice is important to retain. Our findings indicate widespread, numerous and diverse providers are necessary from an accessibility perspective.

The mix of community providers was endorsed in the data as people variously preferred GPs as providers with a generalist primary care expertise, or doctors in women's health clinics as "specialists" and experts in reproductive health. WHC providers are based in urban settings, and consideration should be given to supporting expansion of these providers regionally.

For GPs specifically, data indicates a balance to be struck between widespread availability of community-based providers and skilled, knowledgeable providers. Infrastructure for new and infrequent providers to be supported by more experienced providers can address the issues raised here. Peer support initiatives already informally implemented by committed providers such as START doctors (a task force comprised of doctors committed to helping women with unwanted, unplanned or crisis pregnancies) could be supported formally as a mentoring programme to support and encourage new providers. These could operate alongside mainstreaming of termination of pregnancy in medical training curricula, including for general practice.

<sup>20</sup> https://medicalcouncil.ie/news-and-publications/reports/guide-to-professional-conduct-and-ethics-for-registered-medical-practitioners-amended-.pdf

#### 15.3.i.ii.iii Provision in Hospital Settings

Community-based provision depends on hospital-based services for support through provision of scans or assessments, and offering a clear referral pathway for those needing hospital-provided termination of pregnancy for clinical and/or legal reasons and for those who experience complications following termination of pregnancy. Overall, participants described hospital-based care providers in administrative and clinical roles as non-judgemental, highly professional and maintaining good communication, with the effect of making women feel well cared for.

At present (July 2022) a significant proportion - almost half of maternity hospitals or units – do not provide termination of pregnancy services. Resource and values impediments to implementation within non-providing maternity hospitals should be assessed, and capacity built to facilitate provision. Evidence is needed on why abortion services are not available in each hospital, a question potentially addressed by service provider research strand of the Review.

#### 15.3.i.ii.iv Service User Informed Clinical Guidelines for Early Medical Abortion (EMA)

Specific issues emerged from our data in relation to shortcomings in information and clinical guidelines provided for service users of Early Medical Abortion Services. Patient perspective is a valid component in developing clinical guidelines, alongside clinical considerations. Experiences of self-managing early medical abortion in this data set demonstrate that care could be enhanced by integrating service user perspectives into a review of information protocols for service users and clinical guidelines:

- Information on what to expect in relation to pain, bleeding, passing products of conception and hormonal changes;
- Information on what to do if pill does not fully dissolve;
- Information on what to do if second medication does not work or take effect, including to call the My
  Options nurse helpline and take another set of pills around four hours later;
- Information on the role of blood testing to establish if termination is complete, to respond to criticisms in the data of this as a protracted means of managing queried failed abortion; and
- Guidelines regarding administration of repeat medical abortion or surgical abortion to manage incomplete terminations, given data showed how repeat medical abortion was experienced as protracted and distressing.

#### 15.3.i.ii.v Inpatient Facility in Model of Care

Our findings show that self-managing community-provided early medical abortion requires a person to have a safe, private place where they can care for themselves while administering the medication. The model of care assumes people have a safe home setting where they can self-manage their care. However, as women noted in interviews, this will not be the case for everyone. As well as there being clinical indicators to a person being referred to hospital for ToP services, other indicators should be included in this decision-making, for example homelessness, asylum or domestic abuse status. An assessment of whether the service user has an appropriate setting where they can self-manage an EMA should be carried out. Existing inpatient day-care facilities in community/primary care settings could be incorporated into the model of care to address the unmet need for inpatient facilities for administering EMA.

#### 15.3.i.ii.vi Provision of Scanning Services

Data indicates scanning services provided by private providers were neither acceptable nor accessible to service users. Reliance on private scanning providers should be reviewed (and we note this seems to be already underway).

Regarding hospital-based scanning services, co-location of scheduling and facilities for scanning of people in the abortion care pathway should avoid being co-located with people in advanced pregnancy wherever possible.

#### 15.3.i.ii.vii Facilities in Hospitals Providing Care under s.12

Hospital-based providers have made efforts to locate termination of pregnancy services in dedicated, private and appropriate settings, but in many instances are working within considerable constraints. As a result, our data showed how people attending services found settings out of the way or marginal. Colocating the service with gynaecology units or early pregnancy units should be considered. Data also highlighted concerns that in-patient facilities were not always considered most appropriate or acceptable to service users. Providing private rooms or confining accommodation for people admitted to hospital for this service to gynaecology and early pregnancy units should be considered. The issues raised in this study by service users regarding acceptability and accessibility of hospital based care should be considered by maternity hospitals and hospitals with maternity units at local level.

#### 15.3.i.ii.viii Access to Surgical Abortion in Hospital Settings

Study data indicates that while the medical method of abortion enhances access and acceptability in early gestational stages in particular, demand for availability in choice of method of termination featured. Availability of surgical methods of abortion, including manual vacuum aspiration, in Irish hospital settings is currently very limited and should be reviewed to achieve choice of method in all hospital settings. In particular, provision of surgical method in situations of failed medical abortion featured as the method often preferred by service users if clinically appropriate.

#### 15.3.i.ii.ix Normalising Abortion Services and Care

Our data shows how the legacy of the Eighth Amendment and social and cultural contestation regarding abortion in Ireland shape the experiences of people seeking abortion care since legalisation. The model of care implemented under the 2018 Act to provide termination of pregnancy services plays a critical role in normalising this aspect of reproductive health care by integrating it within wider reproductive health and maternity care pathways within existing community and hospital settings.

The timeframe for this study represented the early implementation phase of legal abortion in Ireland. Some features of the service reflect measures taken to establish provision, e.g. GPs offering appointments outside of usual surgery hours or confining access to details of providing GPs to the My Options helpline only. These are acknowledged as efforts devised to integrate what is often a contested component of health care into existing, general health care settings. Providers who played a leadership role within and across community and hospital settings deserve acknowledgement for detailed, considered, and extensive efforts taken to meet the needs of women seeking care during this establishment phase.

The challenge now is to move into a more consolidated phase of provision, where special measures can be phased out and services can be provided in more open and integrated ways. Enhanced integration of abortion services is driven by NWIHP, its partner programmes within the HSE, and the multi-sectorial CAF is a critical means to evolving normalisation of the service.

### 15.3.i.iii s.11 Health (Regulation of Termination of Pregnancy) Act 2018 as Implemented by NWIHP, HSE.

S.11 of the 2018 Act provides for legal termination where there is a condition likely to lead to the death of the foetus. The study data showed anguish and distress for people seeking care under this section of the Act in particular. As a general point, care experiences under this ground of the Act were characterised as involving protracted assessment periods, during which legislation has a "chilling effect" on communication and qualifying criteria are highly restrictive, such that a comparably high proportion of people continue to travel to access care following diagnosis of foetal anomaly.

A marked feature of the data was high levels of distress and anguish among people seeking care who felt that their circumstances had underpinned support for repeal of the Eighth Amendment and legalisation of abortion here, yet they were denied care under legislation as enacted and implemented.

### 15.3.i.iii.i Caring for Pregnant Person during Assessment for Qualification for Care under s.11 of 2018 Act

Extensive data were generated in this study about the impact on the pregnant person of the procedures followed while undergoing assessment as to whether they qualified for care under s.11 of the 2018 Act. To address these issues, NWIHP could undertake an exercise with physicians, midwives, and all professionals caring for people during the assessment process to review guidelines and practices regarding the following aspects of care:

- Reconfigure counselling resources relating to pregnancy and abortion so as to allocate more resources
  to people in hospital settings who are being assessed to determine if they qualify for care under s.11 of
  the Act, and also to provision of counselling following termination. We suggest this is done in the context
  of the proposed review of counselling services;
- Availability of specialist foetal medicine midwives in all sites (either in person or through telemedicine
  hub and spoke model) where testing for foetal anomaly to determine eligibility for termination of
  pregnancy is provided;
- Provide Provision of clear and detailed information about testing methods, timelines and procedures to people being assessed;
- Choice of either surgical or medical methods of termination in all providing hospitals for second trimester termination, if deemed clinically appropriate;
- Care negotiation of perinatal palliative and bereavement care protocol for each person to ensure full
  consent to participate in the process; and
- A detailed protocol signifying a person is undergoing assessment for foetal anomaly in all antenatal and
  maternity settings would alert everyone the person encounters that they are on this care pathway. Where
  possible, private facilities separate to maternity wards and delivery suites should be provided across this
  care pathway.

## 15.3.ii Issues to Consider As Part of the Review of the Operation of the 2018 Act

#### 15.3.ii.i Remote Consultations in Model of Care

This study's findings show how remote consultations, introduced due to COVID-19, increased accessibility in relation to geography, timeliness and acceptability of care. People appreciated the comfort of being at home in their own surroundings during consultations. Privacy was easier to safeguard while concerns such as childcare, transport and managing symptoms of sickness while travelling were eliminated. Data also

indicated that remote consultations did not detract from the quality of care reported by service users. Thus, the review of the operation of the 2018 Act should consider remote consultations be retained in the model of care on a permanent basis to make for an optimally accessible, responsive service

#### 15.3.ii.ii Mandatory Three-Day Wait

Data showed the mandatory three-day waiting period was inconsistent with concerns of women in the data set to access care in the most timely and accessible way. Data showed how this imposed delay on accessing care added stress and heightened anxiety among service users about certainty of accessing care. The review of the operation of the Act should consider these findings alongside service providers' perspectives on the regarding the effect of the mandatory aspect of the three-day wait. An alternative approach indicated by these findings are a model of care with up to three consultations to facilitate two consultations prior to administration of medication, if clinically necessary or preferred by service users but allowing for a single consultation prior to administration, with the third consultation being retained for aftercare.

#### 15.3.ii.iii Repeat Termination after 12 Weeks' Gestation

Blunt application of gestational age limits leaves people who begin a termination of pregnancy close to the 12-week gestational limit, and for whom the termination does not complete, unable to access repeat administration of the procedure. The Review of the operation of the Act should consider repeat termination after 12 weeks' gestation in these circumstances being provided for.

### 15.3.ii.iv Provisions Criminalising Providers from Health (Regulation of Termination of Pregnancy) Act 2018

Furthermore, data indicated criminalisation provisions in the 2018 Act have a chilling effect on how medical professionals engage with women during the care encounter, particularly when providing care under s.11 of the Act. The data also indicated benefit of widespread, numerous and diverse providers to ensure accessibility of care. Criminalisation provisions within the legislation have a potential chilling effect and may dissuade doctors from opting in as providers. This issue will be further explored in research with service providers to further inform the review of the operation of the Act. Given these findings regarding the impact of criminalisation on both accessibility and quality of care the effect of criminalisation provisions should be considered as part of the review of the operation of the Act

#### 15.3.ii.v Qualification Criteria for Care Under S.11 of the Act

The study findings showed how people receiving diagnosis of a serious foetal anomaly, often in the context of a much-wanted pregnancy, wanted continuity of care from their maternity care providers. Moreover, many expected termination of pregnancy would be available to them under the 2018 Act. To alleviate the distress and anguish witnessed in this study for people seeking termination of pregnancy following diagnosis of foetal anomaly, the review of the operation of the Act should consider the impact of the qualifying criteria. In particular, whether it has the effect of denial of care with consequences for the pregnant person's physical and mental health.

#### 15.3.iii Role of the Institute of Obstetricians and Gynaecologists

## 15.3.iii.i Guidelines Relating to s.11 2018 Reviewed to Remove Multidisciplinary Team (MDT) Assessment

Data shows that the qualification criteria under s.11 of the 2018 Act, and how it is being implemented under the current model of care, entail complex, protracted testing procedures exacerbated by limited genetic testing capacity. The data shows that the effect of this for people seeking care was to remove or diminish their capacity within the decision-making process regarding termination of their pregnancy. The model of care specifies involvement of a multidisciplinary team in assessing qualification under the Act. Research participants experienced this as their request for care being assessed by a distant and anonymous team. The review of the operation of the Act should take note of these findings and the effect of the MDT requirement under the clinical guidelines rather than requirement for assessment and certification confined to two physicians under Section 11 of the 2018 Act, to consider whether this would ensure a timelier and more contained decision-making process

## 15.3.iv Infrastructure of Data for Quality Assurance in Termination of Pregnancy Services

This research was commissioned by the SHCPP as a qualitative study of service user experiences, a valuable source of evidence for enhancing abortion care and services. While not a direct finding from the data, a general observation arising from the process of this research is that data to inform quality, accessible, acceptable and available care should be an integral part of service implementation plans. This corresponds with NWIHP's commitment to develop a quality assurance framework for termination of pregnancy services.

While the 2018 Act does envisage an infrastructure of data relating to abortion provision to inform annual reporting, what has been implemented to date is minimalist and falls well short of a data infrastructure to ensure access to quality and acceptable care for all. Currently data reported is limited to:

- · Date of abortion
- · County of residence
- · Legal ground for abortion
- · Medical Council registration number of provider.

This information provides no insights of value regarding service quality, acceptability, accessibility and availability. A more appropriate data infrastructure would comprise mandated data collection by hospital and primary care providers on services, to include at least the following data additional to that collected above:

- · Age of service user
- Gestation
- · Previous pregnancies
- · Previous abortions
- · Method of abortion
- Ultrasound referral
- · Complications experienced
- Contraceptive service uptake post TOP.

The data items should be continuously reviewed with reference to WHO guidelines for best practice in termination of pregnancy services data infrastructure.

As well as service activity statistics, the review of the operation of the Act should have regard to the adequacy of data infrastructure for abortion care services. An infrastructure of broader reproductive health and maternity care services research should be considered comprising:

- Service provider studies on adequacy of training, resources and service availability;
- Periodic service user surveys and qualitative studies to assess service quality, acceptability and access.

This overall infrastructure would provide a comprehensive, systematic evidence base for termination of pregnancy services within the context of broader reproductive health and maternity care.

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# Appendices

# Appendix 1a. Description of Stakeholder Interview and Focus Groups

Stakeholder/ Providers	Description	No. of One-to-One Interviews Conducted	No. of Focus Groups
	Representatives from the HSE involved in implementing the services	1	0
	Representative of the Irish College of General Practitioners	1	0
Policy and Service Level	Authors/Members of the Development Group of Interim Clinical Guidance relating to Risk to Life or Health of a Pregnant Woman in relation to Termination of Pregnancy of the Institute of Obstetricians & Gynaecologists	1	0
	Service manager	1	0
	Counsellors staffing My Options Helpline	0	2
My Options Service	Caredoc service manager and nurses staffing Freephone Helpline providing information and counselling provided by OneFamily	0	1
	Observation of service	1 day observation	0
Pregnancy Counselling Services	Directors of Counselling	3	0
WHCs	Clinical Directors of women's health clinics	2	0
WHOS	Early Medical Abortion co-ordinator or key administrator	2	0
General Practitioners	GPs who have opted in to provide abortion services under the 2018 Act from diversity of rural and urban areas and representatives of GPs on both closed and open list	4 (distributed between urban and local areas)	0
	Obstetricians leading ToP services	2	0
Hospitals	Administration supporting ToP service	3	0
	Directors of Midwifery/Midwifery staff providing ToP care	2	0
Support Organizations	Abortion Support Network Termination for Medical Reasons Individual Supporting Access in Ireland Focus Ireland	2	0
Total		24	3

# **Appendix 1b. Invitation to Participate**



### **ABORTION & UNPLANNED PREGNANCY CARE STUDY**

Dr Catherine Conlon of the School of Social Work and Social Policy at Trinity College Dublin is carrying out research to understand people's experiences of using abortion care services and unplanned pregnancy supports for the HSE Sexual Health and Crisis Pregnancy Programme. This is the first study of services since abortion care was introduced in Ireland in January 2019.

People using abortion care and unplanned pregnancy supports are being asked to take part by sharing insights on how well services are meeting people's needs. We hope to gather people's experiences through one-to-one confidential interviews with people who have recently used services. This includes people attending pregnancy counselling services, people attending GPs or women's health clinics for abortion care, and people attending hospitals for abortion care.

The study findings will inform the HSE in developing, planning and delivering services in the future. The law on abortion care (Regulation of Termination of Pregnancy Act 2018) will be reviewed in 2021 and people's views from this study will inform that review. This study is a chance for people to have a say on what unplanned pregnancy support and abortion care services and laws would best meet their needs.

The research team (Dr Catherine Conlon and Dr Kate Antosik-Parsons) are asking women and pregnant people attending services to consider taking part in this study. The first stage is to read the enclosed detailed information and, if you are happy to, complete the short form providing your name and contact details. This is so researchers can contact you to discuss the study further with you directly. Please return the form in the sealed envelope to your care provider today. The researchers will then be in touch by phoning you from the telephone number 089-701 0300. You may want to put this into your handset so you can recognise our number when we call.

## Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2. Éire.

# School of Social Work and Social Policy T: +353 1896 2001

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



This study is fully separate to your care and researchers will not tell care providers which people agreed or declined to be contacted. This is a new part of Irish health care and your views will be very important in making sure services are delivered in a way that best meets people's needs when dealing with an unplanned pregnancy.

If you would like to get in touch directly or to have any further information on this study please call us: Catherine Conlon and Kate Antosik-Parsons on 089-701 0300; 01-896 1312 or email <a href="mailto:conlonce@tcd.ie">conlonce@tcd.ie</a> or kantosik@tcd.ie.

## Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

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# **Appendix 1c. Invitation to Participate (electronic version)**



# **UNPLANNED PREGNANCY & ABORTION CARE STUDY**

Dr Catherine Conlon of the School of Social Work and Social Policy at Trinity College Dublin is carrying out research to understand people's experiences of using abortion care services and unplanned pregnancy supports for the HSE Sexual Health and Crisis Pregnancy Programme. This is the first study of services since abortion care was introduced in Ireland in January 2019. This research has ethics approval from Trinity College Dublin.

People using abortion care and unplanned pregnancy supports are being asked to take part by sharing insights on how well services are meeting people's needs. We hope to gather people's experiences through one-to-one confidential interviews with people who have recently used services. This includes people attending pregnancy counselling services, people attending GPs or women's health clinics for abortion care, people attending hospitals for abortion care, and people who have accessed abortion care outside Ireland.

The study findings will inform the HSE in developing, planning and delivering services in the future. The law on abortion care (Regulation of Termination of Pregnancy Act 2018) will be reviewed in 2021 and people's views from this study will inform that review. This study is a chance for people to have a say on what unplanned pregnancy support and abortion care services and laws would best meet their needs.

The research team (Dr Catherine Conlon and Dr Kate Antosik-Parsons) are asking people attending services to consider taking part in this study. The first stage is to read the enclosed detailed information, and if you are happy to be contacted by a researcher to discuss taking part, go to this link: https://tcdecon.qualtrics.com/jfe/form/SV\_es8D7330yh9XU3P

The electronic form allows you to send your contact details to the researcher so they can contact you to discuss the study further with you directly, and allow you to then decide if you will take part. After you complete the form, researchers will be in touch by phoning you from the telephone numbers 085-265 9637 or 083-805 9106. You may want to put these into your handset so you can recognise our number when we call.

## Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



This study is fully separate to your care and researchers will not tell care providers who agreed or declined to be contacted. This is a new part of Irish health care and your views will be very important in making sure services are delivered in a way that best meets people's needs.

If you would like to get in touch directly or to have any further information on this study please call us: Catherine Conlon on 085-265 9637 and Kate Antosik-Parsons on 083-805 9106 or email us at conlonce@tcd.ie or kantosik@tcd.ie.

## Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland

# **Appendix 1d. Invitation to Participate (BPAS Electronic Version)**

# Ref 2020/08/CON

REVISED 15 Feb 2021 - per advice from Patricia Lohr Invitation email drafted in conjunction with Donagh Stenson

Subject line: Help improve services for Irish Women

# Irish Unplanned Pregnancy and Abortion Care (UnPAC) Study

Here at BPAS we have been taking care of women from the Republic of Ireland for the 53 years we have been providing care. We have advocated and continue to advocate for women's rights and access to abortion in Ireland and we were happy to provide clinical and client experience evidence to the political processes that enabled the Eighth Amendment to your country's constitution to be repealed.

BPAS also takes part in clinical research and evaluations with the intention of improving access to and experience of the services we provide.

We are currently supporting the **Unplanned Pregnancy and Abortion Care Study**, funded by the Health Service Executive. **Dr Catherine Conlon of Trinity College Dublin** is researching people's experiences of accessing abortion care services for the Health Service Executive's Sexual Health and Crisis Pregnancy Programme. This is the first study of services since abortion care was introduced in Ireland in January 2019. They are gathering people's experiences through one-to-one confidential interviews by phone or video, including people who accessed abortion care outside of Ireland.

For more information on how you can take part please visit the website (link). BPAS is supporting the study but not conducting it. Your personal data has not been shared and it is your decision to take part.

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Many thanks,

**BPAS** 

# **Appendix 2a. Participant Information Sheet**



### **UNPLANNED PREGNANCY AND ABORTION CARE STUDY**

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to take part.

#### WHO I AM AND WHAT THIS STUDY IS ABOUT

I am Dr Catherine Conlon of the School of Social Work and Social Policy at Trinity College Dublin and I am carrying out this study on behalf of the HSE. The overall aim of the study is to understand people's experiences of using abortion care services and supports relating to unplanned pregnancy within the Irish health service. People using abortion care services and health professionals providing care for pregnant people, e.g. doctors, nurses and counsellors, will be asked to provide information on their experiences of using or providing the service from the perspective of meeting people's needs.

#### WHAT WILL TAKING PART INVOLVE?

Taking part in the research involves an interview, similar to a guided conversation, with a researcher who will ask about your experience of using abortion care and pregnancy support services. Topics covered will include: your prior knowledge of abortion care services, how you contacted services, the help and support you sought in contacting services, your views on how well your needs were met, accessibility of services to you, and other information you think policy makers and service providers should know when reviewing legislation providing for abortion care. Interviews can be conducted in a location of your choosing, e.g. the research team office, a private room in a local community centre, or your home. Interviews will usually last up to one hour. Interviews are usually digitally recorded and then transcribed and made anonymous for analysis. Once transcribed, the audio file will be deleted.

# WHY HAVE YOU BEEN INVITED TO TAKE PART?

You have been invited to take part because you are using the unplanned pregnancy support and abortion care services currently provided by the Irish health care system. All people using this service between November 2019 and April 2020 are being asked to take part in an interview for the study.

## Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

## School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



#### DO YOU HAVE TO TAKE PART?

Taking part is completely voluntary and you do not have to take part. If you do decide to be interviewed you have the right to decline to answer any question during the interview and to withdraw at any time without any consequence whatsoever. Taking part in this study or not will in no way affect your current or future care.

#### WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF TAKING PART?

Laws providing for abortion care and abortion care services were only recently introduced for the first time in Ireland. The law and services will be reviewed in 2021 and this research will inform that review. By taking part in the study you can inform policy makers and service providers about how the current abortion care and unplanned pregnancy support services met your needs and how you think the service can be changed or improved to better meet people's needs. Taking part in an interview will involve you discussing your pregnancy and reasons for using pregnancy support and abortion care services with a researcher. Talking about your overall experience all in one sitting may impact on you as you realise possible strains you were under and difficulties you have overcome. Researchers will provide you with referrals to professional support services who can help you deal with any emotions that taking part in an interview raises for you.

#### WILL TAKING PART BE CONFIDENTIAL?

Taking part in the study is completely confidential. The researcher will not disclose to your doctor, nurse or counsellor whether or not you took part in an interview. All references to information provided by people in the study in published research reports and papers will be fully anonymised so that no person can be identified. Anything you say in interviews will be kept strictly confidential unless the researcher has a strong belief that there is a serious risk of harm or danger to either the participant or another individual (e.g. physical, emotional or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity) or if a serious crime has been committed.

## HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

 Consent forms containing participants' names will be kept secure in locked filing cabinets in locked, private offices belonging to the Principal Investigator, Dr Catherine Conlon, within Trinity College Dublin.
 Consent forms will be stored separately to interview data so they cannot be linked.

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire. Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



- Audio recordings of interviews will be uploaded to computers and stored securely on passwordprotected computers accessible only to the research team listed below, supplied by Trinity College
  Dublin with security safeguards and located in locked, private offices within Trinity College. Once
  uploaded, audio recordings will be deleted from digital recorders. Once transcribed, audio recordings
  will be deleted from computers.
- Transcribed interviews will be anonymised to remove any identifiers to interviewees and will be stored securely on password-protected computers accessible only to the research team located in locked, private offices within Trinity College Dublin.
- After 10 years anonymised interviews will be deposited in a secure data repository to be available for future research related to this topic, with your consent.

#### WHAT ARE YOUR RIGHTS IN RELATION TO YOUR PERSONAL DATA?

Under freedom of information legislation, and data protection legislation, you are entitled to access the information about you at any time up until the point that the data is anonymised. Under the GDPR, you are also entitled to:

- · The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format
- The right to request deletion of your data.

You can exercise these rights by contacting your PI [Catherine Conlon at conlonce@tcd.ie] or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

### WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of this study will be presented to the HSE Sexual Health and Crisis Pregnancy Programme and the Advisory Group which comprises representatives of the Department of Health and the HSE, as well as other professionals involved in providing abortion care. The findings of this research will inform the review of the legislation providing for abortion care in Ireland (Health (Regulation of Termination of Pregnancy) Act 2018) which is scheduled to take place in 2021. By taking part in the study you can inform policy makers and service providers about how the current abortion care service met your needs and how you think the service can be changed or improved to better meet people's needs.

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



The researchers will also publish the results of this study in academic journals and papers to share the insights generated by this research. In all publications, research participants' anonymity and confidentiality will be fully protected.

#### DOES THIS STUDY HAVE RESEARCH ETHICS APPROVAL?

Yes, ethical approval for this research was provided by the Ethics Committee of the School of Social Work and Social Policy, Trinity College Dublin on 05/11/2019.

# WHO IS FUNDING THIS STUDY?

Funding for this study is provided by the Sexual Health and Crisis Pregnancy Programme of the HSE.

### IS THERE ANY PAYMENT FOR TAKING PART?

Participants do not receive any payment for taking part in this research.

# WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

For further information, please contact the research team:

Principal Investigator:

Dr Catherine Conlon, Assistant Professor in Social Policy, Trinity College Dublin Tel. 01-896 1312; 089-701 0300 or email: conlonce@tcd.ie

Research Officer:

Dr Kate Antosik-Parsons
Research Fellow, School of Social Work and Social Policy, Trinity College Dublin
Tel. 01-896 1312; 089-701 0300 or email: kantosik@tcd.ie.

### **THANK YOU**

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire. Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland

# **Appendix 2b. Participant Information Sheet (electronic version)**



#### UNPLANNED PREGNANCY AND ABORTION CARE STUDY

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Take time to decide whether or not to take part. You will then be asked to consent to be contacted by the researchers.

#### WHO I AM AND WHAT THIS STUDY IS ABOUT

I am Dr Catherine Conlon of the School of Social Work and Social Policy at Trinity College Dublin and I am carrying out this study on behalf of the HSE. The overall aim of the study is to understand people's experiences of using abortion care services and supports relating to unplanned pregnancy within the Irish health service. People using abortion care services, people who have accessed abortion care outside of Ireland, and health professionals providing care for pregnant people, e.g. doctors, nurses and counsellors, will be asked to provide information on their experiences of using or providing the service from the perspective of meeting people's needs.

## WHAT WILL TAKING PART INVOLVE?

Taking part in the research involves an interview, similar to a guided conversation, with a researcher who will ask about your experience of using abortion care and pregnancy support services. Topics covered will include: your prior knowledge of abortion care services, how you contacted services, the help and support you sought in contacting services, your views on how well your needs were met, accessibility of services to you, and other information you think policy makers and service providers should know when reviewing legislation providing for abortion care. Given the current social distancing guidelines in place, interviews will be conducted by telephone or video call. Interviews will usually last up to one hour. Interviews are audio and video recorded and then transcribed and made anonymous for analysis. Once transcribed, the files will be deleted.

# WHY HAVE YOU BEEN INVITED TO TAKE PART?

You have been invited to take part because you are using the unplanned pregnancy support and abortion care services currently provided by the Irish health care system or you travelled outside Ireland to access abortion care. All people using this service between November 2019 and December 2020 are being asked to take part in an interview for the study.

## Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



## DO YOU HAVE TO TAKE PART?

Taking part is completely voluntary and you do not have to take part. If you do decide to be interviewed you have the right to decline to answer any question during the interview and to withdraw at any time without any consequence whatsoever. Taking part in this study or not will in no way affect your current or future care.

#### WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF TAKING PART?

Laws providing for abortion care and abortion care services were only recently introduced for the first time in Ireland. The law and services will be reviewed in 2021 and this research will inform that review. By taking part in the study you can inform policy makers and service providers about how the current abortion care and unplanned pregnancy support services met your needs and how you think the service can be changed or improved to better meet people's needs. Taking part in an interview will involve you discussing your pregnancy and reasons for using pregnancy support and abortion care services with a researcher. Talking about your overall experience all in one sitting may impact on you as you realise possible strains you were under and difficulties you have overcome. Researchers will provide you with referrals to professional support services who can help you deal with any emotions that taking part in an interview raises for you.

### WILL TAKING PART BE CONFIDENTIAL?

Taking part in the study is completely confidential. The researcher will not disclose to your doctor, nurse or counsellor whether or not you took part in an interview. All references to information provided by people in the study in published research reports and papers will be fully anonymised so that no person can be identified. Anything you say in interviews will be kept strictly confidential unless the researcher has a strong belief that there is a serious risk of harm or danger to either the participant or another individual (e.g. physical, emotional or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity) or if a serious crime has been committed.

# HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

Consent forms containing participants' names will be kept secure on cloud-based storage in the form
of OneDrive, managed and approved by TCD IT services and protected by username, password and
two-step sign-in procedure. Consent forms will be stored separately to interview data so they cannot be
linked.

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire. Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



- Audio recordings of interviews will be uploaded to computers and stored securely on cloud-based storage in the form of OneDrive, managed and approved by TCD IT services and protected by username, password and two-step sign-in procedure. Once uploaded audio recordings will be deleted from digital recorders. Once transcribed, audio recordings will be deleted from computers.
- Transcribed interviews will be anonymised to remove any identifiers to interviewees and will be stored securely on cloud-based storage in the form of OneDrive, managed and approved by TCD IT services and protected by username, password and two-step sign-in procedure.
- After 10 years anonymised interviews will be deposited in a secure data repository to be available for future research related to this topic, with your consent.

### WHAT ARE YOUR RIGHTS IN RELATION TO YOUR PERSONAL DATA?

Under freedom of information legislation, and data protection legislation, you are entitled to access the information about you at any time up until the point that the data is anonymised. Under the GDPR, you are also entitled to:

- · The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you
- The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format
- The right to request deletion of your data.

You can exercise these rights by contacting your PI [Catherine Conlon at conlonce@tcd.ie] or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

## WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of this study will be presented to the HSE Sexual Health and Crisis Pregnancy Programme and the Advisory Group which comprises representatives of the Department of Health and the HSE, as well as other professionals involved in providing abortion care. The findings of this research will inform the review of the Legislation providing for abortion care in Ireland (Health (Regulation of Termination of Pregnancy) Act 2018) which is scheduled to take place in 2021. By taking part in the study you can inform policy makers and service providers about how the current abortion care service met your needs

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire. Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland

and how you think the service can be changed or improved to better meet people's needs. The researchers will also publish the results of this study in academic journals and papers to share the insights generated by this research. In all publications, research participants' anonymity and confidentiality will be fully protected.

#### DOES THIS STUDY HAVE RESEARCH ETHICS APPROVAL?

Yes, ethical approval for this research was provided by the Ethics Committee of the School of Social Work and Social Policy, Trinity College Dublin on 05/11/2019.

# WHO IS FUNDING THIS STUDY?

Funding for this study is provided by the Sexual Health and Crisis Pregnancy Programme of the HSE.

### IS THERE ANY PAYMENT FOR TAKING PART?

Participants do not receive any payment for taking part in this research.

### WHAT WILL HAPPEN NEXT?

To opt in you will need to click on the link below to send your details to the research team. https://tcdecon.qualtrics.com/jfe/form/SV\_8JmH6PPb8xERvWR

### WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

For further information, please contact the research team:

Principal Investigator:

### **Dr Catherine Conlon**

Assistant Professor in Social Policy, Trinity College Dublin

Tel. 085-265 9637; email: conlonce@tcd.ie

Research Officer:

#### **Dr Kate Antosik-Parsons**

Research Fellow, School of Social Work and Social Policy, Trinity College Dublin

Tel. 083-805 9106; email: kantosik@tcd.ie

# **THANK YOU**

# **Appendix 2c. Participant Information Sheet (BPAS Electronic Version)**



#### PARTICIPANT INFORMATION LEAFLET

### IRISH UNPLANNED PREGNANCY AND ABORTION CARE STUDY

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Take time to decide whether or not to take part. You will then be asked to consent to be contacted by the researchers.

#### WHO I AM AND WHAT THIS STUDY IS ABOUT

I am Dr Catherine Conlon of the School of Social Work and Social Policy at Trinity College Dublin and I am carrying out this study on behalf of the Health Service Executive. The overall aim of the study is to understand people's experiences of using abortion care services and supports relating to unplanned pregnancy within the Irish health service. People using abortion care services, people who have accessed abortion care outside of Ireland, and health professionals providing care for pregnant people, e.g. doctors, nurses and counsellors, will be asked to provide information on their experiences of using or providing the service from the perspective of meeting people's needs.

# WHAT WILL TAKING PART INVOLVE?

Taking part in the research involves an interview, similar to a guided conversation, with a researcher who will ask about your experience of using abortion care and pregnancy support services. Topics covered will include: your prior knowledge of abortion care services, how you contacted services, the help and support you sought in contacting services, your views on how well your needs were met, accessibility of services to you, and other information you think policy makers and service providers should know when reviewing legislation providing for abortion care. Interviews will be conducted by video call using Microsoft Teams or Zoom, or by telephone. Interviews will usually last up to one hour. Interviews are audio and video recorded and then transcribed and made anonymous for analysis. Once transcribed, the files will be deleted.

# WHY HAVE YOU BEEN INVITED TO TAKE PART?

You have been invited to take part because you are using the unplanned pregnancy support and abortion care services currently provided by the Irish health care system or you travelled outside Ireland to access abortion care. All people using this service between November 2019 and March 2021 are being asked to take part in an interview for the study.

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



#### DO YOU HAVE TO TAKE PART?

Taking part is completely voluntary and you do not have to take part. If you do decide to be interviewed you have the right to decline to answer any question during the interview and to withdraw at any time without any consequence whatsoever. Taking part in this study or not will in no way affect your current or future care.

#### WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF TAKING PART?

Laws providing for abortion care and abortion care services were only recently introduced for the first time in Ireland. The law and services will be reviewed in 2021 and this research will inform that review. By taking part in the study you can inform policy makers and service providers about how the current abortion care and unplanned pregnancy support services met your needs and how you think the service can be changed or improved to better meet people's needs. Taking part in an interview will involve you discussing your pregnancy and reasons for using pregnancy support and abortion care services with a researcher. Talking about your overall experience all in one sitting may impact on you as you realise possible strains you were under and difficulties you have overcome. Researchers will provide you with referrals to professional support services who can help you deal with any emotions that taking part in an interview raises for you.

## WILL TAKING PART BE CONFIDENTIAL?

Taking part in the study is completely confidential. The researcher will not disclose to your doctor, nurse or counsellor whether or not you took part in an interview. All references to information provided by people in the study in published research reports and papers will be fully anonymised so that no person can be identified. Anything you say in interviews will be kept strictly confidential unless the researcher has a strong belief that there is a serious risk of harm or danger to either the participant or another individual (e.g. physical, emotional or sexual abuse, concerns for child protection, rape, self-harm, suicidal intent or criminal activity) or if a serious crime has been committed.

# HOW WILL INFORMATION YOU PROVIDE BE RECORDED, STORED AND PROTECTED?

Consent forms containing participants' names will be kept secure on cloud-based storage in the form
of OneDrive, managed and approved by Trinity College Dublin IT services and protected by username,
password and two-step sign-in procedure. Consent forms will be stored separately to interview data so
they cannot be linked.

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire. Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



- Audio recordings of interviews will be uploaded to computers and stored securely on passwordprotected computers accessible only to the research team listed below, supplied by Trinity College
  Dublin with security safeguards and located in locked, private offices within Trinity College. Once
  uploaded, audio recordings will be deleted from digital recorders. Once transcribed, audio recordings
  will be deleted from computers.
- Transcribed interviews will be anonymised to remove any identifiers to interviewees and will be stored securely on password-protected computers accessible only by the research team located in locked, private offices within Trinity College Dublin.
- After 10 years anonymised interviews will be deposited in a secure data repository to be available for future research related to this topic, with your consent.

#### WHAT ARE YOUR RIGHTS IN RELATION TO YOUR PERSONAL DATA?

Under freedom of information legislation, and data protection legislation, you are entitled to access the information about you at any time up until the point that the data is anonymised. Under the GDPR, you are also entitled to:

- · The right to access to your data and receive a copy of it
- The right to restrict or object to processing of your data
- The right to object to any further processing of the information we hold about you
- · The right to have inaccurate information about you corrected or deleted
- The right to receive your data in a portable format
- The right to request deletion of your data.

You can exercise these rights by contacting your PI [Catherine Conlon at conlonce@tcd.ie] or the Trinity College Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.tcd.ie/privacy.

## WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results of this study will be presented to the HSE Sexual Health and Crisis Pregnancy Programme and the Advisory Group which comprises representatives of the Department of Health and the Health Service Executive, as well as other professionals involved in providing abortion care in the form of a final report of high academic publishable standard. This will be published by the Health Service Executive. The findings of this research will inform the review of the legislation providing for abortion care in Ireland

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire. Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



(Health (Regulation of Termination of Pregnancy) Act 2018) which is scheduled to take place in 2021. By taking part in the study you can inform policy makers and service providers about how the current abortion care service met your needs and how you think the service can be changed or improved to better meet people's needs. The researchers will also publish the results of this study in academic journals and papers to share the insights generated by this research. In all publications, research participants' anonymity and confidentiality will be fully protected.

## DOES THIS STUDY HAVE RESEARCH ETHICS APPROVAL?

Yes, ethical approval for this research was provided by the Ethics Committee of the School of Social Work and Social Policy, Trinity College Dublin on 05/11/2019.

## WHO IS FUNDING THIS STUDY?

Funding for this study is provided by the Sexual Health and Crisis Pregnancy Programme of the Health Service Executive.

# IS THERE ANY PAYMENT FOR TAKING PART?

Participants do not receive any payment for taking part in this research.

### WHAT WILL HAPPEN NEXT?

To opt in you will need to click the link sent to you and return your response before the end of February 2021.

# WHO SHOULD YOU CONTACT FOR FURTHER INFORMATION?

For further information, please contact research team:

Principal Investigator:

# **Dr Catherine Conlon**

Assistant Professor in Social Policy, Trinity College Dublin Tel. 01-896 1312; 085-265 9637; email: conlonce@tcd.ie

Research Officer:

## **Dr Kate Antosik-Parsons**

Research Fellow, School of Social Work and Social Policy, Trinity College Dublin Tel. 01-896 1312; 085-265 9637; email: kantosik@tcd.ie

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

## School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland

# Appendix 3a. Consent to be Contacted Form



#### UNPLANNED PREGNANCY AND ABORTION CARE STUDY

### CONSENT TO BE CONTACTED BY RESEARCHERS

I have read the information sheet provided describing the Unplanned Pregnancy and Abortion Care Study and understand what taking part in this study involves	Yes
I understand that information about my age, education and area of residence provided in this form will only be used by researchers to inform their selection of people for interview	YesNo
I understand that my information will be stored securely in locked filing cabinets in locked offices of the researchers in Trinity College Dublin to which only the research team have access	Yes
I understand that the information I provide here will be fully destroyed when this study is completed	Yes
I understand that by providing my name and contact details I am giving the researchers permission to contact me directly	Yes
I understand that I am free at any stage to withdraw from taking part in this study and that all information relating to me will be destroyed at that point	Yes
Age:  Education: Second level Leaving Cert Third Level _	
County of Residence:	

# PLEASE PROVIDE CONTACT DETAILS OVERLEAF

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



# UNPLANNED PREGNANCY AND ABORTION CARE STUDY CONSENT TO BE CONTACTED BY RESEARCHERS

Name:
Contact details (please provide one or more of the following options as you prefer):
Mobile phone:
_andline:
Email:
If you have any preferences as to day or time to be contacted by us, please provide details below:

# PLEASE PLACE THIS FORM IN THE ENVELOPE, SEAL AND RETURN TO YOUR CARE PROVIDER WHETHER YOU COMPLETE IT OR NOT.

THANK YOU

If you are selected to take part in the research, you will be contacted by the research team (Catherine Conlon and Kate Antosik-Parsons) within six to eight weeks of completing this form. Catherine or Kate will contact you using these phone numbers: 085-265 9637 or 083-805 9106. We may not be able to interview everyone, but would like to thank you for your interest in participating.

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland

# **Appendix 3b. Consent to be Contacted Form (electronic version)**



# UNPLANNED PREGNANCY AND ABORTION CARE STUDY CONSENT TO BE CONTACTED BY RESEARCHERS

I have read the information sheet provided describing the Unplanned Pregnancy and Abortion Care Study and understand what taking part in this study involves	Yes
I understand that information about my age, education and area of residence provided in this form will only be used by researchers to inform their selection of people for interview	YesNo
I understand that my information will be stored securely in locked filing cabinets in locked offices of the researchers in Trinity College Dublin to which only the research team have access	YesNo
I understand that the information I provide here will be fully destroyed when this study is completed	Yes
I understand that by providing my name and contact details I am giving the researchers permission to contact me directly	Yes
I understand that I am free at any stage to withdraw from taking part in this study and that all information relating to me will be destroyed at that point	Yes
Age:	
Education: Second level Leaving Cert Third Level _  County of Residence:	

## PLEASE PROVIDE CONTACT DETAILS OVERLEAF

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire. Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



Name:
Contact details (please provide one or more of the following options as you prefer):
Mobile phone:
Landline:
Email:
If you have any preferences as to day or time to be contacted by us, please provide details below:

PLEASE PLACE THIS FORM IN THE ENVELOPE, SEAL AND RETURN TO YOUR CARE PROVIDER WHETHER YOU COMPLETE IT OR NOT.

THANK YOU

If you are selected to take part in the research, you will be contacted by the research team (Catherine Conlon and Kate Antosik-Parsons) within six to eight weeks of completing this form. Catherine or Kate will contact you using this phone number: 085-265 9637. We may not be able to interview everyone, but would like to thank you for your interest in participating.

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland

# **Appendix 4. Study Consent Form**



# **Unplanned Pregnancy and Abortion Care (UnPAC) Study**

# Consent to take part in research interview

I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequences of any kind.	Yes No
I understand that I can withdraw permission to use data from my interview any time after the interview, in which case the material will be deleted.	Yes
I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.	Yes
I understand that participation involves an interview with a researcher at a location and time I arrange, of about one hour's duration.	Yes
I understand that I will not benefit directly from participating in this research.	Yes
I agree to my interview being audio and video recorded.	Yes
I understand that all information I provide for this study will be treated confidentially.	Yes

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland



I understand that in any report on the results of this research my identity will remain anonymous. This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about.	Yes No			
I understand that disguised extracts from my interview may be quoted in research reports, conference presentations and published papers presenting the findings of the study.				
I understand that if I inform the researcher that I or someone else is at risk of harm they may have to report this to the relevant authorities – they will discuss this with me first but may be required to report with or without my permission.	Yes No			
I understand that signed consent forms will be retained in cloud-based storage in the form of OneDrive, managed and approved by TCD IT services and protected by username, password and two-step sign-in procedure belonging to the Principal Investigator, <i>Dr Catherine Conlon</i> , within Trinity College Dublin and only the research team will have access to this data until 2022.				
I understand that a transcript of my interview in which all identifying information has been removed will be stored securely on cloud-based storage in the form of OneDrive, managed and approved by TCD IT services and protected by username, password and two-step sign-in procedure. After 10 years anonymised interviews will be deposited in a secure data repository within the EU to be available for future research related to this topic.				
I understand that under freedom of information legislation and data protection legislation I am entitled to access the information I have provided at any time while it is in storage as specified above.				
I understand that I am free to contact any of the people involved in the research to seek further clarification and information.				
I voluntarily agree to participate in this research study.				
Signature of participant Date				
I believe the participant is giving informed consent to participate in this study.				
Signature of researcher Date				

# Scoil na hOibre Sóisialta agus an Pholasaí Shóisialta

Dámh na nEalaíon, na nDaonnachtaí agus na nEolaíochtaí Sóisialta, Foirgneamh na nEalaíon, Coláiste na Tríonóide Baile Átha Cliath, Ollscoil Átha Cliath, Baile Átha Cliath 2, Éire.

# School of Social Work and Social Policy

Faculty of Arts, Humanities and Social Sciences, Arts Building, Trinity College Dublin, The University of Dublin, Dublin 2, Ireland

# **Appendix 5. Completed Data Protection Impact Assessment**

Data Protection Risk Assessment Template

Project Name: Abortion Care Study	Date: 08.10.2019
Project Owner: Catherine Conlon	Site: School of Social Work & Social Policy
Email address: conlonce@tcd.ie	Phone Number: 01-896 1312/089 7010300

# **Template Version Control**

Reference	Date	Author	Comments
2.0	May 2019	TCD DPO	

### **Risk Assessment Circulation**

Name	Date	Reviewed/Consulted
Project Manager Details	[Insert Date]	Reviewed/Consulted
Other Details	[Insert Date]	Reviewed/Consulted
DPO Details: Evelyn Fox, Deputy DPO (Research)	[22/10/2019] and 18/11/2019	Reviewed/Advised  Reviewed amendments made to PIL, consent and DPIA

# **Risk Assessment - Objective**

In line with the risk-based approach to data processing of the GDPR, carrying out a Data Protection Impact Assessment (DPIA) is not necessary for every processing operation. Instead, a DPIA is only mandatory where a type of processing is "likely to result in a high risk to the rights and freedoms of natural persons".

The Article 29 Working Party, consisting of the representatives from each data protection authority in the EU, has adopted guidelines on DPIAs and whether processing is likely to result in a high risk for the purposes of the GDPR. The guidelines are available <u>here</u>.

The Office of the Data Protection Commission has provided detailed information on DPIAs, available <a href="here">here</a>.

Not all processing activities will require a DPIA to be undertaken. It is recommended, therefore, that you review the examples listed below and answer the screening questions to determine if a DPIA will be necessary. In cases where it is not clear whether a DPIA is required, the Trinity College Data Protection Unit recommends that a DPIA is carried out, as it is a useful process to determine risks and support compliance with data protection law.

It is important to note that a DPIA is required as standard for research studies conducted at St. James's Hospital, Tallaght University Hospital and all clinical sites in which Trinity researchers are active.

If you require further assistance or advice you should contact the relevant Data Protection Officer:

Trinity College: dataprotection@tcd.ie

St James's Hospital: <u>research@stjames.ie</u>
Tallaght University Hospital: <u>dpo@tuh.ie</u>

# **Instructions**

You should complete all of the questions in this template and forward the completed document to the Unit to receive feedback on any risks identified and recommendations on the actions or controls needed to address those risks.

It is the responsibility of the School or Business Unit Project Manager as the ultimate risk owner to ensure that the required controls are put in place and to sign off on any risks arising from the processing.

The Risk Assessment should be updated when appropriate to reflect any material changes to the processing as the Project progresses.

# **Examples**

The following examples should be used to assess whether a particular processing operation requires a DPIA:

Examples of processing	Possible Relevant criteria	DPIA likely to be required?
A hospital processing patients' genetic and health data via the hospital information system.	<ul> <li>Sensitive personal data or data of a highly confidential nature.</li> <li>Data concerning vulnerable data subjects.</li> <li>Personal data processed on a large scale.</li> </ul>	Yes
Storage for archiving purposes of pseudonymised sensitive personal data concerning vulnerable data subjects involved in research projects or clinical trials.	<ul> <li>Sensitive personal data.</li> <li>Data concerning vulnerable data subjects.</li> <li>Possibly prevents data subjects from exercising a right or using a service or a contract.</li> </ul>	Yes
An organisation systematically monitoring its employees' activities, including the monitoring of the employees' workstations, Internet activity etc.	<ul> <li>Systematic monitoring of individuals on a large scale.</li> <li>Potentially excessive or unlawful processing of personal data.</li> <li>Data concerning vulnerable data subjects.</li> </ul>	Yes
The gathering of public Social Media data for generating profiles.	<ul> <li>Evaluation or scoring.</li> <li>Data processed on a large scale.</li> <li>Matching or combining of data sets.</li> <li>Sensitive personal data or data of a confidential nature.</li> </ul>	Yes
Processing of personal data from patients or clients by an individual physician, other health care professional or solicitor.	<ul><li>Sensitive personal data or data of a highly personal/confidential nature.</li><li>Data concerning vulnerable data subjects.</li></ul>	No

# **Project Details**

Project name	Abortion Care Study
Project owner(s)	Dr Catherine Conlon, School of Social Work and Social Policy, TCD
Project start date	Oct 8th 2019
Number of individuals whose personal data will be processed	30-50
IT systems used	MS Word; NVivo
Third parties involved (Provide details including information on the contractual arrangements in place and confirm what due diligence has been carried out)	N/A

## **Description of Project**

### ABORTION AND UNPLANNED PREGNANCY CARE STUDY

The HSE commissioned this research specifying the following objectives:

- To gather in-depth information from women who have availed of unplanned pregnancy support services and clinical abortion services in Ireland and medical professionals providing these services
- · To provide a comprehensive description of the experiences of women who have availed of services
- To provide a comprehensive description of the trajectories of women who have accessed abortion care.

Abortion care is available in Ireland since January 2019 and the study comes at an early stage of implementation. Key components of the abortion service are:

- Unplanned pregnancy counselling services
- GP settings
- Women's health clinic (WHC e.g. IFPA/Well Woman) settings
- · Maternity hospital/department settings.

A qualitative, grounded theory (GT) method will be used involving collecting data early using unstructured or lightly structured methods, starting analysis early to identify emerging concepts and processes and testing how these 'fit' as more data is generated.

Women using the abortion services and medical professionals delivering the service are key informants. Medical professionals include:

- Pregnancy counsellors
- GPs
- · Doctors in WHCs
- Obstetricians in maternity hospitals.

12-15 interviews with professionals will focus on challenges and issues encountered that have hindered or facilitated delivering care to women.

Qualitative interviews with women who have recently engaged with abortion care services will include:

- 1. Women attending unplanned pregnancy counselling services who may decide to continue the pregnancy or not, n = 5-10.
- 2. Women under 12 weeks' gestation seeking abortion care whose care pathway begins by consulting a GP or WHC doctor, n = 12-15.
- 3. Women over 12 weeks' gestation who qualify for abortion care under the 2018 Act, n = 3-7.

Women will be recruited during their engagement with support (helpline and counselling) and medical (GP/WHC or maternity hospital) services. A final assessment of optimum procedure for reaching women will be informed through piloting with health care providers.

# **Screening Questions**

Note: Each screening question should be answered, and you should add any additional, relevant question(s) dependant on the risk and/or processing operation(s) you are assessing. These screening questions will help you to identify if a DPIA is required and provide valuable insight into the processing operation risks and areas to focus on.

Screening Question	Yes	No	N/A	Notes
Does the processing require systematic and/or extensive evaluation (via automated means) of personal aspects of an individual(s)?			х	No systematic and/or extensive evaluation (via automated means) is involved in the study.
Will decisions be based on such evaluations that are likely to produce legal effects, or equivalent effects concerning the individual(s)			Х	
Is the processing on a large scale and/ or does it involve special categories of data (sensitive data)?		х		Data processing will be on a small scale and involves data generated during the course of the study, not any categories of data generated independent of the study.
Is the processing on a large scale and does it involve data relating to criminal convictions and offences?		х		
Does the processing involve systematic monitoring of a publicly accessible area on a large scale? (i.e. CCTV)		х		
Will the project involve the collection of new information about individuals?	Х			All data analysed for this project will be collected in interviews with people using abortion services or professionals providing the service.

Screening Question	Yes	No	N/A	Notes
Will the project compel individuals to provide information about themselves?		X		Individuals will not be compelled to take part in the study, they will only provide data to the study on the basis of fully informed consent.
Are you using information about individuals for a purpose it is not currently used for, or in a way it is not currently used?		X		The project will not be using information generated in any other way than through the study and participants will be informed fully about how that data will be used.
Is the information about individuals likely to raise high risk privacy concerns or expectations?	X			Abortion is a sensitive and private issue and participants are likely to expect full confidentiality relating to their data.

Will information about individuals be disclosed to organisations or people who have not previously had routine access to the information or a third-party without adequate safeguards in place?	X	The data generated in this project will be kept secure and confidential and not disclosed to any organisations or people without adequate safeguards, e.g. through well managed Open Scholarship mechanisms.
Does the processing involve the use of new technology or systems which might be perceived as being privacy intrusive?	х	
Could the processing result in decisions being made or action being taking against individual(s), in ways that could have a significant impact on them?	х	

Screening Question	Yes	No	N/A	Notes
Will the project require you to contact individuals in ways which they may find intrusive?	x			The information about this study and request to give consent to take part in the study will be circulated to women by health care and support professionals they are in contact with for the purposes of accessing abortion care. Participants will not usually expect research to be underway. The project team in conjunction with the HSE will carry out an information awareness campaign to raise awareness that HSE-funded research is underway with women using abortion services so as to reassure women that the project is legitimate. Women will not be asked to provide consent or not to taking part in the project in the presence of health care professionals to safeguard their privacy.
Will any of the processing activities make it difficult for the data subject(s) to exercise their rights?		х		Women's involvement in the study or not will be kept confidential from service providers and the study will not interfere with service users' exercise of their rights.
Will the operation involve processing considerable amounts of personal data at regional, national or supranational level, which could affect many data subjects?		X		
Will the processing involve individuals who are considered 'vulnerable'?	х			Women as a group seeking abortion care are not a vulnerable group in their own right but some members of the cohort may be rendered vulnerable during this time by personal circumstances.
Does the processing operation involve any significant risk of the personal information being leaked or accessed externally?		Х		The research team will adhere to best research practice as regards safe-guarding, storage and anonymising/pseudonymising data.

# **Personal Data**

List the types of personal data that will be collected, used, accessed or shared for the purpose of the Project.

Data Collected	Justification	Processing Activity
Participant names	To arrange and conduct qualitative interviews with individuals requires knowing their names.	Transcribed using MS word, situated in C-drive on PI's password-protected desktop computer in locked private office at School of Social Work and Social Policy site.
Written consent	Ethical and legal basis for collecting, storing and analysing data.	Paper forms, stored in locked filing cabinet in Pl's locked private office in School of Social Work and Social Policy site. Access restricted to Pl and post-doctoral researcher(s) only.
Demographic data (age, area of residence, education level) collected in pro-forma at participant recruitment stage.	This information will be used to inform sampling decisions and allow for demographic profiling of sample.	Data will be anonymised including names changed, age recorded in age-band categories and area of residence recorded at county level. Stored in collated tables generated on MS Excel and Word, situated in C-drive on Pl's password-protected desktop computer in locked private office at School of Social Work and Social Policy site.
Audio files of unstructured interviews with service providers and people using abortion services.	Data used for analysis to answer research questions.	Transferred from audio recorder onto C-drives on research team's password-protected computers stored in locked private offices at School of Social Work and Social Policy site. Permanently deleted from audio recorder immediately after transfer. Transcribed into MS Word, following which audio files will be permanently deleted.
Text files of unstructured interviews with service providers and people using abortion services transcribed from audio files referred to above.	Data used for analysis to answer research questions.	Transcribed using MS Word/alternative text format. Anonymised by removing all identifying information and changing names of participants. Stored on C-drives on research team's password-protected computers stored in locked private offices at School of Social Work and Social Policy site. After 10 years anonymised interviews will be deposited in a secure data repository within the EU to be available for future research related to this topic.

# **Lawful Basis - Ordinary Personal Data**

If processing 'Ordinary' personal data then you must satisfy at least one of the lawful bases as set out under <a href="Article 6 GDPR">Article 6 GDPR</a>:

Consent	
Performance of a contract	
Legal obligation	
Public interest or exercise of official authority	Χ
Vital interests of data subjects	
Legitimate interests	

If using Consent, then describe the consent process and attach supporting documentation.

# **Lawful Basis - Sensitive Personal Data**

Sensitive personal data is defined as:

- Processing of personal data revealing
  - racial origin
  - ethnic origin
  - political opinions
  - religious beliefs
  - philosophical beliefs
  - trade-union membership
- Processing of genetic data for the purpose of uniquely identifying a natural person
- Processing of biometric data for the purpose of uniquely identifying a natural person
- Data concerning health
- Data concerning a natural person's sex life
- Data concerning a natural person's sexual orientation

If processing sensitive personal data then, in addition to the Article 6 lawful basis, you must also satisfy one of the conditions as set out under Article 9 GDPR:

Explicit Consent	X ( safeguard)
Employment / DSP rights	
Vital Interests of the data subject or another person	
Carried out (internally) by a not-for-profit organisation	
Information that has been already made public by data subject	
Necessary for the establishment, exercise or defence of legal claims	
Necessary for substantial public interest	
Necessary for the provision of medical care/ administration	
Necessary for reasons of public interest in the area of public health	
Archiving purposes in the public interest/ Scientific or Historical Research purposes/ Statistical purposes	X

If using Explicit Consent, then describe the consent process and attach supporting documentation.

# **International Data Transfers**

Will the data be transferred or stored outside the EEA at any point or placed with Cloud providers that store data outside the EEA? Provide details.

Description of data transfers
No

If you are transferring personal data outside of the EEA have you ensured that suitable conditions for transferring the data are in place? Provide details or state if unsure:

Adequate jurisdiction	
US Privacy Shield	
Standard Contract Clauses	
Binding Corporate Rules	
Authorisation from the Data Protection Commission	
Unsure	

# **Data Retention**

How long will the data be retained for and why? Provide details.

# Data retention

Data will be retained by the Trinity College Dublin research team for 10 years in the following format:

Transcribed interviews will be anonymised to remove any identifiers to interviewees and will be stored securely on password-protected computers owned by the research team located in locked, private offices within Trinity College.

After 10 years anonymised interviews will be deposited in a secure data repository to be available for future research related to this topic. This is in the interests of supporting Open Scholarship and the FAIR framework for Findable, Accessible, Interoperable and Reusable data. Provision for each of these components is considered in turn below.

#### Findable:

The PI will deposit (meta)data into accredited, searchable data repositories at national level and European level. (Meta)data will be assigned a globally unique and persistent identifier, that will be clearly and explicitly included. Data will be described with rich metadata devised with the support of TCD Library and Information expert staff.

#### Accessible:

Metadata will be retrievable by identifier using a standardised communications protocol that is open, free, and universally implementable and allows for authentication and an authorisation procedure. Data not classified as critical confidential will be fully open and accessible, e.g. policy documents; situational, relational and positional maps; policy interviews. Data classified as critical confidential, particularly transcripts of qualitative interviews and related materials, will be deposited under Restricted Access. Files will only be made publicly available and sharing will only be possible on the basis of the approval of the PI on grounds that confidentiality of participants is safeguarded in adherence with ethical approval governing the original project. FAIR accessibility of the data set will still be striven for within the Restricted Access process which involves the absence of FAIR publication of the data itself through the publication of rich metadata to facilitate discovery, including clear rules regarding the process for accessing the data.

### Interoperable:

Metadata will be developed according to principles of formal, accessible, shared, and broadly applicable language for knowledge representation developed with the support of TCD Library and Information expert staff. Metadata will use vocabularies following FAIR principles including qualified references to other (meta)data.

#### Reusable:

Meta(data) will be richly described with a plurality of accurate and relevant attributes developed with the support of TCD Library and Information staff. (Meta)data will be released with a clear and accessible data usage license associated with detailed provenance and in formats that meet domain-relevant community standards.

# **Data Subject Rights**

What plans are in place for responding to a request from an individual in relation to their data protection rights?

## These include:

- right of access;
- right to rectification;
- right to erasure;
- right to object to processing based on legitimate or public interest;
- right to data portability;
- right to object to profiling or making decisions about individuals by automated means.

# Data Subject rights requests

## Right of Access:

Research participants are informed on information sheets and consent forms that they have the right to access their data at any time. A register of pseudonyms and individuals' names will be retained separate to the interview data to allow the PI identify which anonymised interview relates to any individual participants should a request be submitted. This key will be retained for one year following publication of the research report, after which it will be deleted.

### Right to rectification:

Participant wishes to change/rectify any of the data held relating to them will be complied with as the data generated from the study is the views and opinions of the participants and they are entitled to change these at any time.

# Right to Erasure:

Participants will be informed that they have the right to withdraw their interview data in full or part at any time during the project.

# **Training**

What guidance and training will be provided to individuals involved in this project or activity to enable them to understand their data protection responsibilities? Provide details.

# Data protection training

All researchers working on this project will participate in TCD's GDPR online training in advance of beginning work on the project.

# **Processing Risks**

Describe the source of risk and nature of potential impact on individuals. Include associated Compliance and Corporate risks as necessary.

	Risk rating			
Risk detail	(High, medium, low)	Solutions/Mitigating Actions	Effect	Outcome
Hacking into computers where project data is stored.	Low	All computers storing data are password protected. The external hard drive and remotely accessible computer are also encrypted and locked in an office on Trinity's campus. Access is restricted to designated research project staff only.	Reduced	Low
Accessing filing cabinets where project data is stored.	Low	All filing cabinets storing data will be locked and held within the private, locked office of the PI. Access is restricted to designated research project staff only.	Reduced	Low
DPO Advice 30 October 2019		19/11/2019		
Governance DPO requests sight of HSE contract.	Low	DPO has contract for records. DPO will review and revert if any amendments required.	Reduced	Low
<ol> <li>Transparency</li> <li>Data subject rights were missing from original information leaflet – needs to be amended as I have advised.</li> <li>Consent must be granular in compliance with GDPR.</li> </ol>		Amended in line with GDPR.	Reduced	Low
3. As this is health research – explicit consent is required – fully informed, unambiguous, affirmative (tick each section).		Amended in line with GDPR and HRR.	Reduced	Low
2. Categories of data being collected DPIA needs to be amended to reflect all categories of data being collected – as outlined in the procedure document (some demographic data, audio and transcripts of interviews (pseudonymised).	Low	Amended.	Reduced	
3. Data retention Some confusion over whether data being kept is anonymised irreversibly or coded (pseudonymised). PI to confirm and amend throughout to reflect which is being retained.	Low	PI response: Data will be pseudonymised for one year following the publication of the report to facilitate research participants accessing or seeking amendments to their own data. After this point, the key will be deleted and the data retained in a fully anonymised format.	Reduced	Amended in information leaflet

4. Explicit consent
Can only be obtained from
health practitioner – as this is
health research – research team
cannot contact individuals for
pre-screening. This would be
in contravention of the HRR.
Relationship exists between
individual and their care team.

Medium

PI Response:

team.

The consent process for this study is designed to ensure health practitioner will not know whether or not a woman has agreed to participate in the study. This involves a two-stage consent process. In the first stage, the health practitioner asks the woman would she give consent to the researcher contacting her to fully inform her of the study and seek her consent. At this first stage the woman will have read the information sheet and will return a pro-forma where she has provided demographic data (age, education, and area of residence), name and contact details of either telephone number and/or email. The second stage of the process entails the researcher contacting the woman, reiterating the full information sheet and completing the explicit consent process. This process is designed to avoid their care team having knowledge of whether or not a woman participated to safeguard anonymity and avoid any potential risk of participants' decision to participate in the study or not impacting on their care relationship with their care

Reduced – clear health practitioner has link to patient initially Low

# Appendix 6. Codebook used for analysis of emails to WoW by people in Ireland in 2019 and 2020

Core Theme	Sub-theme	Example
No local provision B1  Necessity to travel B2		"abortion is available in Ireland but barely any doctors provide it espically in the country side the nearest is 3 hours on a bus."
		"the clinics are not within travel distance for me."
Barriers to	Childcare B3	"At the moment it is very difficult for me to get into a clinic as I do have any childcare or anyone to take my children for me."
accessing Migrant/ services on holidays/ overseas B4	"I am not legal here nor I don't have a Gp"	
	Financial concerns B5	"I can't afford 4th child."
	No GP/PPSN B6 (see also A2)	"have no access to free medical care ie a medical card that's why I opted for women on web."
	Lack of clarity on legal provision – general A1	"They only provide abortion in exceptional circumstances in Ireland"
legal provision – financial A2 (see also B5) Doctors embedded in the community A3 GP as gatekeeper to services	financial	"it is not free as the GP requires €450 for the 3 visits. I simply cannot afford this, even if I stretched myself as thin as I could go."
	embedded in the community	"I know it's legal here in Ireland but I'm not in a situation where I can go to my GP as my GP is a family friend and I don't want anyone finding out about it."
	gatekeeper to	"went to my G.P today and asked about abortion she said I need to get 3 counselling sessions. I can't let me partner know and if I take time off work on three occasions he'll know."
Accessing abortion at primary level	Knowledge of GP's negative stance A5	"my gp was very much against abortion becoming legal in Ireland so I wouldn't feel comfortable explaining to him that I am not able to provide for a third child when I already have two that he sees regularly!".
Need to keep private/secret A6  Fear of judgement A7	"I would like to receive discreetly, me and my partner would not like to tell anyone as some family members would not agree with our decision"	
	judgement	"My family are not in favour of abortions and I would prefer to handle the situation myself"  "I don?t want to do my abortion in a clinic as I?m scared about judgement and protestors. I feel more comfortable doing it at home without judgement where my partner can support me."  "The clinic I attend is attended by my whole family. I feel like I would be judged by going there and I don't think that I'm strong enough for that right now.  I feel comfortable doing it in the safety of my own home and not being questioned by others about my decision."  "I am afraid to get one off gp or hospital as ill be judged by my doctor and protesters and i also dont want anyone to know in my family"

"I do not want to go and explain to my doctor because I find her very judgmental" "for years it has been illegal and a lot of people especially the older generation disagree with abortion in Ireland and I on't want to feel guilty for making this choice. I feel it will be the next generation that will feel safe and unjudged in Ireland for making this decision. This is my decision and I don't want anybody to know that I am making it."  "I also do not want to access an abortion via a clinic or my GP as I feel ashamed that I have to make this decision as I cannot care for a baby at this time."  "I live in a very small town and I don't want anyone to know that this is my decision. Even my gp. I own my own business and I feel I will be judged by this choice even now."  "I just want to keep it private and dont want to b judged."  "I would love to keep this private and I don't want to be judged out there"  "I don't want to go to a local GP here, it's a very small town in the country and people will know. I already rang one and she was very judgemental and questioning."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around abortions in my local area."  "there is a lot of stigma around a wailable in Ireland no but I feel that there is still alot of stigma and I don't want to pay parents to know. I just want to be able to do this at home like the last time. I'm a private person at the best of times and this is a very private matter."  "I don't want to have one here there is still alot of stigma and I don't want my parents to know. I just cannot ge	Core Theme	Sub-theme	Example
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Core Theme	Sub-theme	Example
		"I really don't want to have any contact with anyone in Ireland as the country is too small and I don't want to be on a clinical register."
		"I cannot available of an abortion in Ireland as it will be on my medical records and due to my job is can't have this on my records"
		"I live in rural Ireland in the North West in a small town. I am part of the religion and one of our members works in the Hospital as a Consultant. My fear is that my decision will be found out and in the faith ,abortion is punishable by excommunication."
		"abortion is available in Ireland now.I am aware of this but my reason for not taking that route is because I do not want it on my medical file and want it to be kept very private"
	Mistrust in the medical system	"I actually would prefer to go through the confidential service that Womennin web offer. I don't feel I can trust doctors at this point."
	A9	"I am terrified of of the stigma caused by having abortion on my medical record here in Ireland"
		"I live in a very small community where Evan the most confidential information leak and this is a matter that I would like to keep very much private."
		"I don't want anyone knowing about this. People are still protesting outside hospitals carrying out abortions in Ireland alot of peoples private info has been made public because of this"
		"If I go to my gp for the pill, it will be on my medical records. I don't know what the full impact is to having it on my records."
		"I don't want my doctor or husband to know I'm pregnant that's why I don't want to go to my gp. Also it will go on my doctors record that I have had another abortion and I don't want that."
		"private information being leaked and also being followed by protestors."
		"I also want privacy away from protestors and i dont want to be seen around there as my family is extremely religious and I'd be disowned if they knew i was pregnant before marriage."
		"There are people picketing outside hospitals here in Ireland and videoing people still. I need to do this privately"
	Fear of protestors A10	"I still feel there is a lot of stigma here in Ireland against abortion, at the moment there are a lot of protesters and this makes me very uncomfortable, and I also feel unsafe.
		My parents are also very against abortion and I fear that if I have the procedure locally they will find out."
		"unfortunately there is still a lot of stigma around abortion in my country and some public naming and shaming I would not be comfortable to go to my GP for help in this situation due to my religion and the community I live in there is still a lot of stigma"
Preference for telemedicine services	Maintaining privacy P1	"I don't feel comfortable going to my GP and would much rather prefer to do the abortion privately."  "I would prefer to do this in private as it very personal and not have anybody know. I am confident that this is the best and most discreet route for me."
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	Friend/partner with them during procedure P2	"I would prefer to carry it out at home with my husband alone."  "I would like to keep this pregnancy discrete and handle the abortion in the comfort of my home and under the supervision of my best friend who'll be with me."

	"The reason I want to buy abortion pills online is that I am in an abusive situation
Abusive relationship P3	with my boyfriend. I am trying to end the relationship with him but he wont allow me and said that he would make me pregnant to stay. Which he did and I have no job and just left school. I cant go on with this."  "I can not access abortion at my local GP due to ongoing issues with the abisive ex who made me pregnant."  "I can not get an abortion in Ireland because I can't leave my house unless my husband or children Are with me Abortion is against my husbands strong Islamic beliefs I have to do this privately if he was to find out I fear what he may do."  "I cannot get an abortion over here as my partner is abusive . He always wants to know where I am and there's no way I'd get away with gettling one over here ."  "I have been living abroad in Spain for the last 4 years and have had to make a sudden flea to come back home to Ireland due to an abusive and controlling boyfriend who is still trying to watch my every move. I have to be very discreet and careful"  "i'm afraid If i try to access it here my abusive partner will find out"  "I am in an abusive situation with my boyfriend. I am trying to end the relationship with him but he wont allow me and said that he would make me pregnant to stay. Which he did and I have no job and just left school."  "I am in an abusive relationship i can't go to my GP without him knowing i want to leave, my 2 kids are 12 and 17 and old enough for us to get out . The abortion service here is by phone consultation I'm not gonna be on my own long enough without him knowing what's going on."  "I'm in a abusive relationship and would prefer to avail of the abortion pill please as I'm living with my partner, he has complete control, we are unemployed and I literally cant even leave the house to do food shopping without him. He is all in favour of my pregnancy which in his eyes will tie me to him for the rest of our lives. I can't go through with it. I would not be able to get away to have the abortion by the hse without him finding out."  "I am trapped in a very volatile relationship
	"I am in a controlling relationship and am too afraid to go to the doctor or hospital
	as my boyfriend will notice"
More comfortable at home P4	"I just want to do it in the comfort of my home"  "I just wanted to take care of my own abortion at home without all the stress of appointments"
Time constraints P5	"I really don't want to drag things along which is another reason I've opted for the tablets."  "I don't want the fetus to get more developed so taking the tablets at home without having to go and see a costly GP is really the best option for us."
	More comfortable at home P4

Core Theme	Sub-theme	Example
COVID-19	Travel restrictions C1	"I am currently in isolation for 2 weeks after travelling so cannot access the services in Ireland now and I don't want to wait until after I have completed the isolation period."  "Due to COVID19 I have no way of travelling a distance to go to a clinic to receive the medical abortion pill. I am a single mother and I would be putting myself and my child at risk making the journey to do so."
	Childcare C2	"At the moment it is very difficult for me to get into a clinic as I do have any childcare or anyone to take my children for me. Children are not suppose to be on public transport either.
	Revised model of care C3	"the abortion service here is by phone consultation and I'm not gonna be on my own long enough without him knowing what's going on."
Other reasons	Revised model of care C3 Family complete O1 School/student O2 Rape O3 Not ready O4	"the abortion service here is by phone consultation and I'm not gonna be on my own long enough without him knowing what's going on." "I'm 37 yrs old and have 4 kids my family is complete." "I want to finish school."



