



## 'Still travelling': Access to abortion post-12 weeks gestation in Ireland

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### ABSTRACT

This article focuses on access to abortion in Ireland post-12 weeks gestational age. It critically examines abortion access under the legislative sections 9, 10 and 11 of the Health (Regulation of Termination of Pregnancy) Act 2018, the Multi-Disciplinary Team (MDT) process, as well as the appeals process in place. We highlight existing ambiguities in diagnosing and certifying cases of risk to health during pregnancy, particularly mental health, as well as the challenges in diagnosing and certifying cases of fatal fetal abnormality (FFA). The article incorporates service users' experiences in obtaining abortion in Ireland post-12 weeks, particularly in cases of FFA, and includes recommendations for policy and legislative change.

### Background

In 1983, Ireland introduced a constitutional ban on abortion, which was not lifted until 2018. Grassroots advocacy organisations in Ireland pushed for legislative reform which eventually led to a referendum (Carnegie & Taylor, 2015; Chakravarty et al., 2020). In May 2018, 66.4 % of the Irish population voted to remove the Eighth Amendment from the Constitution, which allowed Ireland's abortion laws to move in line with most other European countries (Lavelanet et al., 2018). Abortion is now permitted in Ireland on request up to 12 weeks gestation, and after 12 weeks in cases of risk to the health or life of the woman or fatal fetal anomaly (FFA).

A number of recent studies have focused on the implementation of the service in Ireland, mainly focusing on access under 12 weeks gestation (Mullally et al., 2020; Horgan et al., 2021; Dempsey et al.,

2021; Mishtal et al., 2022). The UnPAC study, funded by the Irish Health Service Executive (HSE), found that many women are still travelling abroad for abortion care, particularly those with fetal anomalies (Conlon et al., 2022). Research by a grassroots feminist organisation, the Abortion Rights Campaign (ARC), reported that hospital services were inadequate, staff were lacking in training, and many were still travelling abroad to access abortion (ARC & Grimes, 2021). The World Health Organization (WHO) study, on which this paper is based, outlined that capacity, limited staffing, workload burden, and inadequate facilities acted as a barrier to establishing TOP care in Irish hospital settings (Stifani et al., 2022). Other research has also raised issues of sustainability and burnout of the service (Dempsey et al., 2021; O'Shaughnessy et al., 2021).

While some research exists on access to abortion under FFA in Ireland (Power et al., 2020, 2021; O'Shaughnessy et al., 2021), primary

**Abbreviations:** FFA, Fatal Fetal Anomaly; HSE, Health Service Executive; OBGYN, Obstetrics and Gynaecologist; SU, Service User; TOP, Termination of Pregnancy; MDT, Multi-Disciplinary Team; WHO, World Health Organization.

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data from service users with fetal anomalies are lacking, and more research is needed on access to abortion under grounds 9 and 10. Specifically, Power et al. (2021) found challenges with the interpretation of the legislation, particularly, in determining if a fetal anomaly is fatal within 28 days of life. Drawing on qualitative in-depth interviews with medical practitioners, key informants, and service users, this paper supports the findings by Power et al. but further explores the objectivity in defining a fatal diagnosis by examining the ambiguities in the interpretation of the legislation, as well as problems with the implementation of second-trimester services, and how this impedes abortion access. This article is part of a larger study funded by the WHO, which set out to analyse the implementation and sustainability of an expanded abortion service, examine the barriers and facilitators to the implementation process, and identify policy implementation gaps.<sup>1</sup>

This paper focuses on the barriers experienced by patients<sup>2</sup> whose pregnancies exceed 12 weeks gestation, particularly in cases of fatal fetal anomaly under Section 11. Although limited in our sample, we also critically analyse access under Section 9, the risk to health or life including mental health. We contextualize these experiences with data from service providers and key informants involved in the policy-making sphere, as well as quantitative data related to abortion travel. We further critically analyse the appeals process available to patients when they are denied care. Overall, we argue that a more 'patient-centred approach' is needed to improve abortion policy implementation in Ireland for individuals who seek access to abortion post-12 weeks gestation.

## Methods

We conducted data collection from May 2020 to March 2021. We recruited key informants, those involved in abortion policy development and implementation, through direct contact with relevant Health Service Executive (HSE) offices and stakeholder organisations. We recruited healthcare providers through the Irish College of General Practitioners (ICGP) membership, and through a WhatsApp provider network. We recruited service users through a flyer advertising the study which was posted on Twitter and Facebook. Twenty-three General Practitioners (GPs) who are providers also shared the flyer in their practices.

We used contextual interaction theory (CIT) to frame the study. CIT focuses on three key areas: motivation, information, and power. Motivation examines the personal motivations to implement the service incorporating external pressures such as economic, social, and political forces. Information relates to general knowledge about the policy, and accessibility of information. Power includes both capacity and control, such as finances, personnel, or time, examining those with decision-making ability and those who are expected to fulfill the policy requirements.

The research team developed interview guides for in-depth interviews, which were closely followed in the interview process. The research team coded all interview transcripts using 'Dedoose', a Computer Assisted Qualitative Data Analysis Software (CAQDAS), used to manage data files such as interview transcripts. We carefully developed a 'Codebook' based on a close analysis of research material. Grounded theory was used to identify topics that emerged from interview

<sup>1</sup> Mishtal, Joanna, Reeves, Karli, Chakravarty, Dyuti, Grimes, Lorraine, Stifani, Bianca, Chavkin, Wendy, Duffy, Deirdre, Favier, Mary, Horgan, Patricia, Murphy, Mark, Lavelanet, Antonella F. (2021) 'Abortion policy implementation in Ireland: Lessons from the community model of care', PLoS ONE, 17(5): e0264494. doi:10.1371/journal.pone.0264494.

<sup>2</sup> This paper blends gendered language (women, maternal) with language that recognizes that people capable of pregnancy are not all women: trans men and non-binary people also seek abortion care. In our sample, all Service Users identified as female. We use the terms pregnant person/patient/woman interchangeably throughout the article where possible.

transcripts. Topics included those discussed regularly or those which formed questions in the interview guides. A topic, for example, 'fear of criminalisation' was clearly defined with explanation and the appropriate text in the transcripts was added to that code. Authors LG, JM, KR, DC, BS, conducted the initial open coding until they reached a consensus and refined the codebook as a group. Coding of transcripts was initially done independently, then double-coded by another on the research team, and resolved until an agreed codebook was established. The coding process followed the "dynamic and fluid process" of the grounded theory approach (Strauss & Corbin, 1998). The codebook established major themes within the data which formed the basis of our main findings.

This study has ethical approvals from the University of Central Florida and the World Health Organization Ethics Review Committee, and the project was in full compliance with the European Union General Data Protection Regulation.

## Results

### Participant characteristics

We conducted 108 in-depth interviews (IDIs) with service users, healthcare providers and key informants. We conducted IDIs with 51 healthcare providers, 28 of which were hospital-based and included the fields of obstetrics/gynaecology (OBGYN), midwifery, nursing, theatre management, psychiatry, and anaesthesia. Twenty-two interviews were carried out with healthcare providers in the community setting: one midwife, one administrative coordinator for abortion services, and 20 GPs. We also draw on interviews with 27 key informants who were involved in the development of the legislation and guidelines, as well as non-governmental organisations and advocacy groups, including an organisation for people who experience a fetal anomaly diagnosis. We conducted interviews with 30 service users (SUs). Eligible SUs were at least 18 years old and had sought abortion services in Ireland in 2020; they did not need to have had an abortion. Of the 30 SUs, 26 were employed, four were unemployed; 21 had third-level education, six were currently on a university programme, and four had second-level education. Six of the 30 SUs had experienced a fatal fetal abnormality and sought an abortion under Section 11. This paper takes a micro-study approach by focusing on the SUs who sought abortion post-12 weeks gestational age in Ireland, particularly under Section 11. No participants in this study sought an abortion under Section 9; however, we include interviews with service providers, and include relevant service users' experiences, in order to provide an analysis of access to abortion under Section 9. All participants whose experiences are addressed in this manuscript described themselves as 'White Irish'. In this article, we draw on data from those service users who experienced a fatal fetal abnormality. The details of their cases are described below.

Participant no.	County resident	Age	Diagnosis	Care pathway
1	Dublin	34	Hydrocephalus and heart defect	Refused a termination. C-Section at 34 weeks. Baby died shortly after birth.
2	Waterford	30	Severe cystic hygroma	Refused a termination. Travelled to United Kingdom (UK).
5	Dublin	47	Anencephaly and endocarditis	TOP at 15 weeks
6	Cork	40	Edwards Syndrome	Two Failed EMAs, D&C at 15 weeks
10	Kildare	43	Severe hyperemesis gravidarum	TOP at 9 weeks
14	Dublin	39	Cystic hygroma and heart defect	Refused termination at 12 weeks & 3 days, arranged travel to

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Participant no.	County resident	Age	Diagnosis	Care pathway
28	Donegal	35	FFA diagnosis (unknown)	England but had a miscarriage. Termination at 14 weeks.

## Analysis

The data analysis identified four themes around access to abortion post-12 weeks: Section 9 (Maternal Health), Section 11 (FFA), MDT decision-making and the appeals process, as well as service users' experiences of access, travel and care. The desire for policy change is expressed by both medical practitioners and service users throughout. Interview data are analysed utilising grounded theory, and in addition, our critical analysis also takes a 'patient centred approach' (Mead & Bower, 2000). Laine and Davido (1996) describe patient-centred care as 'closely congruent with, and responsive to patients' wants, needs and preferences'. This approach involves understanding and giving importance to the patient's situation and wishes.

### Section 9 risk to the health of the woman

Unless abortion is carried out under the criteria of the 2018 Act, abortion is criminalised with sanctions of up to 14 years imprisonment for providers (but not patients). The criminalisation component of the legislation has a 'chilling effect' on providers in Ireland and may lead to a tricky balancing of diagnostic criteria and legal repercussions (Erdman & Cook, 2020). Risk to health or life may be defined or interpreted differently and there is uncertainty about certification. As illustrated by one obstetrician gynaecologist (OBGYN), 'It's the medical-legal fear... fear of getting something wrong.' (OBGYN48).

One provider we interviewed explained the personal judgment needed around certification under mental health grounds when scrutinising the language of the legislation:

"The Act, Section 9...is saying 'It is appropriate to carry out the termination in pregnancy in order to avert the risk'. That is unquantifiable. It cannot be measured...It is so subjective, and we haven't received any guidance from any professional body on how to make that slightly more objective. We are left with personal interpretation, and so one [specialist] might view it one way, another might view it the other, and there is a lot of wiggle room in either direction."

(Provider 45)

Guidelines relevant to Section 9 were released five months after the service was introduced, which meant that medical practitioners were unclear about pathways of care, which delayed prompt processing of cases. Speaking to one provider before the guidelines came into effect, they said.

"There isn't a formalised pathway... Patients can self-refer any time after they've booked ...We might link them with their community mental health team."

(Provider 45)

While this provider was critical of the lack of a formalised pathway related to Section 9, it could be argued that the lack of a formal pathway could lead to more liberal interpretation of the guidelines as patients could technically self-refer. The issue is that patients must be knowledgeable and confident to self-refer. This can be limited to those who do not know how to effectuate the pathway. A complementary approach may be preferable where self-referral is possible and exists alongside a formalised pathway through a provider.

According to our data, before the introduction of the 2018

legislation, there was a fear that allowing abortion under mental health grounds would lead to 'a flood of cases' (Provider 45) but this has not been the case. Moreover, the small number accessing abortion under Section 9 was 42 in 2019 and 2020 (Department of Health, Annual Report, 2019, 2020). This would suggest that 'the health of the woman' is not being interpreted to a large extent to include mental health.

For example, a service user (SU) in our study, with a history of complicated pregnancy, suffered from dehydration and mental health effects in a subsequent pregnancy. She went to the hospital but because she was under 12 weeks she was turned away and told to ring her GP who was then expected to manage her care or refer her to the hospital. She explained,

'I had hyperemesis gravidarum with my last pregnancy... I felt very sick and I went to hospital. I was very dehydrated and had suicidal dehydration.<sup>3</sup> I was nine weeks. I wasn't admitted at the time. The midwife recommended that I be sent home, that I wasn't dehydrated enough to be admitted. She said I could ring the MyOptions helpline at home.'

(SU10)

The risk to physical health was not regarded as severe, although psychologically, she needed support. Although it was a wanted pregnancy, SU10 decided to safely manage her own abortion at home under Section 12.

Another example where a dual diagnosis can complicate care is in the case of fatal fetal abnormality.<sup>4</sup> For example, a participant was told that her fetal diagnosis 'was not severe enough' to qualify for an abortion under Section 11, even though her baby would 'most likely' die shortly after birth (SU2). However, this information had a major negative impact on her mental health; she stated:

'I have struggled with my mental health on and off for many years and the thought of having to carry my baby for the next six months waiting for it to pass away inside me was horrific to me. How could I go on for months being pregnant with a bump and people asking me how far along I am knowing my baby was going to die.... Mentally and physically, I just could not continue with the pregnancy waiting for this to happen.'

(SU2)

This service user travelled to the United Kingdom (UK) to seek care. It should be noted that none of the service users in our study were referred under Section 9 when they were refused an abortion under Section 11, despite the potential impacts of a fatal fetal diagnosis anomaly on mental health, raising questions about the extent to which there are sufficient supports for patients in these circumstances.

Providers in our study outlined that it is potentially easier to diagnose physical risk, which may be more obvious than psychological risk. One provider, for example, described a case similar to that of Savita Halappanavar (Boylan, 2019; Holland, 2013):

"A woman presented to the hospital with sepsis. The OBGYN was contacted and told: 'There was fetal parts in the vagina. She's got a temperature. She's running a tachycardia. She wants an abortion, you know, and I think that she actually could get quite sick if we don't proceed' ... We knew that there was a consultant coming on who wouldn't be comfortable certifying."

(OBGYN24)

As the research participant explained further, the abortion was carried out immediately under Section 10 'where there is risk to the life of the woman in an emergency'. In this case, such care was influenced by the knowledge that the incoming doctor was 'known to be a

<sup>3</sup> Suicidal as a result of dehydration.

<sup>4</sup> Fatal fetal abnormality will be explored further in the MDT decision making and appeals process section below.

conscientious objector'.<sup>5</sup> This is despite the fact that according to a midwife in our study, 'in the event of an emergency, nobody can opt-out. Nobody. If a woman is bleeding, regardless of whether she's a miscarriage, an abortion, an abruption, we're all on board.' (MW23) Reports such as this highlight that conscientious obstruction should be monitored to ensure patients receive the medical treatment they need.

### Section 11 cases of fatal fetal anomaly

In the case of FFA, there are similar uncertainties regarding the diagnostic and certification criteria for abortion under Section 11. The legislation states that two medical practitioners, one of whom must be an obstetrician, must certify that the fetus will die within 28 days of birth (Health Act 2018:9).

While the Institute of Obstetrics and Gynaecology (IOG) guidelines list a number of recognized fatal anomalies, it does not provide all possible fetal complications, making it difficult for teams of providers to draw their own line, as this doctor explains:

'The national guideline that was disseminated initially set out a series of perhaps about 15 lethal fetal conditions...then you get into territory that's not entirely black and white...The outlook is really, really bleak, but maybe it wouldn't die in the first 28 days of life.'

(OBYN43)

However, where laws contain a specific list of health indications for which an abortion can be performed, questions may arise as to whether 'service providers will interpret these lists restrictively or whether they will consider them as illustrations, which do not preclude clinical judgment' (2018:8). Furthermore, although the condition may not be fatal within 28 days, the legislation makes no allowance for considering the newborn's quality of life, as some service users noted (SU1, SU6). Those whose fetus with a condition that poses a challenge for certification have either had to continue the pregnancies or travel abroad for care. One provider stated:

'Once you put a timeline in law, it's a real problem...There are certainly pregnancies that should have the option of termination of pregnancy that our legislation really doesn't facilitate, you know.'

(OBYN 48)

Moreover, as with mental and physical health conditions for the pregnant person, a number of OBYN physicians implementing abortion under FFA grounds noted 'fear of getting it wrong', and had issues with diagnoses that were 'not fatal enough' for termination. For example, one provider recalled:

'We had a very severe cloacal (malformation with malformed) extremity...and big lesion at the bottom of the spine, which is associated with a horrific outcome, numerous operations in childhood, and a terrible prognosis, but it just didn't comply with our law, so the woman travelled to the UK.'

(OBYN43)

'The problem is the baby who has multiple anomalies...is going to die at the age of one, five, 10, 15 or whatever.'

(OBYN48)

Service users also recognized the fear of making a wrong decision among medical practitioners. For example, one interviewee was told 'there was a 10% chance of survival past 28 days'. She said, 'they know that the baby is going to die but the doctors are trapped. They are scared.' She travelled to the United Kingdom (UK) for care. Another was told that the fetus would most likely not survive because it suffered from hydrocephalus (fluid on the brain) and a heart defect, but she was

refused a termination.

'It's not black and white...Not every fetal abnormality has a name. This is the thing. We didn't tick a box. Fatal abnormalities don't fit into boxes. [The] fetus's condition would be 'compatible with life'. But she was essentially brain-dead. She would have had no quality of life...No one knew if she was going to live for a day, or at all... Doctors thought she would survive a few weeks and that we could bring her home.'

(SU1)

Ultimately, this participant had a Caesarean section delivery at 34 weeks, and the 'minute they took her off the ventilator she died.' (SU1) These events demonstrate the consequences of 'medical authoritative knowledge' (Browner & Press, 1996), whereby restrictive interpretation of the legislation has omitted patients from the decision-making process. Specifically, 'authoritative knowledge...is a way of organizing power relations in a room... it is the active suppression of whatever it is that women might know, think, or imagine about themselves.' (Rapp, 1997).

A recent study carried out with Fetal Medicine Specialists (FMS) in Ireland found that half of FMS expressed 'uncertainty' regarding a diagnosis of a fatal anomaly as it depends on an individual's 'definition' of what is fatal (Power et al., 2021). Similar uncertainties were experienced by our participants, as one OBYN stated:

'I think we would like to have our expert views taken more into consideration and that there be a greater trust of the fact that we can make those decisions, that we don't need five other people...We need support rather than being threatened.'

(OBYN48)

Our interview data demonstrate the strong fear of litigation within the medical community, including among consultants who evaluate cases for certification, resulting in a preference for conservative management. Ambiguity and complexity are inherent in the current legislation which forces a level of subjectivity, rather than objectivity, which is usually the dominant view in medicine. However, as demonstrated by Browner and Press (1996), authoritative knowledge is more complex. In their research, pregnant women did not consider prenatal recommendations to be authoritative simply because they were issued by physicians. Instead, 'patients [were] active interpreters of medical information' as individuals who 'pick and choose, using and discarding advice according to internal and external constraints and considerations' (Browner & Press, 1996). Macleod et al. (2017: 611) further argue that 'the legal framing of abortion as a decision that belongs to the medical profession [rather than the woman], creates ongoing ambiguities about women's autonomy in this process'. Thus, to better involve patients in the decision-making process, a patient-centred approach would consider these complexities, including the intersection of medicine and law in the unique circumstances around abortion.

### MDT decision making and appeals process

Decisions on abortion eligibility for fetal anomalies under Section 11 are made by MDT, which 'is a formally-constituted committee of the hospital – this is likely to be at hospital group level where the fetal medicine expertise is concentrated' (Institute of Obstetrics and Gynaecology, 2019). The MDT protocol is not required by the 2018 Health Act, which mandates that two practitioners sign for termination under Section 11 but rather, stipulated within the IOG guidelines. The MDT is made up of specialists in obstetrics, gynaecology, neonatology, paediatricians, and any other specialists, including for example cardiologists or neurologists. FFA cases are presented by the patient's doctor to the MDT where they are discussed, debated and a decision, regarding options of care and whether abortion care should be included, is made on a case-by-case basis. According to the IOG guidelines, 'MDT consensus' is needed on the 'procedures, timing and mode of delivery – personnel to be involved', and other details in the care plan (Institute of Obstetrics

<sup>5</sup> Those who conscientiously object are legally obliged to carry out an abortion under Section 10 if the woman's life is in danger and it is medically necessary.

and Gynaecology, 2019).

The outcome is largely dependent on the presentation of the case to the MDT. This critique is conveyed in SU1's observation:

'Our OB/GYN doctor told us there was a case for interrupting the pregnancy. She needed to build a case... As the pregnancy progressed everything was not progressing. There were now three things wrong and yet our doctor could still not get a consensus for a termination... They are not blasé about doing these things and it's ridiculous that you need two or three doctors for consensus. They should be able to decide. In cancer treatment they don't need to ask three other doctors'

(SU1)

As previously outlined, SU1's baby had both hydrocephalus (fluid on the brain) and a heart defect and had been told her baby would 'mostly likely' not survive, yet defining the anomalies as fatal within 28 days of life, as per the Act, proved difficult. Different units include different personnel which can lead to varying decisions as was pointed out by this OBGYN:

'I've sat in in different units on these meetings and it's very dependent on the people involved. Some can be more lenient than others, you know, and obviously that comes in a lot to their background and their own beliefs and that, how strict they would be in terms of FFA. So I know that something might meet criteria in one hospital and not in another and that's frustrating.'

(OBGYN31)

Consensus can also be extremely difficult to achieve in MDT, as an OBGYN observed:

'The decision-making has been challenging. I've certainly seen one or two of my colleagues crash and burn through not presenting it properly and once you don't present it properly and make the case strongly and have it all set up, all it needs is for a couple of people then to be undermining that and the neonatologist, you know, to be difficult. So that's been a bit of a challenge.'

(OBGYN28)

Different relationships between MDT members can also lead to inconsistent or differing outcomes, which may have implications for 'fair and transparent' access to abortion, an obligation under human rights principles (Cook et al., 2006:189). One OBGYN stated:

'We're now involving our neonatal colleagues and their training has never been to discuss termination of pregnancy. They've always been kind of handed the baby and have advocated for the baby...So now we're having these meetings and almost like you've to sell the story to get consensus in the room.'

(OBGYN26)

Our data align with existing research, which found that there can be 'difficulties in providing abortion care as part of a team' and that 'feelings of disapproval and disrespect from colleagues', as well as 'resistance and conflict' can exist (Dempsey et al., 2021). The MDT may also include doctors who oppose abortion in principle, therefore deepening the conflict:

'There can be good and open discussion, but if people in the room intrinsically don't agree with termination of pregnancy, it's very hard for that to be a good discussion. Our neonatologists just do not engage.'

(OBGYN48)

It is unknown how many women have been denied an abortion under Section 11 or gone before the MDT process. This information is not available from the Health Service Executive (HSE) or the Department of Health. Any patient that disagrees with the MDT decision can appeal it, however the process is likely to create a significant delay in their ability

to secure timely abortion care. Under Section 13 of the 2018 Act, if a medical practitioner is requested to give an opinion and the opinion does not qualify for certification of a termination, then 'a pregnant woman, or a person acting on her behalf, may make an application in the prescribed form and manner to the [Health Service] Executive for a review of a relevant decision' (Health Act 2018:10). In this situation, the HSE should 'establish and maintain a panel of medical practitioners...for the purposes of the establishment of a review committee' (Health Act 2018:10). The review panel must be established within *three days* and must notify the woman of their decision in no later than *seven days* after the establishment of the committee. This is a potential ten-day delay in waiting for an appeal of a decision. In addition to risks associated with increasing gestational age, delay in decision-making could add significant stress or anxiety to the pregnant person. Additionally, according to the IOG guidelines, the woman has the right to come before the committee to represent their case or to send a representative in their place. This process may be extremely intimidating for a patient.

It is unknown how many have availed themselves of the review process to date. No participants in our sample availed of the appeals process and our data suggest that the numbers are extremely low and this information is not available from the HSE or Department of Health. One provider reported that 'there has really only been a handful of cases. And I think even there hasn't been an appeal on mental health grounds.' (Provider 45) Similarly, a midwife provider noted, 'they're entitled to have a review of that within a timeframe and I think I only know of one case that that's happened' (MW23). This also raises questions as to how many patients are aware of the appeals process or are informed of this legal right. It is also unclear how many providers are aware of the process. A study carried out in Ireland in 2021, found that knowledge of the termination of pregnancy legislation, guidelines, methods, and complications is lacking among hospital staff, and almost all staff expressed a wish for training (O'Shaughnessy et al., 2021).

#### *Service user's experiences of travel and abortion care with FFA*

Our study found that there is an uneven distribution of fetal anomaly consultants, scanning, testing, and other resources outside of Dublin and Cork, which means many women must travel from rural parts of Ireland to Dublin to receive care. For example, SU28 "had to travel to Dublin twice, once for the CVS [chorionic villus sampling] test and then back at the local hospital" all of which "took a toll on [her] emotionally." She stated:

I think every hospital in Ireland needs to offer the services. If it's in Ireland, it is in Ireland. Hospitals shouldn't get to pick and choose. Also, there should be more places around the country that do testing [CVS test] and it shouldn't just be in Dublin.<sup>6</sup>

(SU28)

Compounding the issue of delay was the lack of clarity surrounding qualification for a TOP. For example, service user 2 was told her baby had a 'severe cystic hygroma'<sup>7</sup> and said, 'my partner and I came home confused, shocked and heartbroken wondering why we had to wait a week to see the consultant.' SU2 was ultimately denied abortion care and decided to travel to the UK for an abortion. Providers also shared experiences about the impacts of travel on their patients. As one provider recalled, one patient "really wanted to deliver at home in her own [maternity] unit because she said... 'I am so far away from my home and I just want to be at home'. And so nobody would facilitate down there" (OBGYN35).

In 2019, with the introduction of the 2018 Act, the number of Irish women travelling to England and Wales for abortions declined

<sup>6</sup> While in the experience of our research participant CVS was only available in Dublin, this test is offered in a small number of other locations in Ireland.

<sup>7</sup> A congenital condition which entails an abnormally formed lymphatic vessel resulting in the accumulation of lymph fluid and the formation of cysts.

significantly from 2879 in 2018 to 375 in 2019, a decrease of 87 % (Abortion Statistics, England and Wales, 2020). However, Irish women still made up 17.6 % of non-UK residents who had an abortion in England and Wales in 2019 (Department of Health and Social Care UK, 2020). Moreover, the experience of travel, particularly during the COVID-19 pandemic, was particularly stressful. (Taylor et al., 2020) For example, SU2 recounted the difficulties of travelling abroad and how difficult it was 'accepting that I couldn't get access and support here... leaving a small rural town to go to another country' (SU2).

'My partner then had to contact his employer and had to explain our situation because he was going to need the time off to travel to London with me and also the time off to quarantine when we came back for 14 days... It was difficult to find a hotel close to the clinic due to everything being closed because of lockdown restrictions. I couldn't ask to have my baby's ashes because we would have had to travel back to London three months later.'

(SU2)

Travelling abroad, for those who have the capacity to do so, can be an emotionally and physically traumatic experience (Aiken et al., 2018).

Delays were not only associated with consultations and travel, but for some service users, conscientious obstruction contributed to delay of care. Key Informant 16 from an organisation familiar with families that received a fetal anomaly diagnosis recalled a case where the patient attended the doctor at 20 weeks, she had to attend multiple scans before she was told at 24 weeks that there was a problem with the brain. 'She had to beg for a referral'. (KI16).

'She said her doctor wouldn't make an appointment with her for three or four weeks...She felt that there was a four-week delay in her being referred to a scan and then the doctor delayed giving her results, and kind of cancelled appointments with her and whatnot. When she finally got her results, she said to her that you're 28 weeks' pregnant. You can't have an abortion now, so you have to remain pregnant.'

(KI16)

Many of our research participants, however, spoke of the support they received from doctors and nursing staff who managed their cases. SU5 recounted that when her baby was diagnosed with anencephaly and endocarditis, she was provided a termination at 15 weeks. She said that the hospital staff were 'very compassionate...They were all around checking up on us' (SU5). Those who received a termination expressed gratitude for having access to care without having to travel abroad: 'I am happy that I could access care in Ireland. I was extremely aware that if it [her pregnancy] had happened 2 years ago, I would have to go to England to access services' (SU18). Service user 28 said she received great support from her abortion providers:

'They were very supportive...They rang me up to see how I was doing. After they had transferred the reports to my doctor, and he had my files, he called me up as well. The care I received was fantastic.'

(SU28)

Some service users also expressed sympathy for their physicians whose 'hands are tied' because of the legislation. For example,

'Staff and doctors were nice. The consultant, he was particularly nice. There were two other consultants who weren't as nice as him. He was very apologetic... He then googled the British Pregnancy Advisory Service on his computer and told us we could travel there for a termination but that we would have to organise it ourselves... I am grateful that our consultant was able to provide us with appropriate information on where to go for a termination but I really wish we could have been supported here.'

(SU2)

Unfortunately, the provision of information related to abortion care is not always consistent, and 'there's not the same knowledge of the support available for people who need to travel to access abortion care' (KI2).

A support group for people with FFA diagnosis has advocated for better support services over the last few years:

'We've met with the HSE three times to try and develop these pathways for women when they get a diagnosis. So we did a kind of like, this is what we think should happen if someone comes in and gets a diagnosis that's fatal. This is what should happen if a woman comes in and gets a diagnosis that's not fatal.'

(KI16)

Service users from our sample positively reported on the bereavement counselling support they received in the hospital. Although SU2 was denied an abortion and travelled to the UK, she stated:

'A bereavement midwife sat in on the meeting with the consultant... She stayed in contact with me during the days leading up to travelling...She told me to contact her six weeks after I came back from London to check if I was healing properly and to provide counselling.'

(SU2)

Additionally, a midwife described her job as 'really to enforce that element of compassionate care for whoever comes through the door.' (MW33).

'Acknowledgement and support after the termination and the trauma, and oftentimes very traumatic experience of travelling, and organising all that on their own. So yes, for sure, we would have been here to support them and still are for couples who travel for the non-fatal fetal abnormality.'

(MW33)

However, bereavement support is not offered in every hospital in Ireland and those who travel abroad for abortion care may be less likely to avail of it. Instead, bereavement support is provided by a small number of dedicated and experienced midwives and our study has found that the support they offer is extremely valuable.

#### *Desire for policy change*

Our study data indicate that there is a desire for policy change by both service users and medical practitioners to allow for improved access to abortion post-12 weeks. Specifically, both providers and service users expressed a desire for policy change in terms of fatal fetal diagnosis. One OBGYN believed some fetal anomalies which are not fatal, should still be grounds for an abortion, 'There's a whole proportion of ostracised anomalies now that are not fatal and that are not ok. They're horrible, but they're not getting the choice' (OBGYN8). Fatal fetal abnormalities are usually not discovered until later gestational age, SU1 said 'I don't like this rhetoric around the later stage. You don't know what will happen until much later in the pregnancy' (SU1). SU2 argued that while the change to legislation has been positive, there needs to be a change for those with fetal anomalies.

'I feel very broken and raw. I understand that repeal the eight has helped thousands of women in Ireland which is absolutely amazing. But what about people like me and my partner who have had a fatal diagnosis in our baby but it wasn't fatal enough to be helped in our own country...I also dread to think of people in our situation that do not have the money to travel like we did.'

(SU2)

SU2 further said the consultant told her and her husband that 'if this was discovered at 11 weeks, they could have helped us here in Ireland... They should take away the 12-week thing altogether. It's crazy.' (SU2). Similarly, SU6 said, 'I think in the case of fetal abnormalities, it needs to

be extended...You can only get a fetal diagnosis after 12 weeks.' (SU6) The conservative interpretation of Section 11 leaves many with fetal anomalies in an ambiguous situation. SU1 stated:

'People need to know that the law doesn't work. We have had to do things that no one should ever have to do. No one should have to go through what we went through...I presumed that if there was an issue you would be looked after. There are people falling through the cracks.'

(SU1)

Overall, our findings clearly show that these rigid definitions create challenges for both providers and patients that may result in delays and denial of abortion care.

### Limitations and strengths

This study is not meant to be generalisable, but rather the overarching objective is to be informative about the abortion legislation and policy implementation in Ireland, with a focus on access to abortion care post-12-weeks' gestation. Our team was mindful of the potential for selection bias with purposive sampling, therefore we sought to minimise this limitation by inviting participation from as many geographic and stakeholder communities as possible. One limitation, however, is the use of gendered language in recruitment and study design which could have affected participation from non-binary and trans individuals.

Additionally, it may be difficult to fully appreciate the difficulties related to the diagnosis of mental or physical health conditions, as women can access care on request before 12 weeks. Yet, the three strengths of the study are: (1) the triangulation of data from three samples (SUs, providers, and key informants), (2) capturing experiences of women who experienced FFA – a challenging sample to access because of the limited numbers of patients that meet the criteria for this diagnosis, and (3) capturing the perspectives of a range of medical specialists, including those working in obstetrics/gynaecology, psychiatry, and midwifery.

### Conclusions

Our study makes an important contribution to the emerging scholarship about the implementation of abortion legislation and services in Ireland since 2019 by focusing on access to abortion care post-12 weeks' gestation, particularly in relation to FFA. Our findings demonstrate that there are many challenges and ambiguities to accessing abortion in Ireland after 12 weeks gestation, and there is a desire for further clarification, guidance and policy change in a number of areas. Sections 9 heavily focuses on abortion for reasons of physical health, although mental health is also included in the interpretation of 'health' in the legislation. Low numbers recorded by the Irish government under Section 9 are likely due to providers' fear of criminalisation if mental health is used as grounds for abortion too liberally. Section 9 guidelines have left too much to medical professionals' interpretation, while guidelines for Section 11 have been too specific and restrictive in the interpretation of the legislation, both contributing to compromised 'patient-centred care'.

There are significant challenges surrounding the diagnosis of FFA. Many patients have been denied access to abortion in cases of severe fetal anomalies. While the legislation states that two medical practitioners are needed for certification, the MDT process includes multiple specialists examining each case, which may constitute a barrier for patients. The MDT process also leads to difficulties between consultants on subjective diagnoses. This can lead to inconsistency or differing outcomes by different teams which, in turn, can lead to uncertainty related to access for service users.

The MDT process and rigid limitations decentre the pregnant person as an autonomous agent in the abortion care process. Both medical practitioners and service users expressed a strong desire to expand the

definition of FFA in order to ease the challenges of ambiguities so inherent in the current decision-making process. Information on the review process following a denial of an abortion request has not been distributed by the HSE and there appears to be a general lack of knowledge among both service users and physicians on the process. In addition, the appeals process could potentially lead to significant delays. Overall, since the introduction of the Health Act in Ireland in 2019, abortion has become easier to access however, several difficulties remain, particularly in relation to abortion post-12 weeks.

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