Submission to the Citizens' Assembly on Repealing the 8th Amendment

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Submission to the Citizens' Assembly on Repealing the 8th Amendment by Dr. Deirdre Duffy and Dr. Claire Pierson (Manchester Metropolitan University),

This submission, based on empirical research conducted by academics at Manchester Metropolitan University as part of a study of abortion travel funded by the Wellcome Trust, advocates the repeal of the 8th amendment on the following grounds:

1. **That the amendment is an inherent clinical risk to safety**
2. **That the amendment acts as a barrier to safe abortions to Irish women**

For further details of methodology (Appendix 1) and a tabulated summary of key findings (Appendix 3), see the attached appendices to this submission.

Opposition 1: The 8th amendment is an inherent clinical risk to patient safety

International guidance on health and safety assessment of health systems identify four categories of risk – hazards, risks, clinical risks, and inherent clinical risks. The most severe types of risk – and greatest safety concern – are **inherent clinical risks**. These constitute **systemic issues** that create a **persistent likelihood of causing harm to patients' health and wellbeing**. The risk is a result of a systemic problem **not** the clinical practices within the system or the conditions of these practices.

Evidence from health professionals in Ireland collected as part of a study of abortion travel between Ireland and Liverpool indicates that serious risks to Irish women's health and wellbeing associated with abortion – including **infection**, **haemorrhage**, and **prolonged emotional trauma** – are augmented by the need to travel for abortions due to the limitations under 8th amendment. This is an inherent systemic problem and thus these risks will not be minimised by alterations to clinical practice or 'better care' in maternity and reproductive health services. Abortion travel sustains these risks and they will only be neutralised when abortion travel is not required.

Opposition 2: The 8th amendment acts as a barrier to safe abortions to Irish women

Globally, unsafe abortions account for an estimated 47,000 maternal deaths and 5 million cases of injury and long-term chronic disability each year (RCOG, 2015). Central to the World Health Organisation's guidance on best practice in abortion care is the need for well-functioning, cohesive, efficient referral pathways and consistent quality assurance. Anti-abortion legislation does not limit *abortion*; it limits *safe* abortion.

In the Republic of Ireland in 2015, 3541 women travelled to England/Wales; 1054 of these women travelled from counties without an airport/ferry to a city where abortion services are available (30%) indicating that these women encounter more than one abortion journey and therefore increased risk.

The 'care pathway' for Irish women seeking abortions is **fragmented**, **high risk**, **inefficient** and **inconsistent**.

- There is no shared clinical governance between lead consultants in Ireland and health professionals in services accepting Irish patients.
- The 'movement' of patients is not regulated and the onus is on women to navigate their own way to safe, quality assured services.
- There are frequent delays as services outside Ireland place limits on the number of Irish patients they will accept.
- The design of the care pathway under the terms of the Protection of Life During Pregnancy Act 2014 is inefficient.

- The care experience of Irish women (from the point they decide to travel to the point they return) is not quality assured or evaluated.

Because of the 8th amendment there is no way of ensuring women are cared for safely, effectively, or in accordance with international standards and no way of protecting women from rogue agencies.

1. Background

This briefing describes the findings from an interdisciplinary scoping study of care for Irish women travelling to Liverpool for abortions. The study was designed to explore the perceptions and perspectives of care workers on the 'abortion corridor' between Ireland and Liverpool. An expanded definition of care which included the provision of health information/advice, clinical care, health service management, and non-clinical practical support (i.e. financial and accommodation) was used. Academics from Manchester Metropolitan University led the research with the support of the Wellcome Trust and colleagues at University College Dublin, University of Liverpool, and Edge Hill University. The researchers gathered primary and secondary data through face-to-face, telephone and email interviews (individual and group) and archival research. Methodological and sampling details are provided in the appendix.

The briefing summarises the main problems with current care for women seeking abortion as articulated by research participants.

2. Key findings

1. There is no co-ordination or collaborative working between care providers and professionals on abortion care.
2. Communication between counselling and other health services is limited.
3. Lack of availability of geographically proximate care.
4. Lack of affordable services and financial prohibition on abortion.
5. Lack of timely care options.
6. Lack of a clearly defined referral pathway.
7. Lack of accountability structures and opportunities for monitoring and improvement.
8. Lack of availability and access to treatment for abortion-related or post-abortion complications.
9. Restrictive legislation affects patient disclosure.

3. Recommendations

1. Repeal of the 8th amendment is necessary.
2. Documentation, standardisation and evaluation of care provision and care pathways.
3. Open and consistent provision of information about pre- and post-abortion care to women.
4. Development of abortion care policy and quality frameworks in line with international standards.

5. Engagement by the Citizens' Assembly with expert counsellors and services such as the IFPA and Well Woman Clinic who provide pre- and post-abortion counselling to significant numbers of women.
6. Greater regulation of rogue crisis pregnancy agencies.
7. Systematic management of abortion care from beginning to end.

4. Detail

Findings from the scoping study indicate that the care available to Irish women, while safe in the sense that the mortality and morbidity rate and occurrences of abortion-related complications are low, is not of high quality. There are a number of risks associated with accessing abortion care in England. The remainder of this submission will focus on aspects of lack of quality abortion care (see Appendix 2 for models of quality care) that were most prominent in our data.

1. There is no co-ordination or collaborative working between care providers and professionals on abortion care

Co-ordinated service provision is emphasised as good practice by HIQA quality guidelines. However, the Eighth Amendment limits systematic design of abortion care services. As a result of legal prohibitions, women are frequently accessing services without support or advice from the health service. As a consequence, they do not always receive all necessary pre- and post-abortion care. There is no multiagency working in care for women seeking abortion and no collaborative service provision.

Care pathways are thus fragmented, with numerous gaps and no systematic, centralised management of the care women receive. This lack of co-ordination results in women not being cared for, not being directed to essential services (particularly counselling and post-abortion care), and exploitation by rogue agencies.

'Well, quite simply, at a moment in time when a woman needs care the most you're kind of abandoning ship. And [if] you're not abandoning ship you're trying to put something in place. But that something is going to another country, another health system.' (Interview 24, Healthcare Professional, ROI)

2. Communication between counselling and other health services is limited

Counselling is an essential part of effective pre- and post-abortion care. The WHO advises that counselling services be integrated with health care pathways. However, our findings indicate limited communication between counselling services and other health professionals. The critical importance of trained counsellors to ensuring positive health outcomes for women accessing abortion is under-recognised.

'It's not joined up thinking and what I feel is that for certain providers we are used as a dumping ground. We do the dirty work…go over to them, talk to them, they'll give you the information. It's a lack of taking responsibility. Their work is underpinned by an ethic of care yet they don't appraise themselves of what this is about how they inform this woman. It's not taking responsibility for this bit of healthcare.' (Interview 26, Counsellor, ROI)

3. Lack of availability of geographically proximate care

Both HIQA guidelines on safe healthcare and WHO guidelines on safe abortion care underline the importance of geographically proximate care. Article 40.3.3 directly interferes with this, compelling women to travel long distances to access appropriate care. The majority of Irish women accessing abortion must incur at least one journey to another legal and health jurisdiction, with a significant portion of women travelling for abortion having to utilise two or more forms of transport to access health services. In 2015, 3541 women travelled from ROI to England/Wales to access abortion. In addition to this, 1054 of these women (30% of those who provided a county address) travelled from counties without direct link to a city outside Ireland where abortion services are available.

'Also rural women – they don't have these services in their village and even if they do they don't want to go there as everyone will know. They travel from Galway and Cork, then home and then back to get the flight. For them it's very difficult.' (Interview 25, Counsellor, ROI)

4. Lack of affordable services and financial prohibition on abortion

Irish women must access abortion services as private patients in England (the impact of Brexit on this is yet unknown). The cost of abortion travel includes both travel costs, procedures and accommodation if necessary. This can result in amounts between 500 and 2000 Euros depending on travel prices, gestation and procedure chosen.

5. Lack of timely care options

Having to access services abroad and pay for them plus travel costs means that women from Ireland are unable to access services quickly. During our research, it was reported that women often have to wait for flight prices to be affordable by which time their gestational limit has increased and the procedure may cost more. In addition, because of the illegality of abortion and the stigma associated with it, women may wait longer to confirm a pregnancy test or may travel to England without having a scan to determine their length of pregnancy in Ireland. This puts them at risk of being turned away by clinics (for being too early or too late) and having to make a repeat journey.

6. Lack of a clearly defined referral pathway

One of the key findings from our scoping study is that when abortion is mentioned by women, they are immediately referred out of conventional healthcare pathways. Healthcare professionals are disallowed from referring women to abortion services outside the state under the Regulation of Information (Services outside the State for Termination of Pregnancy) Act 1995. There is no structured, referral pathway to support women or mechanism for ensuring that she receives appropriate care from beginning to end. Any advice about services or communication with services receiving women – even where this communication is essential to safe, effective care - is highly dependent on the individual practitioner and is not standardised. Often women are referred to independent advisory services such as the Irish Family Planning Association or the Well-Woman clinic, who although providing expert advice, are also expressly prohibited the 1995 Act from making referrals. Some women are simply told by their healthcare practitioner that they cannot be provided with an abortion in Ireland; they must access information on the internet or through social networks. As such, there is no defined care pathway and women must make all arrangements themselves.

In cases of foetal abnormality and for women with more complex medical needs, informal systems for communicating information essential to patient care have emerged between hospitals in England and Ireland. This includes informing receiving hospitals to expect patients. However, these are ad

hoc, do not represent a high quality, care pathway, and are not subject to standardisation throughout Ireland.

7. Lack of accountability structures and opportunities for monitoring and improvement

The legal prohibitions on establishing a structured, care pathway from the 1995 Information Act also means that there is no mechanism for evaluating the care that women have received in England. As a result there is a lack of monitoring of treatment, no key performance indicators (identified by HIQA as essential to good healthcare), and no systematically assessed quality frameworks for the care experienced by thousands of Irish women annually.

'But the bottom line is can I actually have clinical governance over what is happening to that woman? And the answer is I don't. I'm not sitting on their hospital, I don't review their results – what complications you had – so it's very hard for me to say to a woman 'look, this is a fantastic place.' A lot of our women go to [NHS facility] and they do…the women say they have a very good service. But I actually can't look her in the eye and say 'look, this is a really good place, you're going to get fantastic service' because I don't really have any input. I don't have access to their results, I don't go to their monthly meetings where they look at their complications, they don't certainly send me any published data to show how many they did, these were the complications…you know…so I've no input. So it's very hard to be sure how she's going to do.' (Interview 23, Healthcare Professionals, ROI)

8. Lack of availability and access to treatment for abortion-related or post-abortion complications.

As noted below, many women, for fear of illegality, do not want to report accessing a legal abortion in England. This results in a lack of presentation for standard after care on return to Ireland. In addition, this may result in women delaying accessing treatment in cases where complications arise after the abortion procedure.

'If someone is admitted and has had a procedure with us. We do give everyone a copy of their discharge letter which tells them exactly what they've had done, gestation, HB levels, it's quite comprehensive. We say to them if you have a problem just give someone that letter but a lot don't as they don't want to be travelling with that sort of information so I'm sure as soon as they go or even in our shredder bin – a lot of them go there before they leave the building. So that's another thing you would find with Irish women.., The shared documentation [provided to women by the clinic], they don't always want to take that with them. Even if you go to the airport and they're rummaging through your bag and they see that.' (Interview 28, Clinic Manager, England)

9. Restrictive legislation affects patient disclosure.

Participants in our study reported that many women – particularly vulnerable women – are uncertain of, or misinterpret current legislation. Women often interpret the constitutional promotion of the unborn's right to life as a prohibition on all abortion – including abortions procured in other jurisdictions. Health professionals interviewed perceived that women are disinclined to disclose vital medical information to protect themselves from the effects of Article 40.3.3. This

creates a situation where full and frank discussions about abortion are unlikely within formal healthcare settings.

The stigma and attitudes towards abortion, in conjunction with misinterpretation of legislation, was also cited as a reason why practitioners may refuse to engage in any conversation with a woman who wishes to access abortion. Crisis pregnancy counsellors referred to being used as a 'dumping ground' for the health profession.

'So I work in the emergency room so I see women who would come in after having had abortions in the UK. I have seen a number of problems after. That women are delaying their access to medical care because they don't know if they are in a legally OK place. Like, I've had a woman come in, y'know, bleeding so much and she had delayed coming into see us and she was asking me "am I going to get in trouble?". You know and she had legally travelled for an abortion. So that's even those women. It's such a grey area for people.' (Interview 22, Healthcare Professionals, ROI)

Appendix 1

Information was gathered through qualitative research interviews – primarily face-to-face but also telephone and email interviews where face-to-face meetings were not possible – with a sample (n = 19) of professionals involved in co-ordinating and providing care to Irish women seeking abortions. This included clinicians (n = 10), counsellors and advisory agencies (n = 6), and clinic managers (n = 3). Participants were contacted through a combination of purposive sampling and via gatekeepers. The sample included participants based in Northern Ireland (n = 6) and the Republic of Ireland (n = 11). One clinic manager from England was also interviewed as part of the research. Key organisations were identified through desktop and archival research and contacted via email. Respondents to the initial request for participants were invited to circulate the invitation and details of the study to colleagues they perceived as important figures in the provision and co-ordination of care.

Although the sample size means that the findings cannot be generalized to all practitioners, the diversity of professional backgrounds, centrality to the provision and co-ordination of care, and amount of experience (see table below) mean that the qualitative data can provide a robust indication of problems created by the current legislative arrangements. As the research was designed as a scoping study, the extent to which the problems identified can be generalized across the health profession in Ireland, Northern Ireland, and England was not its focus. These findings can be used as the basis for a more in-depth exploration.

Appendix 2

Evaluative Models of Abortion Care

Model 1

Based on a systematic review of articles and 'grey matter' reports relevant to quality abortion care published before January 2015 (excluding papers not written in English), Dennis et al (2016) provide a thirteen-point performance indicators framework. This framework synthesises existing process, output, and outcome-focused indicators proposed as essential to high-quality abortion care by current academic and practice research and policy. The performance indicators identified are:

1. Availability of trained staff to provide care
2. Whether referrals for, or direct provision of, a range of sexual and reproductive health services are offered
3. If all aspects of abortion care are explained to women
4. If information about a range of sexual and reproductive health services is offered
5. Whether staff offer respectful care
6. If staff work to ensure privacy
7. If high-quality, supportive counselling
8. If abortion complication rate
9. If services are offered in a timely manner
10. If services are geographically accessible
11. Whether policies support access to abortion
12. If women have the opportunity to express concerns, ask questions, and receive answers
13. The rate of maternal deaths due to abortion complications

Model 2

Benson (2005) provides an alternative evaluative model which connects quality to facilitating what she labels the 'ultimate' objectives/outcomes of universal safe, high-quality abortion services – (i) reduced maternal morbidity and mortality; (ii) increased reproductive choice; and (iii) reduced repeat unintended pregnancy and unsafe abortion. This model resonates with a 'Theory of Change' (ToC) approach to evaluation (Weiss, 1972) where the objects of evaluations (evaluands) are assessed by comparison with a model of how core aims can be best reached. ToC is useful both a mechanism for formative programme planning ('how can we achieve our goals?') and for summative programme evaluation which bases judgements of quality on processes and workings as well as outcomes. In the context of abortion care, quality is evaluated not through an audit of maternal morbidity and mortality or repeat abortion, but through appraising whether the mechanisms through which these outcomes were achieved were as effective and facilitative as possible. Put simply, ToC quality evaluation asks 'did we reach our goals in the best way possible?' rather than 'did we meet our goals?'

Benson's framework evaluates the quality of the abortion care by process and outcome. It considers both the outcomes of abortion care and the dynamics of abortion care. This is important as it highlights that delays and inhibitions to the achievement of safe abortion care indicate a systemic quality issue even where, for example, morbidity and mortality rates are low. Benson assesses processes through a list of intermediate outcomes including:

- The restrictiveness of abortion legislation, policies, regulations, and guidelines
- The supportiveness of public officials and health professionals
- The existence of benchmarks for abortion care
- The training of health professionals in abortion care
- The provision of resources for abortion services and abortion care in national health budgets
- The attitudes towards women seeking services
- Women's knowledge of services
- The information about abortion and abortion services available to women
- Women's confidence in obtaining services
- The financial, cultural and geographic barriers to abortion care
- The geographic distribution of abortion services
- The existence of effective referral and transport systems
- The availability of post-abortion contraception and counselling
- The availability of a range of technologies
- Women's experience of services and opportunities for feedback to be received and responded to

Benson's model is much broader than the framework provided by Dennis et al and many of her indicators require extended quantitative and qualitative analysis.

Model 3

In addition to Benson and Dennis et al's frameworks, an evaluative framework for care quality for Irish women can be drawn from international and national guidance on good care (in health and in abortion). This guidance can act as a counterfactual to evaluate the quality of abortion care available to Irish women. The table below illustrates this drawing together two guidance documents specific to abortion care - the Royal College of Obstetricians and Gynaecologists' Best practice in comprehensive abortion care (2015) and the World Health Organisation's Safe Abortion: Technical and policy guidance for health systems (2012). No quality framework for abortion care exists in the Republic of Ireland but there are quality indicators for health care in the Health Information Quality Authority's Standards in Safer, Better Healthcare (2012).

Quality indicators from these documents divide into three categories – clinical/procedural, interpersonal, and structural/processual.

<u>Clinical/procedural indicators include:</u>
- Clinic and instrument hygiene
- Availability of adequately trained medical personnel
- Availability of treatment (vacuum aspiration or treatment with misoprostol) for incomplete abortions
- Availability of treatment for abortion-related or post-abortion complications

<u>Interpersonal indicators include:</u>
- Attitudes towards women seeking and receiving abortions
- Attitudes to contraception and abortion among health workers
- Quality of patient experience (i.e. whether patient was treated with dignity and respect)
- Availability of post-abortion counselling and availability of staff trained in providing emotional support
- Patient satisfaction with feedback process
- Respect for and responsiveness to women's wishes

- Protection for persons with special needs
- Informed and voluntary decision-making
- Confidentiality and privacy

Structural/processual indicators include

- Existence of a clearly defined referral pathway between services
- Availability of geographically proximate services
- Affordability of abortion
- Effective and efficient management of services
- Existence of accountability structures and opportunities for continual monitoring and improvement
- Opportunities for reporting issues in care quality and care experience

Appendix 3

Interim findings - Perceived risks and outcomes of abortion legislation and discourse among care providers: Interim findings from a study of care workers and co-ordinators in Northern Ireland, Republic of Ireland, and England.

Label	Detail	Reported by	Perceived Risks
Communication pathways between providers	Due to absence of referral system communication between care providers depended on actions of individuals	Health professionals (RoI/NI), care service managers (Eng/NI), advisory agencies (RoI/NI)	Care destinations (clinics) may not be prepared for/aware of pre-existing medical conditions (RoI) Lack of follow-up as patients move between services – **patients fall out of health care system**. (NI/RoI) **Movement between providers/systems not standardized**. Informal, ad hoc pathways. **Problems of co-ordination/coherence**. (RoI/NI)
Patient disclosures	Confusion surrounding responsibility of staff to report abortion travel may lead to patients withholding information Patients may not disclose important or sufficient details about their medical conditions to destination clinics	Health professionals (NI/RoI)	Difficulty in providing appropriate treatment – **potential for acute health concerns (haemorrhage, infection) to be missed upon return or for medical conditions to be missed/inappropriately handled at destination.** (NI/RoI) Fear among staff about asking patients about abortion pill usage– **'Don't ask, don't tell' (NI)**
Patient engagement	Stigma and social discourse around abortion may deter patients from accessing appropriate/necessary post-abortion care	Health professionals (RoI/NI), advisory agencies (RoI/NI)	**Persistent psychological/emotional difficulties and unreconciled post-abortion trauma** (particularly related to bereavement and grief) (RoI) Undiagnosed medical/health concerns (RoI/NI)

Staffing	Trained, specialist staff may not be available at care providing agencies in Ireland due to limitations in opportunities to perform/discuss abortion. Lack of communication between providers and prohibitions on referral mean patients may not access services with appropriately/adequately trained staff. Particular concern for women with pre-existing/on-going medical conditions. Lack of opportunities to perform abortions/provide abortion care mean staff in Irish hospitals may not be fully trained or sensitive to patient needs	Health professionals (RoI/NI)	Inappropriate care provided to patient or **patient harmed due to lack of specialist care at receiving clinics** (RoI). **Lack of skilled, specialist staff at Irish hospitals**. (NI) **Availability of specialist bereavement and post-abortion counselling a particular concern**. (RoI)
Practical/logistical	Costs of travel mean patients may not stay overnight or may travel to destinations where free accommodation is available (with family or friends). Availability of transport for foetal remains.	Health professionals (RoI/NI), advisory agencies (RoI/NI), non-clinical care providers (Eng)	Patients travel **before** process has completed (i.e. while still bleeding or before success has been confirmed). **Risk of haemorrhage, infection, incomplete abortions**. (RoI/NI) Patients travel to services without specialist staff (in cases of pre-existing, specific medical conditions) or where appropriate care is unavailable. **Risk of inappropriate or inadequate care**. (RoI) Infant remains transported in a way which **compounds complex grief patterns**. (RoI/NI)
Feedback processes	Lack of communication/referral pathways mean feedback is not collected or evaluated systematically. Reports of quality delivered by some patients but in an ad hoc	Health professionals (RoI)	**Care quality assessment cannot take place** – health professionals cannot pass comment on or evaluate quality of care in another setting. Impossible to ensure problems in service/care

	manner.		are dealt with adequately or effectively. (RoI)
Transferral of remains/post-mortems	Absence of transferral pathway for foetal remains (in cases of termination for medical reasons) and inability to conduct post-mortems on remains from clinics outside Ireland.	Health professionals (RoI)	**Diagnoses of chromosomal anomalies or underlying medical conditions cannot be confirmed**. Limits the design and provision of treatment for future pregnancies. (RoI)

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