PRIVACY INTERNATIONAL

Submission to the UK Government's consultation on a new legal framework for abortion services in Northern Ireland

December 2019

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Submitted via online form

Privacy International (PI) welcomes the opportunity to respond to this consultation. Established in 1990, PI is a non-profit organisation based in London, dedicated to defending the right to privacy around the world.

The right to privacy is one of the precedents used to establish reproductive rights, and it is established by several international and regional legal instruments. The primary link between the two stems from the fact that laws and policies which impede upon individuals' rights to access sexual and reproductive health services may also interfere with individuals' right to privacy and to make autonomous decisions as it pertains to their health and fertility.

Sexual and reproductive rights, which are contained within Economic, Social, Cultural, and Environmental Rights, include the right to access to contraception, the right to safe and legal abortion, the right to sexual health information including about contraception and abortion, and other reproductive health services. For example:

The Right to Health is in part established by Articles 10 and 12 of the International Covenant on Economic, Social and Cultural Rights. This refers to all persons' right to the highest attainable standard of health and includes the right to sexual and reproductive health. With respect to sexual and reproductive health, states have an obligation to eliminate discrimination in accessing these services, ensure free and informed consent, reduce infant and maternal morbidity and mortality, ensure that dangerous practices do not impede pre- and post-natal care and access to contraception, and protect vulnerable or marginalized groups of society.

The Right to Non-Discrimination and Equal Treatment in Law is in part established by Article 2 of the International Covenant on Economic, Social and Cultural Rights, Article 1 of the American Convention on Human Rights, and Articles 1 and 2 of the Convention on the Elimination of All Forms of Discrimination against Women. This right refers to every person's right to enjoy human rights without discrimination. With respect to reproductive rights, the Convention on the Elimination of All Forms of Discrimination Against Women prohibits all expressions of discrimination against women. Laws or policies that inhibit women's right to control their fertility, by restricting access to Sexual and Reproductive Health services or by requiring women to have their husband's consent to access sexual and reproductive health services violate this right.

The Right to Life is in part established by Article 3 of the Universal Declaration of Human Rights, Article 6 of the International Covenant on Civil and Political Rights, and Article 4 of the American Convention on Human Rights. This right pertains to signatory states' obligations to implement positive actions to protect life. According to the World Health Organization (WHO), in 2017 approximately 810 individuals died every due to avoidable

causes during pregnancy and childbirth. Preventing individuals from accessing the vital sexual and reproductive health services that will allow them to prevent or delay pregnancy or ensure a healthy pregnancy increases their risk of mortality, and represents a violation of this right.

The Right to Physical Integrity is in part established by Article 7 of the International Covenant on Civil and Political Rights and Article 5 of the American Convention on Human Rights. This right refers to individuals' right to freedom from torture and other cruel, inhumane, or degrading treatment and to be free from medical or scientific intervention, except with their full consent. This right necessitates every persons' right to exercise control over their own bodies, including with regard to their sexual and reproductive life. Rape, forced abortion, forced sterilization, female genital mutilation, and domestic abuse may all constitute violations of this right.

The Right to Marry and Establish a Family is in part established by Article 23 of the International Covenant on Civil and Political Rights, Article 19 of the International Covenant on Economic, Social and Cultural Rights, and Article 16 of the Convention on the Elimination of All Forms of Discrimination. This right refers to couples' right to choose if they would like to have children, become pregnant and have a child, as well as their right to choose the number, timing, and spacing of their children. In 1990, the Human Rights Committee which monitors the International Covenant on Civil and Political Rights published a General Comment specifying that any signatory state sponsored family planning policies should not be discriminatory or compulsory, in line with Article 23.

The Right to Privacy is established by Article 17 of the International Covenant on Civil and Political Rights, Article 16 of the Children's Rights Convention, Article 22 of the Disability Rights Convention, Article 8 of the European Convention on Human Rights, Article 10 of the Convention on Human Rights and Biomedicine, and Article 11 of the American Convention on Human Rights. This right includes the right to confidentiality in the provision of sexual and reproductive health services, especially as it pertains to potentially sensitive issues like HIV/AIDS status, pregnancy, and visits to sexual and reproductive health service providers. This is particularly important for vulnerable groups like adolescents, people living with HIV, and people living with disabilities. This right may be violated by policies which require women to have their husband's consent for sterilization or those which require health personnel to disclose individuals who have undergone abortion.

In our submission, PI will respond to the questions that relate to the introduction of abortion certifications and notification in Northern Ireland. As the consultation questions outline, both abortion certification and notification are based on the model in England and Wales.

Privacy International is concerned that the current abortion notification and certification requirements in England and Wales are out of step with modern data protection law. Northern Ireland has the chance to ensure that law surrounding abortion care is fit for purpose and is privacy and data protection protective by default.

Question 2
Should a limited form of certification by a healthcare professional be required for early terminations of pregnancy?

No.

In the England and Wales, the requirement of abortion certification is tied to Victorian-era law, namely the Offences Against the Person Act 1861 and subsequent Abortion Act 1967. In England and Wales, abortion is legal, but remains within the scope of criminal law. Therefore, certification, which serves no medical purpose, provides protection to health professionals in England and Wales, given the underlying criminality in the mechanisms that regulate it.

In contrast, in Northern Ireland the Northern Ireland (Executive Formation etc) Act 2019 (NI EF Act) decriminalises abortion and requires a new framework to provide lawful access to abortion services, which this consultation seeks to address. Therefore, introduction of certification does not have the same basis nor serve the same purpose.

Certification should not be introduced without a clear need and purpose and no such justification is provided in the consultation document.

Data protection law, in Northern Ireland as in the rest of the UK (the UK Data Protection Act 2018 together with the General Data Protection Regulation) requires that the collection and sharing of data (which would be inherent in a certification process) be necessary and have a clear purpose and legal basis. Furthermore, personal data should be adequate, relevant, and limited to what is necessary for such purpose (data minimisation). Therefore, introducing unnecessary certification, with the data collection and sharing it entails risks going against important data protection principles such as data minimisation and other requirements of data protection law.

Question 10
Do you consider a notification process should be put in place in Northern Ireland to provide scrutiny of the services provided, as well as ensuring data is available to provide transparency around access to services?

No.

If you answered 'no', what alternative approach do you suggest?

Privacy International is concerned that the abortion notification procedure in England and Wales is out of step with modern data protection law, namely the General Data Protection Regulation (GDPR) as supplemented by the UK Data Protection Act 2018.

As acknowledged in the consultation document, the Northern Irish context varies greatly from the English and Welsh contexts, namely that as a result of the NI EF Act, abortion is a medical procedure outside the scope of criminal law. However, there are other contextual

factors that must be taken into consideration in the introduction of a notification scheme, including that abortion in Northern Ireland is newly legal, is still a highly contentious issue and Northern Ireland is also far smaller.

The HSA4 form used for notification in England and Wales covers vast amounts of personal information from unique identifiers such as name, NHS number postcode or full address, and date of birth, together with ethnicity, marital status, information about previous pregnancies, details of the treatment as well as grounds for terminating the pregnancy and any complications. It also contains the details of the practitioners that certified the abortion.

The form thus contains intimate and sensitive personal data, including special category personal data (including health data and data about an individual's ethnic origin) which are subject to even more stringent protections under Article 9 of GDPR.

Notification in England and Wales is mandated by law under the Abortion Act 1967, and the form included in the Abortion Regulations 1991. As noted in the consultation document, the purported purposes is to ensure appropriate public and parliamentary scrutiny and trust in the data, that is then used for statistics that are published anonymously by the Department of Health for use by a wide range of people and to inform policy and services decisions, debate and scrutinise the application of legislation.

However, from the available information, there is no clear justification provided for the inclusion (and collection) of each of these data points on the form nor any explanation of why this extremely sensitive information is gathered and shared in such a format that immediately identifies those involved, with no attempt to minimise, separate or even pseudonymise the personal data.

Furthermore, from the Department of Health guidance available online, it is unclear if and how patients are informed that this information will be shared and why, who it is shared with, and how long this information is stored as well as how it will be kept and transferred securely.

It appears that the form has not been revised since 2006 and the Department of Health Guidance on filling it out since 2013.

Therefore, it is unclear how the collection and sharing of this personal data complies with the data protection principles set out in Article 5 of GDPR including transparency, fairness, purpose limitation, data minimisation, storage limitation and integrity and confidentiality. Furthermore, given the inherent risks, how the obligation of data protection by design and by default has been implemented.

Taking into account these concerns with the current notification system in England and Wales, together with the differences in the Northern Irish context Privacy International's view is that no similar notification requirement should be introduced and the gathering of any data for statistical purposes should be built on data protection by design and default and ensure compliance with data protection law. Given the sensitivity of the information it may advisable to do this in consultation with the Information Commissioner's Office.

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