

Birth information and tracing law: the GP role

Stephen O'Leary looks at the important role of the GP in acting as a conduit for the release of information on patients under recent birth tracing legislation

SOME GPs MAY BE ASKED TO ACT as a conduit for the release of medical information to their patients under the Birth Information and Tracing Act 2022.

The Act introduced welcome access to important personal information held by the State and various residential institutions, to those who have been adopted. The provisions of the legislation also apply to people who were the subject of an illegal birth registration, were resident in a mother and baby home institution or were placed in a care arrangement.

Much of the records in question will relate to the applicant's own personal and care history: birth records and general information, such as information about their birth and early life.

It is also possible for an adopted person to obtain limited medical information about a genetic relative which is relevant to their own medical history or health, and this is where a GP may be asked to assist.

Given the sensitive nature of this information, and the need to respect the privacy of those relatives, the Department of Children, Equality, Disability, Integration and Youth has published guidelines¹ on the type of health information that should be released to doctors, and their role in providing this information to their patient. Under these guidelines, which are addressed in more detail below, any genetically relevant information is released to a nominated registered medical practitioner – typically, but not always, a GP.

The Act permits an individual to have access to a third party's information. Given the potentially serious ramifications if any step of the process is not carried out correctly, it is important that GPs familiarise themselves with the role and obligations of a doctor under the Act and the guidelines made thereunder.

Application

Section 16(1) of the Act provides that a person over 18 may apply in writing to the Child & Family Agency, the Adoption Authority of Ireland or a specified relevant body as appropriate for medical information that is:

- Contained in a record held by a relevant body which comes under the Act
- Relates to his or her genetic relative, and
- Is relevant to the person's genetic health. There is a similar process for applicants aged 16 and 17.

Section 16(2) of the Act states that the relevant body shall provide the information sought to the relevant person only if it is satisfied that the information applied for is relevant to the health of the applicant. This health information will only be released to the applicant via the applicant's nominated medical practitioner.

The Act is very clear that any information that is released to an applicant must comply with data protection obligations and the information provided shall not disclose:

- The name of the person whose information is being released, or
- The genetic relationship with the applicant.

Guidelines were published in October 2022 which set out in more detail how the process for the release of genetically relevant health information should work.

The guidelines

The Department of Children, Equality, Disability, Integration and Youth (DCEDIY) published its guidelines under the Act in October 2022.¹ Section 3 of those guidelines covers the release of genetically relevant information via a nominated medical practitioner. Given that the Act permits access to third party medical information, there are safeguards in place to ensure that this is dealt with appropriately.

The role of the registered medical practitioner in the process is to explain the medical terminology used, provide some context around the use of antiquated medical terms which may well cause upset, and to follow up with any necessary tests or examinations that may be necessary.

As part of the process, the medical practitioner will be provided with a 'Medical Information Statement'. This statement will contain all the relevant information regarding the genetic or hereditary conditions that the applicant is to be informed of.

Under the Act, an applicant's 'genetic relative' is defined as:

- His or her mother or father
- A child or parent of his or her mother or father
- A sibling, uncle, aunt or first cousin of his or her mother or father, whether the relationship is of the whole blood or half-blood
- A person to whom, but for the adoption of any person, the above would apply.

The Medical Information Statement will not name the relative or specify which relative(s) had the particular genetic or hereditary condition but will instead state 'male relative' or 'female relative'. This is in order to protect the privacy of the person whose information is being released.

It is important to note that Section 3.9 of the guidelines clearly states that the applicant will not be provided with a copy of their relative's medical records, but rather they will only receive the Medical Information Statement. The guidelines also state:

- It should be noted that once information is identified as relating to a genetic condition, the material is to be

released without knowing anything about the medical history of the applicant. The description of medical information should provide the precise wording of the condition minus any identifying information.

Section 3.3 of the guidelines makes clear that medical information encompassing diseases, syndromes or medical conditions believed to be genetically transmissible will be released. Where it is unclear whether a particular disease or condition is genetic or hereditary in nature, the relevant body which is compiling the Medical Information Statement can seek guidance from the DCEDIY Adoption Policy Unit.

It is not the role of the registered medical practitioner to make any decision or determination about whether the information on the Medical Information Statement is genetically relevant or not.

Potential issues

Doctors deal with highly sensitive and confidential information every day. The key change brought about by this Act is that they are now being provided with the highly sensitive personal information of a third party – with whom they have no relationship – in order to pass this information on to another.

As part of the process, the patient will be informed that the Medical Information Statement has been sent to their nominated GP. It is crucial, therefore, that before releasing any information to the patient, the GP carefully reviews the Medical Information Statement that has been provided to them to ensure that it is correct. The Statement should

only include relevant genetic or hereditary conditions and nothing further. This statement should also only provide this information on an anonymised basis by referring to a ‘male relative’ or ‘female relative’.

If there is any additional material provided, or a GP believes any inappropriate material has been included, or any individual is identifiable, then it is imperative that they contact the information officer who provided them with the information as a matter of urgency. This will ensure that the concerns can be addressed before a meeting with the patient to discuss the information.

Finally, it is important to bear in mind that the Medical Information Statement will be compiled without any knowledge as to the health of a GP’s patient. Therefore, it will be important that the release of this medical information to the patient is handled in a sensitive and appropriate way and if follow-up testing or counselling is required that it is borne in mind.

The government website www.birthinfo.ie provides the contact details for various bodies providing counselling. Should you have any queries in relation to this process, you should contact the Child and Family Agency, the Adoption Authority of Ireland or your indemnifier for further advice. 

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Reference
1. <https://www.birthinfo.ie/about-the-legislation>

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