

Joint Committee on Children, Disability, Equality, Integration and Youth
Pre-legislative scrutiny of the general scheme of the Birth Information and Tracing Bill
Opening Statement of the Data Protection Commission
13 July 2021

I thank the committee for the invitation to contribute to your deliberations on the general scheme of the Birth Information and Tracing Bill. I am one of the Deputy Commissioners at the Data Protection Commission (DPC), with responsibility for the DPC's supervision, guidance and international affairs functions. Also in attendance is David Murphy, Assistant Commissioner, from the DPC's supervision section.

By way of general observation, we note that the broad intention of the draft Heads of Bill is to provide "relevant persons" aged 16 or over with access to a range of records and information including their birth certificate, early life information, care information, and medical information

The 1998 ruling of the Irish Supreme Court in *IOT v B and the Rotunda Girl's Aid Society*, and *MH v Rev GD* and the society found that neither of two constitutional rights – the right to know about your origins and the right to privacy – were absolute and that each might be constrained by the weight of the other, as well as the weight of the common good. This has resulted in a position where agencies in Ireland tasked with providing access to birth and early life information of adopted persons have had to do their best case-by-case to balance the competing rights in the cases on-hand.

The DPC notes the intention of the Oireachtas to now pass legislation codifying how the balancing of these non-absolute rights should be achieved with a start and end point in favour of the right to identity information.

The DPC considers that it is important in the context of this Bill that clear articulation is given to the proposed policy position to be adopted in favour of providing birth certificates to relevant persons over 16 without any process allowing for objection (for example, on grounds that it would seriously harm them) by a birth parent. Given that the previous iteration of this Bill outlined such a process, it is important that there is clarity around the policy change and why the balancing of rights in these sensitive situations is now deemed to have changed in favour of an absolute right to identity data. To be clear, the DPC does not advocate for either position – rather we simply point out that data protection and privacy issues arise and the State must be able to articulate how it has come to the policy position and what considerations underpin the balancing of rights presented in the bill.

With regard to the balancing of rights, it is clear that in terms of the General Data Protection Regulation (GDPR), Article 15 – the right of access to personal data – is not absolute. Article 15.4 states that the right to obtain a copy of personal data shall not adversely affect the rights and freedoms of others. This underlines the need for the Oireachtas to be clear in the context of the bill as to how the rights and freedoms of the birth mother are not adversely affected to the extent they would restrict the right of access.

In order to be of assistance to the work of the committee, appended to my opening statement are the preliminary observations of the DPC on the Bill, as provided to the Department of Children,

Equality, Disability, Integration and Youth. These observations address the balancing of rights in addition to other data protection considerations such as the importance of transparency, the difficulties in treating data (including medical data) as anonymous in this context, and the limitation or restriction of rights provided under GDPR. The Department has responded positively to the DPC's observations and has committed to further addressing the matters raised.

As part of the consultation process, we have been advised by the Department that a Data Protection Impact Assessment (DPIA) is currently being developed, which is welcomed. The DPIA process provides an opportunity to interrogate the proposed processing of personal data in depth in terms of its justification on the basis of necessity and proportionality, in particular the balancing of the right to access to identity on the one hand, and data protection and privacy rights on the other. The DPIA process also provides an opportunity to identify and mitigate any data protection risks that arise.

We note that many of the operational aspects of this Bill may be formulated by way of Guidelines, including the conduct of the tracing function. The DPIA process will also be key to formulating guidelines and consideration should also be given to the implementation of appropriate data protection policies by the bodies involved to ensure the correct application of technical and organisational measures to ensure compliance with data protection law.

I hope these comments will be of assistance to the committee and I am very happy to answer the questions members may have.

Observations on the Draft Birth Information and Tracing Bill 2021

1. The Data Protection Commission ('DPC') welcomes the opportunity to provide observations on the Draft Bill and, in general is in favour of seeking to bring legislative clarity to an extremely sensitive subject matter while ensuring that appropriate data protection safeguards are in place.
2. By way of general observations, we note that the draft Heads of Bill seek to provide "relevant persons" aged 16 or over with their birth information, early life information, care information, medical information and provided items (Head 5). The DPC considers (while acknowledging that a Data Protection Impact Assessment remains to be completed) that it is important in the context of this Bill that clear articulation is given to the policy shift that has occurred in favour of giving out birth certificates to relevant persons over 16 without any process allowing for objection (on grounds it would seriously harm them) by a birth mother. Given the previous Bill outlined such a process, it is important that there is clarity around the policy change and why the balancing of rights in these sensitive situations is now deemed to have changed in favour of an absolute right to identity data. To be clear, the DPC is not advocating either position – it is simply pointing out that data protection and privacy issues arise and the controller (the State) must be able to articulate how it has come to the policy position and what considerations underpin the balancing of rights.
3. Clearly the proposals outlined in this draft Bill may heavily impede on the data protection rights of a birth parent in favour of the right of an individual to their identity. Whilst it is noted that the rights at play are not absolute, it is worth restating that in order to be compliant with data protection rules, the proposals as set out in this draft Bill which involve the processing of personal data need to be applied in a proportionate manner and demonstrate they are not overly prejudicial to the fundamental right of the individual to data protection. Any restriction to the right to data protection as enshrined in Article 8 in the EU Charter of Fundamental Rights must also comply with the requirements laid down in Article 52(1) of the Charter. Therefore, if enacting such provisions, the Department needs to conduct a careful balancing test to ensure the right to data protection in this case must cede - in a necessary and proportionate manner - to the legitimate interests of the State and the public interest in ensuring that the primary and underlying policy objective will be met by the processing of this personal data.
4. The DPC would also be interested to understand what consultation in advance of the Bill publication has taken place with Tusla, AAI and, representatives of the birth mothers that may be concerned with the proposed changes the Bill will bring.
5. The DPC understands that a Data Protection Impact Assessment ('DPIA') is being drafted to accompany the draft legislation. This should assist in the assessment of the

conflicting rights at play, the right to identity on the one hand and the right to data protection and privacy on the other. It is also noted that many of the operational aspects of the Bill will be formulated by way of guidelines (Head 14). A comprehensive DPIA will be key to formulating appropriate guidelines.

6. There are various actors, which are set out as primary and secondary sources in Head 2, that are involved in the release of the different types of information that are required to be provided to a relevant person. Furthermore, the Act foresees that “a person” who can be designated as a secondary information source or “a person” other than an information source is required to provide information to the Authority. The legislation should make it sufficiently clear who are the data controller(s) with respect to the personal data stored in the Contact Register, the personal data stored with the primary and secondary sources and with “a person” other than an information source.
7. The following paragraphs provide comments on specific Heads in the Bill.

Head 3 and 7: Applying for a copy of a birth certificate and birth information

8. The DPC notes that where an application is made in accordance with Head 6, Head 3(1) and Head 7(1) provides that a relevant person who has attained the age of 16 shall have a right of access to his or her birth certificate and birth information.¹ There are no circumstances under which an individual will be refused access to their birth certificate.

¹ Birth Information, means the categories of information contained in the register of births maintained under section 13 (1)(a) of the Civil Registration Act 2004 but excluding the Personal Public Service Number of a birth parent. Pursuant to Part 1 of the First Schedule the following information forms part of “birth information”

- Date and place of birth.
- Time of birth.
- Sex of child.
- Forename(s) and surname of child .
- Personal public service number of child.
- Forename(s), surname, birth surname, address and occupation of mother.
- Former surname(s) (if any) of mother.
- Date of birth of mother.
- [Civil status] of mother.
- Birth surname of mother's mother.
- Forename(s), surname, birth surname, address and occupation of father.
- Former surname(s) (if any) of father.
- Date of birth of father.
- [Civil status] of father.
- Birth surname of father's mother.
- Forename(s), surname, birth surname, address and occupation of parent.
- Former surname(s) (if any) of parent.
- Date of birth of parent.
- Civil status of parent.
- Birth surname of parent's mother.
- Forename(s), surname, qualification, address and signature of informant.
- Date of registration.
- Signature of registrar.

9. Acknowledging that the release of a birth cert raises data privacy issues, the Bill proposes a number of measures, these include:

- That only an individual aged 16 or older can be issued a birth certificate, (Head 3 (1)),
- Allowing birth parents to register their contact preference on the Contact Preference Register, (Head 3 (2)),
- An information campaign during the three month time period following the commencement of Section 3 of the Bill (Head 3(4)),
- That a relevant person can only apply for a birth certificate following the passing of the three month time period as set out in Head 3(4)),
- The requirement for relevant persons to attend an information session with a social worker if a birth parent has indicated that they are not willing to be contacted by the specified person (Head 3 (12)).

10. The DPC notes that the time period of the information campaign (3 months) and the time period for a birth parent to register a contact preference are tied, and it amounts to the same time period that must pass before a relevant person can make an application for a birth certificate. In the DPC's view, the information campaign will need to provide individuals with adequate notice and information to understand the implications of this piece of legislation. Ultimately, it is a matter for the legislature to assess whether the three month time period, which on the face of it, seems quite short, is adequate given the data protection and other rights at play. Consideration should also be given to whether additional outreach is required for individuals who indicated a no contact preference in the National Adoption Contact Preference Register, which will be transferred over to the Contact Preference Register pursuant to Head 20.

11. The DPC notes that the information session that a relevant person is required to attend if the birth parent has indicated that they are not willing to be contacted will inform the person of:

- a) the birth parent's contact preference,
- b) the birth parent's privacy rights, and
- c) the importance of respecting their contact preferences.

However, this session is only required where a no contact preference is registered. Taking into account the short timeframe for birth parents to register their preference, the fact that it is very feasible that many birth parents will not know about the change in legislation despite the information campaign that will be launched, (also taking into account the short timeframe), and the fact that many birth parents may not be minded to do so given the fact that their no contact preference will not negate the release of the birth information, it is recommended that the information session is also extended to relevant persons whose birth parent(s) have not entered a preference on the register.

12. In instances where both birth parents indicate a different contact preference (one not willing to be contacted the other willing to be contacted) clarity would be welcome as to whether an information session is required prior to the release of a birth certificate.

13. The Head places no obligation on the relevant person to abide by the wishes of a birth parent. Similarly, there is no requirement for a relevant person to sign a declaration stating that they attended the session and they intend to abide by the wishes of the birth parent. Neither is there a sanction available if a relevant person does not abide by the wishes of the birth parent. It is recommended that an assessment is carried out as to whether the attendance of the information session by itself is adequate to protect the data protection rights of the individual or whether alternative or additional safeguards are available for consideration. As part of this assessment, it is recommended that Section 36, and in particular Section 36(2) of the Data Protection Act 2018 are considered when assessing the relevant safeguards required to protect the rights and freedoms of the relevant parties.
14. Clarity would also be welcome on what steps can a relevant body take to verify the identity of a relevant person prior to the release of the information where a person reasonably believes themselves to be a relevant person as defined in Head 6.

Head 8 and Head 9: Release of early life and care information

15. Where a relevant person makes an application to a relevant body for their early life and care information, Head 8 and Head 9 respectively provides that the relevant body shall provide the applicant with a copy of the information requested.
16. Early life information is defined in Head 2 of the Bill. The DPC notes that the explanatory note neither in Head 2 nor in Head 8, make reference to the possibility that early life information might be considered the personal data of a third party. Point (h) in the definition of “early life information” refers to “*information on whether a birth parent or birth relative visited or inquired in relation to the person, including the degree of relationship to the relevant person but excluding the name of the birth parent or birth relative*”. This information can also constitute the personal data of a third party.
17. Care information includes the names of persons who cared for the relevant person as part of different care arrangements set out in Head 2 as well as the names of any person who made arrangements for the adoption, the foster care arrangement or nursed or boarded out arrangements for the relevant person. These records will contain third party data related to people who provided care to the applicant on behalf of, or paid for by, the State. It could also include those who made arrangements for the provision of such care. While the DPC understands the importance of the right to identification and information relating to early childhood, the Department should satisfy itself that it is necessary and proportionate for this information to be provided to a relevant person. Particular care in relation to processing of special category data as defined by Article 9 is required.

Head 10: Relevant Body to provide medical information

18. Head 10 provides that where a relevant person makes an application in accordance with Head 6, a relevant body shall provide the applicant with a copy of medical

information. Head 2 provides that “medical information” means, “*in relation to a person, information relating to his or her medical history, or the medical history of his or her birth parent, or a birth relative, insofar as it is relevant to a person*”.

19. The DPC requests clarification as to how the *relevance* of the medical information of a birth parent or relative is determined. This is third party special category personal data, likely to be subject to medical confidentiality, and the process of the assignment of “relevance” in the context of the consideration of disclosure should be clear. It notes that the Authority may issue guidelines with respect to the type of medical information that is likely to be of relevance and which is necessary to be released for reasons of substantial public interest. The DPC notes that this provision may come into effect prior to any guidelines being drafted, and also notes that the drafting of said guidelines are not obligatory. The development of such guidelines should also be considered in the DPIA the Department is currently preparing, taking into account the potentially serious encroachment on the privacy and data protection rights of the third parties affected.
20. In considering the necessity and proportionality of this particular provision, it would be useful for the Department to explain how the provisions of this Head tallies with access to medical information that might be provided to a person in relation to a birth relative outside the context of this Bill. The DPC also notes the definition of a birth relative is quite broad, which includes any person “*who would, but for the adoption of any person, be a relative of his or her birth mother or birth father*”.
21. Subsection 2 provides that the release of the medical information will only be where it is necessary for reasons of “substantial public interest” that the applicant is provided with such information. The DPC asks the Department to identify the substantial public interest benefits in processing the special category data in the manner set out in Head 10, and demonstrate that the foreseen processing is necessary, proportionate and complies with the data minimisation principle.
22. Subsection 3 provides that the identity of the birth parent or relative, will not be provided unless necessary to do so for medical reasons. The explanatory note provides that the information related “*shall not identify the birth parent or relative*”. However, depending on the make-up of a particular family and the particular medical information being disclosed, it may be quite possible to identify the person who has a particular medical condition. From a data protection perspective, personal data is defined in a broad manner and means any information relating to an identified or identifiable natural person. An identifiable natural person is one who can be identified, directly or indirectly.
23. It appears that the birth relative will not be asked for permission to disclose the information in question nor will they be informed that their medical information will be released. The DPC highlights the transparency obligations that are required of a controller set down in Article 13 and 14 GDPR. The explanatory note references Article 23 GDPR and provides that the rights of data subjects/others would be covered by Article 23(1)(i) GDPR. However, no reference is made to the particular right(s) that may be curtailed. The DPC would ask that clarification is provided as to what right(s) it

proposes to curtail with respect to this provision, if any. Any restriction must respect the essence of the right and be necessary and proportionate to safeguard the measure in question. The DPC also points out that legislation restricting data subject rights must be explicit as to which rights are being restricted and have regard to the requirements of Article 23(2). Note that pursuant to Article 23(2)(h), data subjects have the right to be informed of the restriction.

24. Any release of medical information, should give consideration to the potential for harm to the physical or mental health of the relevant person, birth parent, or birth relative in line with the Data Protection (Access Modification) (Health) Regulations, 1989. This is also true for the sharing of medical information pursuant to Head 18 of the Bill.

Head 12 and Head 15: Provision of a tracing service and the facilitation of contact or information between parties.

25. It appears that the operational aspects of the tracing service have not been set down in the Heads of Bill and will instead be formulated by way of guidelines (Head 14). Similarly, the steps taken to conduct a trace are also left to guidelines. Head 15 provides that once an application is received, the AAI or Tusla will take all reasonable steps in accordance with any guidelines produced pursuant to Head 14 to locate the specified person concerned. Any reasonable steps to locate the individual would, if it involves processing personal data, require a lawful basis under Article 6 GDPR. How a relevant person or a birth relative will be informed of a trace application and the consequence of the trace, if located, are of utmost importance in light of these individual's data protection rights. It is noted that Head 16(4) provides that a person will be notified of the circumstances in which the information contained in the entry relating to him or her, may be released to a third party. It is recommended that a DPIA also considers the issue of notification and consider measures which ensure the data protection rights of individuals are appropriately protected.
26. With respect to subsection 5 of Head 15, the DPC asks the Department to confirm whether the sharing of information will take place on the basis of consent? If so, what measures will be put in place to ensure the validity of consent? Article 4(11) GDPR sets down the definition of consent, and amongst other criteria, requires it to be freely given and informed. How will the AAI or Tusla be in a position to satisfy themselves that all data subjects sufficiently understand the consequences of data sharing with another party?
27. Linked to this, Head 17 provides that "*a person may lodge medical information or provided items which they wish to be shared with a specified person*". It is important that the AAI be in a position to satisfy itself that persons fully appreciate the consequences of the release of their medical information to a relevant person, and that they are properly informed of the consequences to meet the consent definition as set down in Article 4 (11) GDPR.
28. Head 18 provides that when medical information is lodged in the Register with respect to a specified person, the specified person will be provided with the contact details of

the person in order to facilitate contact. It is not clear if contact details will also be provided for other purposes (for example, if a birth parent willingly wants to make contact). While it is not necessary to set down the exact procedure by way of legislation, it is important, in light of the principles of fairness and transparency, that individuals are aware of how their data will be treated and when and how their details will be passed on to third parties.

29. The DPC notes that as part of the tracing service, subsection 4 of Head 12 provides that the Child and Family Agency (Tusla), and/or the Adoption Authority of Ireland (AAI) shall have the power to conduct a trace, upon direction of the Minister when the Minister deems it necessary and in the public interest in relation to specific individuals or cohorts of individuals. While the DPC notes the limited circumstances this provision can be invoked, it could result in a significant encroachment in an individual's data protection rights.

30. Subsection 2 sets out when a trace can be carried out, which includes:

- facilitating contact;
- in the case of a relevant person, requesting further information in relation to the relevant person's birth, early life, care or any other matter, medical information or any contemporaneous information;
- in the case of a relative or birth relative of a relevant person, requesting further information in relation to the relevant person or providing information relevant to that person.

It appears that subsection 4 is not limited to a particular tracing service. The Department should demonstrate that it is necessary and proportionate for a Minister to authorise an unlimited trace, unbeknownst to the individual, which could include the release of medical information. The Department should also note the lawful basis under Articles 6 and 9 GDPR for the processing of such personal data.

Head 13: Agency and Authority may request information

31. This Head provides a basis for Tusla or the AAI to request information from third parties to facilitate a trace. The DPC notes that this provision is not limited to State Agencies or organisations, but extends to a person with information or access to information that is in their possession or control for the purpose of facilitating a trace. Subsection 3 provides that *"Notwithstanding any enactment or rule of law, a person who receives a request made under subsection (1) shall comply with the request"*.

32. This provision provides a statutory basis for the sharing of information with Tusla and AAI. The explanatory note provides that the third parties in question include Government Departments, the HSE and Church authorities. However, the provision, as currently worded, applies to "a person" who meets the criteria set out in subsection (1). Clarification is sought as to whether reference to "a person" is limited to persons prescribed under Head 22 to be a secondary information source. The standard as to when a request can be made by Tusla or the AAI, is when they "reasonably require" the

information, and the provision does not specify what type of information could be reasonably required to facilitate a trace. The Oireachtas should satisfy itself that it is necessary and proportionate to require a person to provide information reasonably required by the AAI or Tusla to conduct a trace taking into account the extent and level of the interference which all parties are obliged to comply with.

33. Head 23 also provides that where “a person” is in possession of relevant records, they shall as soon as possible inform the AAI and maintain them appropriately. Head 24 empowers the AAI to issue a direction to a person, other than an information source, to transfer relevant records to it. It is suggested that any information campaign also highlights the obligations on “a person” in possession of relevant records to notify the AAI and handle them appropriately.

Head 31 Amendment or Cancellation of entries in the Register of Births

34. This Head provides that An tArd-Chláraitheoir is entitled to register, amend or cancel an entry in the Register of Births to ensure that the particulars of birth of an affected person are accurately and correctly recorded in the Register of Births. Subsection 2 provides that An tArd-Chláraitheoir will make reasonable attempts to notify the individuals affected, and that affected persons can make submissions in respect of same and they are also provided with a right of appeal. The DPC notes that in effect, the result of this provision could be that a person’s entry is changed unbeknownst to them. Consideration should be given to the practical consequences of this, and the requirements of Article 14 GDPR.

Head 40: Restriction of rights and obligations under the GDPR

35. Head 40 provides that all rights and obligations, as provided for in Articles 12 – 22 and Article 34 and Article 5 GDPR, (in so far as any of its provisions correspond to the rights and obligations in Article 12 to 22), will be restricted pursuant to Article 23 (1)(i) GDPR, *“to the extent necessary to enable persons to access birth and related information in accordance with the provisions of this Act and to enable the Agency and the Authority to provide a tracing service in accordance with the provisions of this Act”*.
36. Any restriction needs to respect the essence of the right in question, and must be shown to be necessary and proportionate to safeguard the protection of the data subject or the rights and freedoms of others. Furthermore, any restriction would need to meet the criteria set out in Article 23(2) GDPR, including informing data subjects about the restriction (Article 23(2)(h)). The extent of the restriction (potentially all rights) for a potentially unlimited amount of time raises serious questions as to whether Head 40 meets this standard. The Department should review this provision in light of the requirements of Article 23 and demonstrate how the provision as currently worded, meets the standard prescribed by Article 23. For more information on the restriction of data subject rights see our guidance note on [limiting data subject rights and the application of Article 23 of the GDPR](#).