

Department of Children, Equality, Disability, Integration and Youth

Data Protection Impact Assessment (DPIA) For Institutional Burials Bill, 2022

Drafting of the DPIA

The drafting of this Data Protection Impact Assessment is an iterative process and this document will continue to be reviewed and updated depending on the stage of the legislative process being completed. Previous versions of this DPIA have been used for consultation with the Department's Data Protection Officer and the Data Protection Commission.

Executive summary

High level description of Project

The Institutional Burials Bill seeks to ensure that the remains of those who died in residential institutions, and who were buried in a manifestly inappropriate manner, may be recovered and re-interred in a respectful and appropriate way. It also provides for the identification of remains and their return to family members, where possible. The paramount aims of the legislation are to accord dignity to the deceased and give effect to the rights of their family members.

In summary, the Bill provides for:

- The Government to direct intervention at a site and to approve the appointment of a Director to head up an Office (Office of the Director of Authorised Intervention) to oversee and manage this intervention. A Director will be a corporation sole but will be responsible to the relevant Minister for the performance of his/her functions.
- The establishment of an Advisory Board to provide advice and guidance to a Director in undertaking his/her functions. The Advisory Board will be chaired by a person with coronial expertise and will include members with scientific expertise and former residents or family

members of deceased persons believed to be buried at the site. Consultation with the Advisory Board will be required at regular intervals, including at key decision points in the intervention.

- A legal basis for a phased, step-by-step approach to an intervention which will comprise the following steps:
 - Excavation of the site
 - Recovery of human remains
 - Post recovery analysis of remains
 - Identification of remains through DNA familial matching (if possible)
 - Return of remains to family members or respectful re-interment of remains in line with the wishes of their family members

All of the steps will be undertaken to a forensic-standard in line with international standards and best practice.

The legislation also provides for temporary rights of access to the land where an intervention is to take place, with an obligation to provide reasonable compensation and to restore land to its original condition and use upon completion.

Central to data protection considerations is the identification programme, which involves processing personal and genetic data of living persons (as well as human remains).

Summary: scope of processing

Entry to the Identification Programme:

- Public records (e.g. birth certificates, death certificates), affidavits and other documents (copies of registers, institutional records, letters) submitted by potential relatives;
- Public records (e.g. birth certificates, death certificates), institutional records, medical records - obtained by the Director

Taking and storing biological samples; generating DNA profiles and testing:

- DNA profiles – generated from biological samples taken from potential relatives by authorised persons appointed by the Director
- DNA profiles – generated from elimination samples taken from employees, contractors and relevant FSI personnel by authorised persons appointed by the Director
- DNA profiles – entering DNA profiles into the DNA (Historical Remains) Database for the purpose of DNA profile comparison. DNA profiles generated from samples taken from potential relatives will be compared with profiles generated from samples of human remains

Results of forensic tests

- Notification of the results of forensic testing from FSI to the Director
- Notification by the Director to potential relatives of whether or not familial link has been established based on the results of forensic testing and non-genetic data (birth/death certs, institutional records, other documents (e.g. letters) and post-recovery analysis of remains). To note: As post-recovery analysis relates to deceased persons it is not considered processing of personal data

Employment and engagement of contractors

- Personal information (name, address, contact details) disclosed by employees, contractors (including advisors/consultants), Advisory Board members and the Director in the context of employment and business contracts

Access to burial land

- Personal information (name, address) obtained in relation to owners and occupiers in the context of accessing burial land for the purpose of carrying out excavation and related works. Genetic data will not be required from owners and occupiers.

Summary: purposes for which processing will occur

The legislation seeks to provide for the excavation, recovery, analysis, identification (if possible) and re-interment of human remains buried in a manifestly inappropriate manner.

Personal data and genetic data will be processed to enable the implementation of an Identification Programme. Personal data (documents) will be processed to establish eligibility to participate in the Programme. Genetic data will be processed (generating and comparing DNA profiles) alongside non-genetic information (examination of records and finding of post-recovery analysis e.g. age of death) to establish the likelihood of a familial link between living relatives and human remains. Arrangements will subsequently be made for the dignified re-interment of remains.

Personal and genetic data of employees and contractors/advisors/consultants will also be processed in relation to the administration of the Office of the Director of Authorised Intervention and the implementation of the Identification Programme. Personal data of owners and occupiers will be processed in the context of accessing burial lands associated with former institutions.

Summary: intended benefits for data subjects, third parties and the organisation

The Institutional Burials Bill seeks to ensure that the remains of those who died in residential institutions, and who were buried in a manifestly inappropriate manner, may be recovered and re-interred in a respectful and appropriate way. It also provides for the identification of remains and their return to family members, where possible.

Summary: rationale as to why a DPIA is required

This DPIA is required on the basis that the legislation underpins:

1. processing of personal data (including date of birth, name, address, family relationship, objection or no objection to the participation of family members in an Identification Programme),
2. processing of special categories of personal data (generating and comparing DNA profiles and providing results of such forensic tests to family members).

The Data Protection Impact Assessment supports an evaluation of the approach taken in the legislation to realise the objectives of recovering and identifying human remains and providing for

their dignified reburial, with a particular focus on data processing activities envisaged. In light of the fact that personal and special categories of personal data will be processed, and the potential consequences of any potential breach and misuse of such data, the DPIA helps ensure that sufficient consideration is given to safeguarding the rights and freedoms of data subjects through the legislative framework and as well as through the future operational infrastructure.

Step 1a: DPIA Screening Checklist

Does your project involve:	Yes	No
Evaluation or scoring of personal data (including profiling and predicting)		x
Automated decision-making with legal or similar significant effects		x
Systematic monitoring including through a publicly accessible place on a large scale		x
Sensitive data or data of a highly personal nature (including special categories of data and criminal data)	x	
Data processed on a large scale		x
Datasets that have been matched or combined	x	
Data concerning vulnerable individuals (including children)	x	
Innovative use or applying technological or organisational solutions	x	
Data transfers across borders outside the European Union	x	
Processing preventing data subjects from exercising a right or using a service or contract		x
If you have answered 'Yes' to any of the above questions, you must carry out a DPIA.		

Step 1b: Need for a DPIA

Explain broadly the business context – what the overall project aims to achieve and what type of processing of personal data it involves. It would be useful to list the categories of personal data and the data subjects affected (although this is provided for further below). You may find it helpful to refer or link to other documents, such as a project proposal. Summarise why you identified the need for a DPIA (this can draw on your answers to the screening questions).

The Commission of Investigation into Mother and Baby Homes was established in 2015 to investigate and report on a wide range of issues associated with the institutions, including burial practices. In March 2017 the Commission confirmed the presence of juvenile human remains at the site of the former Mother and Baby Home in Tuam, Co Galway. In response, the then Minister for Children and Youth Affairs commissioned an Expert Technical Group (ETG) to outline the options available for responding appropriately to the situation.

In October 2018 the Government decided that a phased forensic standard excavation, recovery, identification (if possible) and re-interment of the remains should be carried out at the full available site at Tuam. The Attorney General advised that new legislation was required to implement the decision. In December 2019 the Government approved and published the General Scheme and Heads of Bill, which set out the main legal changes or provisions of the proposed legislation. The General Scheme was scrutinised by an Oireachtas Committee during the first half of 2021. The legislation was reviewed to take account of feedback from the Oireachtas Committee and other stakeholders.

The Institutional Burials Bill seeks to ensure that the remains of those who died in residential institutions, and who were buried in a manifestly inappropriate manner, may be recovered and re-interred in a respectful and appropriate way. The legislation provides the required legal basis for intervention at sites of former institutions where manifestly inappropriate burials took place. Under the legislation the Government may, by order, direct a relevant Minister to establish an Office of Director of Authorised Intervention to intervene at a burial site for a specific period. The order shall specify the functions to be carried out by the Director such as accessing and carrying out works on burial land associated with a former public institution, excavation of burial land, recovery of human remains, post-recovery analysis, managing an identification programme and making final arrangements for the re-interment of remains.

Personal data and special categories of personal data will be processed under this legislation:

A. Personal data will be processed as part of an Identification Programme

The initial stage of the Identification Programme consists of two steps.

1. Before an Identification Programme begins, a Director will hold a public information campaign to raise awareness that a Programme is taking place and how eligible family members and spouses/civil partners of a deceased person can register an interest in participating in a Programme, an objection to another person's participation or an interest in receiving remains. A Director will maintain a register of notifications received from eligible family members and spouses/civil partners of deceased persons. The following notifications can be made to a Director:
 - Eligible family members of a deceased person can notify the Director of an interest in participating in an Identification Programme.
 - Eligible family members and spouses/civil partners can notify the Director of their interest in being the person to whom any identified recovered remains are returned, as well as their wishes as to the final arrangements for remains.
 - An eligible family member who is a parent, child or sibling can notify the Director of an objection to the participation of another, less closely related, eligible family member in an Identification Programme

In submitting a notification of their interest in participating in an Identification Programme, eligible family members can include a letter of support (in the legislation termed a "letter of non-objection") from relatives who would otherwise be able to object to their participation.

Eligible family members are people who have reasonable grounds to believe that they are a child, parent, sibling, half-sibling, grandparent, grandchild, aunt, uncle, niece or nephew of a person who is buried at an intervention site. Eligible family members and spouses/civil partners are expected to submit evidence regarding the relationship they assert. The details of such evidence are to be prescribed in regulations but are expected to include public records (birth and death certificates) or if those are not available,

affidavits and any other supporting documents (institutional records, copies of register, letters etc.).

2. The second step concerns the formal entry into the identification programme. The legislation prescribes that the Director has to be satisfied that applicants are eligible persons and provide evidence demonstrating their link with the deceased. It should be highlighted that registering an interest (as per above) is not a condition to participation. Where another family member, who is entitled to object to a person's participation, has registered an objection to that person's participation, the Director must take this into consideration before reaching a decision on whether or not a person can participate in the Programme. It should be noted that the Director is required to make reasonable efforts to contact close relatives who are entitled to register an objection but they have not notified the Director of their interest in participating in the programme or of an objection, or a letter of support (letter of non-objection) has not been provided on their behalf.

The other factors to be considered by the Director in this context include the closeness of the genetic relationship of the person who wishes to participate in the Programme as well as the public interest of identifying human remains.

Applicants will receive information about the details of the programme and have to confirm their decision to participate. Once confirmed, applicants become "relevant persons".

The next stage in the identification programme involves processing genetic information: taking biological samples from 'relevant persons' (potential relatives) as well as from human remains recovered from the site and forwarding the samples to FSI to generate DNA profiles and carry out DNA profile comparisons. The aim of the programme is to assess the likelihood of familial relationships asserted by 'relevant persons' (potential relatives) in respect of deceased persons. It is worth highlighting that establishing a familial link with a deceased person may be based on comparison of DNA profile of the deceased person against the profiles of more than one relative. To take an example, the genetic data of a mother, a sibling and a niece may all be processed and inform the result.

B. The Office of the Director may obtain personal data from information sources: public bodies, bodies that receive public funding, data controllers or processors who hold records relating to an institution or any other source the Minister may designate. The Director will also have access to the database of the Mother and Baby's Home Commission, which was transferred to Tusla.

Data may be requested from these bodies to assist the Director in the execution of his or her functions. Examples of such records include public records (birth and death certificates), medical information, institutional records, baptismal certificates etc...

C. The Office of the Director will process data related to employees and contractors as well as consultants and advisors that are engaged. Data concerning Board members will also be processed.

This processing of personal data is not explicitly set out in the Bill as it is governed by employment law and contracts. However, DNA profiles will be generated from 'elimination samples' taken from employees/contractors and FSI staff for the purposes of addressing any potential contamination of samples by them. This is covered in the legislation explicitly.

D. The Office of the Director will process data concerning owners and occupiers of principal and ancillary burial land and ancillary land.

The data will be processed in the context of seeking access to land for the purpose of relevant works including any court applications and calculating compensations by valuation experts. Similar to C), this is not explicitly outlined in the Bill given that processing such data is governed by existing laws and the processed data is not considered special categories of personal data.

Relationship between the DPIA and the Project:

The Data Protection Impact Assessment helps anticipate risks that may arise in undertaking a range of data processing activities under the proposed legislation. In particular, the implementation of an Identification Programme will involve the processing of personal and special categories of personal data of living persons and the making of medico-legal decisions in relation to the identity of deceased persons, decisions which will be notified to (certain) living relatives.

It should be noted that the Bill is subject to change throughout the legislative process. The DPIA will have to be reviewed and revised by an Office that is to be established when the legislation is enacted.

Rationale as to why a DPIA is involved:

As set out above, the legislation underpins the processing of personal data including special categories of personal data such as:

- Public records (birth and death certificates) and other documents or information, including those related to another data subject (e.g. a second order relative submits a document related to a first order relative or the Director obtains a document or information related to a relative or another data subject).
- Objections registered by close relatives (child/ parent/sibling) to the participation of other eligible family members and letters of support (known as 'letter of non-objection') from close relatives furnished by other eligible family members as part of their application to the register.
- Sharing of personal data between public bodies and persons who may be controllers, processors or holders of information, and the Office of the Director.
- Generating DNA profiles from biological samples taken from relevant persons (potential relatives) as well as employees and contractors of the Office of the Director and staff of Forensic Science Ireland
- Forensic testing of DNA profiles of relevant persons (potential relatives), human remains and employees/contractors and FSI staff as may be necessary.
- Making determinations in relation to familial links between deceased persons and relevant persons (potential relatives), using genetic and non-genetic information, and notifying relevant persons about determinations where such information may not have been known to them previously.

The DPIA supports an evaluation of the approach taken in the legislation to realise the objectives of recovering and identifying human remains and providing for their dignified reburial, with a particular focus on the data processing activities envisaged. In light of the fact that personal and special categories of personal data will be processed, and the potential consequences of any potential breach and misuse of such data, the DPIA helps ensure that sufficient consideration is given to safeguarding the rights and freedoms of data subjects through the legislative framework and as well as through the future operational infrastructure.

Step 2: Describe the Processing

2.1 Nature of the processing:

2.1.1 - What are the sources of the data?

- Public records (birth certificates, death certificates), affidavits and other documents - submitted by potential relatives.
- Public records (birth certificates, death certificate), institutional records and other documents (e.g. baptismal certificate) - obtained by the Director.
- Notifications on the register: 1) notification of an interest in participation in the identification programme; 2) notification of an objection by close relatives (parent, child and sibling) to the participation of other eligible family members; 3) notification of an interest in being the person to whom the remains are returned.
In submitting a notification of their interest in participating in an Identification Programme, eligible family members can include a letter of support (in the legislation termed a 'letter of non-objection') from relatives who would otherwise be able to object to their participation.
- Personal information (name, address, contact details) disclosed by employees, contractors (including advisors/consultants), Advisory Board members and the Director in the context of employment and business contracts.
- DNA profiles generated from biological samples taken from relevant persons (potential relatives) by authorised persons appointed by the Director.
- DNA profiles generated from elimination samples taken from employees, contractors and relevant FSI personnel by authorised persons appointed by the Director.
- Personal information (name, address) obtained in relation to owners and occupiers in the context of accessing burial land for the purpose of carrying out relevant works (excavation and recovery of remains).

2.1.2 - Data flows. Will you be sharing data with anyone?

Data sharing will take place between:

- Public bodies or a person who is a holder, processor or controller of data and the Director: public records and other documents such as institutional and medical records, as well as other information relevant for the identification of a person who died at the institution and establishing familial relationship between the deceased person and potential relatives.
- Director and FSI: Biological samples from potential relatives and deceased persons, as well as personal information of relevant persons (potential relatives) such as name, date of birth and relationship asserted.
- FSI and Director: notifications regarding the outcome of DNA profile comparisons between relevant persons (potential relatives) and deceased persons.
- Director and adjudicator:
(1) information and documents concerning a determination about participation in an Identification Programme;
(2) information and documents concerning a determination about the likelihood of familial relationships, including detailed results of DNA profile comparisons and assessments of non-genetic information (public records, institutional records etc...).

- Director and valuation expert: information related to the burial land accessed by the Director for the purposes of relevant works (excavation and recovery of remains).
- Director and District/Circuit Court: information related to the burial land to be accessed by the Director for the purpose of relevant works (excavation and recovery of remains)

2.1.3 - What types of processing identified as likely high risk are involved?

- **Collecting and forensic testing of biological samples and producing genetic data of potential relatives and employees/contractors**

As part of an Identification Programme, biological samples will be collected, stored and then used to generate DNA profiles, which is genetic data. DNA profile comparisons may reveal personal information e.g. someone's sibling has been buried in a certain place. Potential misuse and breaches such as unauthorised access to DNA profiles, the results of DNA profile comparisons or a combination of genetic information (DNA profile) and related personal information (e.g. describing a relative's name and date of birth), would have potentially serious consequences.

Notification about a familial link will reveal information previously unknown to participants in an Identification Programme. Notifications of such information is restricted to relevant persons who met the conditions for participation in an Identification Programme and that will include consideration of any objections from close relatives who are eligible to object. Disclosing of information to unauthorised family members may constitute a breach of privacy rights.

- **Collecting, storing and transferring personal data related to eligible family members**

Personal data will be collected from eligible family members (such as name, contact details, date of birth and familial relationship) in respect of the register of notifications as well as applications to the Identification Programme. Documents may reveal the name of family members, their date of birth and their mother's (or other family members') name; other personal information such as those related to an institution or their medical history. Second order relatives may submit documentation related to first order relatives to evidence a familial relationship with the deceased.

Close relatives (parent, child and sibling) may notify objections to the participation of other equal or lower ranking eligible persons where they outline grounds for their objections, a sensitive piece of information. Eligible persons may also submit letters of support, known as letter of non-objection, from close relatives. It should be noted that if close relatives do not engage with the Identification Programme and eligible persons do not provide a letter of non-objection from those relatives, the Director has to make reasonable efforts to contact them.

The Director may obtain personal data contained in institutional records including admission documents and personal information (e.g. baptismal records, correspondence).

2.1.4 - Are there multiple sets of data processing operations involved?

Data will be collected, stored, transferred and combined with other pieces of data (genetic and non-genetic data to be analysed together to determine the likelihood of familial link). Data subjects will retain their rights under GDPR and Freedom of Information legislation and, therefore, may put in subject access (or FOI) requests, which is an additional data processing operation. The future organisation may develop guidelines and training regarding various data processing operations and ensuring streamlining the responses to any requests.

2.2 Scope of the processing:

2.2.1 - How will you collect, use, store and delete data?

The Office of the Director of Authorised Intervention will be the data controller.

Data processors will include:

- Forensic Science Ireland and contracted laboratories
- Adjudicator
- Valuation expert (re compensation for accessing land)

Where consent is not forthcoming regarding accessing land, the Director may apply to the District Court or Circuit Court for an order authorising the Director to carry out relevant works in the land. The District or Circuit Court is regarded as a data controller in respect of personal data processed by or for courts when acting in a judicial capacity.

The operationalisation of data processing will be a matter for the Office of the Director when the Director is appointed. The legislation provides for the following:

- Personal information will be collected by the Director from eligible family members as well as employees and contractors in the context of an Identification Programme. The Director may also obtain personal information from other public bodies or persons who hold relevant data. The staff of the Director will carry out the actual processing of data.
- The Director will authorise suitably qualified persons to take biological samples from relevant persons (potential relatives) as well as employees and contractors (the latter known as “elimination samples”). These samples will be stored by the Director.
- Biological samples and relevant personal information (name, date of birth) will be transferred by the Director to FSI for the purposes of forensic testing. FSI will securely store elimination samples from employees/contractors of the Director. FSI will also store elimination samples from its own employees involved in the programme.
- FSI will subsequently generate DNA profiles and these will be entered into the DNA (Historical Remains) Database which comprises three indexes. DNA profiles associated with relevant persons (potential relatives) will be entered in the family members’ index. DNA profiles associated with human remains will be entered in the human remains’ index. DNA profiles associated with employees/contractor of the Director and FSI personnel will be entered in the elimination index.
- FSI will compare the profiles in the family members’ index with profiles in the human remains index to establish the likelihood of a familial link. If necessary, profiles in the family members’ index or human remains index will be compared with profiles on the elimination index to address contamination of samples by employees and contractors as well as FSI staff.
- The results of DNA profile comparisons together with non-genetic information will be used to determine if, on the balance of probabilities, a familial link can be established.
- In general biological samples will be destroyed and DNA profiles deleted and personal records returned at the end of the Identification Programme. When a familial link has been established, relative samples in question will be destroyed at that point. Subject to consent from relatives, samples can be retained for future testing under Ministerial regulation when no familial association has been made in respect of those samples.
- Where a relevant person (a potential relative) withdraws from the programme, his/her sample will be destroyed and profile will be deleted.
- It is anticipated that personal data will be also collected regarding owners and occupiers in the context of accessing land for the purpose of relevant works (excavation and recovery of remains). This is not set out explicitly in the legislation.

2.2.2 - What types of data subject are involved?

- Eligible family members (potential relatives of deceased persons): first order relatives (parent, child, sibling, half-sibling) and second-order relatives (aunt, uncle, niece, nephew, grandchildren or grandparents)
- Employees of the Office of Director and those the Director has entered into contract with (including consultants and advisors)
- Advisory Board members
- FSI employees
- Owners and occupiers of burial land

2.2.3 - What categories/types of personal data will be used?

Personal data:

- Register of notifications from eligible family members and spouses/civil partners: *name, contact details*
- Documentary evidence provided by eligible family members and spouses/civil partners to establish relationship with the deceased (e.g. birth certificate): *name, date of birth, date of death; name of mother, sex*
- Documentary evidence related to first order relatives that second order relatives submit to provide evidence of the relationship with the deceased (aunt submits documentation related to her sister who is the mother of the deceased); *name, date of birth, date of death; name of mother, sex*
- Affidavits provided by eligible family members: *name of the person, familial relationship, other information*
- Support documents provided by eligible family members (institutional records, letters etc.): *name, address, age, genetic relationship*
- Employment and procurement contracts: *name, address, contact details*
- Information about owners and occupiers obtained through correspondence and public records such as the property register: *name, address, their status (e.g. owner), contact details*
- Institutional records including admission documents, medical records and other information: *name of child, name of mother, name of other family members (e.g. they might have visited the deceased person etc.)*

Special categories of personal data:

- *DNA profiles* of relevant persons (potential relatives), employees and contractors of the Director and employees of FSI, generated from biological samples
- *Results of DNA profile comparison*
- *Medical records* (name, personal details e.g. date of birth) related to family members where
 - eligible family members provide those records, or
 - eligible family members disclose records related to another family members (to show evidence of the relationship with the deceased)
 - the Director obtains those records from another public body, person or Tusla (which holds the database and related records of Commission of Investigation into Mother and Baby Homes)

Information not required for processing (for the purpose of identification of deceased person) may be redacted.

No data related to criminal offences will be processed.

2.2.4 - Frequency / How often will the data be collected?

ELIGIBLE FAMILY MEMBERS/RELEVANT PERSONS

- Eligible family members will provide names, contact details and evidence to satisfy the Director of the relationship with the deceased when entering the register.
- Names, contact details and evidence to satisfy the Director of the relationship with the deceased will be also collected when potential relatives apply to an Identification Programme. Applicants do not have to join the register in order to apply to participate in the Identification Programme, however, it is anticipated that many will do so. In such a scenario, the Director is not expected to assess the documents that they have already examined at the point of registering an interest. If necessary, the Director may request additional documentation from the relative.
- Relevant persons: following approval to take part in an Identification Programme, biological samples of relevant persons (potential relatives) will be taken and used to generate DNA profiles by FSI. Where a sample is insufficient, the authorised person appointed by the Director might have to take a second biological sample. Furthermore, where comparison of DNA profiles does not yield results, a new type of DNA profile may be generated from the biological samples.

EMPLOYEES AND CONTRACTORS

- Personal data will be collected from employees and contractors at the point of recruitment or engagement; elimination samples (biological samples) will be taken when an Identification Programme commences. Where a sample is insufficient, an authorised person appointed by a Director may have to take a second DNA sample. Where there is reasonable risk of contamination, DNA profiles will be generated from elimination samples. If a new type of DNA profile is generated from relative samples, a new type of DNA profile may need to be generated from elimination samples to deal with issues of contamination.

ADVISORY BOARD MEMBERS

- Personal data will be collected at the point of appointment to the Board.

OWNERS AND OCCUPIERS

- It is envisaged that personal data will be collected when acquiring documentation related to the land; subsequent correspondence may contain additional personal data.

2.2.5 - How long will you keep it?

In general biological samples will be destroyed and DNA profiles deleted and personal records returned at the end of the Identification Programme. When a familial link has been established, relative samples in question will be destroyed at that point. Subject to consent from relatives, samples can be retained for future testing under Ministerial regulations when no familial association has been made in respect of those samples.

Where a function related to accessing land and remedial works transfers to a Minister on dissolution of an Office of the Director, it is expected that relevant personal data about owners and occupiers will be retained. When the function is completed, only administrative information will be retained for the statutory time.

Similarly, employment and procurement contracts will be retained for the statutory time.

2.2.6 - How many individuals are affected?

It is difficult to estimate the number of relatives that will participate in an Identification Programme. If the legislation is enacted, the first intervention will be at the site of the former Mother and Baby Home in Tuam. It has been estimated that the programme may receive up to 70 applicants but it is not possible to give precise numbers.

It is envisaged that the Office of a Director will be a relatively small organisation but this will depend on the size and scale required for a particular intervention site (in the case of Tuam it is

estimated that the Office will require approximately 5-6 staff). However, the Director will also engage a range of contractors to assist with an intervention (in the case of Tuam it has been estimated that excavation alone may require a team of 20-25 people).

The Advisory Board will have six members.

It is expected that the Office of the Director will need to engage with only a limited number of owners and for the purposes of access to land to undertake an intervention. It is difficult to provide any precise estimate at this point.

2.2.7 - What geographical area does the project cover?

Interventions under the legislation are limited to inside the State. However, potential relatives who reside outside Ireland may wish to participate in an Identification Programme. Scientific assistance may be procured from outside the State where necessary in the context of forensic testing. Therefore, human remains and biological samples of potential relatives may need to be transferred to a laboratory or similar institution outside Ireland. In this case, this will be communicated to relevant persons who take part in the Identification Programme.

2.2.8 - Assets/technology involved with processing the data:

The operationalising of data processing will be a matter for the Office of a Director when a Director has been appointed. It is expected that due regard will be given to establishing the necessary systems and acquiring technology and devices to protect personal data and special categories of personal data adequately.

2.3 Context of the processing:

2.3.1 - What is the nature of your relationship with the individuals (whose data is being processed)?

Primary Information sources

The data controller (the Office of the Director) will have no prior relationship with data subjects. FSI will be a data processor and it will collaborate closely with the Director in relation to an Identification Programme, including in relation to data sharing. Potential relatives as well as owners/occupiers (in the context of accessing burial land) can be considered clients or customers of the organisation. Regarding the latter, it should be noted that owners and occupiers may wish not to consent to the Director accessing land and the Director may subsequently have to apply for a court order to obtain access.

While the Office of the Director will be the data controller, its employees and contractors as well as FSI employees will also be data subjects – they will provide personal data in respect of their contracts and will provide elimination samples in order to deal with potential contamination of samples of relevant persons. The Advisory Board of the Director will also provide some (albeit limited) personal data in the context of their membership of the Board.

Secondary information source

The Director can obtain data from other public bodies and persons who hold, process or control data. The Director can also request Tusla to provide certain information contained in the database and related records of Commission of Investigation into Mother and Baby Homes.

2.3.2 - How much control will they have over their data?

In general data subjects will be able to exercise their GDPR rights. Potential relatives can withdraw from the programme and have their records deleted and samples and DNA profiles destroyed.

In line with the general approach in this area, employees and contractors will be required to provide personal data as part of their contractual relationship with a Director. Such future employees/contractors, where handling samples, will be also required to provide samples that will be used to generate DNA profiles to help to deal with DNA contamination of samples. It is important to underline that elimination samples will only be kept for as long as a risk of contamination exists.

2.3.3 - Would they expect you to use their data in this way?

Under the legislation, when the Office of a Director is established, an information campaign will be carried out to raise awareness of an Identification Programme and its purpose. It will also provide the opportunity for people to register as eligible family members. Under the legislation relevant persons (potential relatives who participate in an Identification Programme) will be informed about the details of the Programme at the point of entry including how and why samples are taken, how they will be notified of a familial link and how they can withdraw from the programme. They will be also be informed about the destruction of samples and deletion of profiles.

2.3.4 - Are there prior concerns over this type of processing (e.g. security flaws)?

No. A future Office of a Director can draw on the experience of other organisations such as Tusla and the Adoption Authority that have gained relevant experience in processing historical data. Furthermore, FSI has a strong track record of processing genetic data and carrying out forensic tests under the Criminal Justice (Forensic Evidence and DNA Database) Act 2014. Robust safeguards will be put in place by the Office of the Director to minimise the risk of breaches and misuse of data.

2.3.5 - Is the processing novel in any way?

To a large extent, the processing involves existing types of activities. Generation of DNA profiles may involve implementing recently developed technological solutions.

2.3.6 - What is the current state of technology in this area?

Detailed operationalisation of the programme of intervention will be overseen by a future Director. However, there are a number of existing, proven technological solutions for operating safe and effective record management systems. Similarly, forensic testing by FSI uses accredited technological solutions. As mentioned above, given the rapid nature of developments, DNA testing may involve newly developed solutions but any recently developed method will be subject to strict quality assurance measures. It is expected that all data will be held in secure networks.

2.3.7 - Are there any current issues of public concern that you should factor in?

The proposed legislation is to give effect to a major action under the *Action Plan for Survivors and Former Residents in Mother and Baby Homes*. It builds on the commitment from the previous Government to direct a phased forensic-standard excavation, recovery, identification (if possible) and re-interment of human remains interred in a manifestly inappropriate at the site of the former Mother and Baby Home in Tuam.

2.3.8 - Are you signed up to any approved code of conduct or certification scheme (incl. any awaiting approval)?

N/A

2.4 Purposes of the processing:

2.4.1 - What do you want to achieve?

The legislation seeks to provide for the excavation, recovery, analysis, identification (if possible) and re-interment of human remains buried in a manifestly inappropriate manner. Genetic data will be processed and considered alongside non-genetic information (examination of records and findings of post-recovery analysis e.g. age of death) to establish the likelihood of a familial link between living relatives and human remains. Arrangements will subsequently be made for the dignified re-interment of remains.

2.4.2 - What is the intended effect on individuals?

The legislation will potentially enable family members to confirm whether their relatives (who resided and died in a former institution) were among the human remains that were buried in a manifestly inappropriate manner. Subsequently, they may be able to rebury the deceased family member in a dignified way.

2.4.3 - What are the benefits of the processing?

The proposed legislation provides an opportunity to identify deceased persons and enable their family members to arrange for a dignified burial of the human remains where possible. Where identification is not possible, a dignified re-interment will be arranged.

Processing personal and genetic data from eligible family members is central to realising those goals, but processing of other personal data also plays an important role. Elimination samples taken from employees/contractors/FSI staff will help to address contamination of samples and enable a more effective delivery of an Identification Programme. Processing of data related to owners and occupiers is necessary and proportionate in the context of accessing land in order to undertake an intervention.

2.5 Describe the Technical and Organisational Measures for securing personal data:

2.5.1 - What security arrangements will be in place to secure the data?

The legislation provides a broad framework for an intervention. The Office of the Director established under an intervention will consider necessary security arrangements in detail and arrange appropriate, secure IT systems.

The legislation specifies that personal records will be returned to relevant persons (relatives) and personal information deleted at the end of the Identification Programme. Furthermore, biological samples will be destroyed and DNA profiles deleted when an Identification Programme is completed unless, subject to consent from relatives, samples are retained in line with Ministerial regulations for the purposes of future testing.

2.5.2 - What organisational measures will be in place?

Putting in place the necessary organisational measures will be a matter for the Office of the Director if the legislation is enacted and an Office is established. It is recognised that the Office of a Director will need to adopt appropriate safeguards to minimise the risk of data breaches and the misuse of personal data and special categories of personal data. The legislation specifies some measures such as restricting the taking of biological samples to authorised persons and ensuring that DNA profiles and related personal information are held in separate databases.

Step 3: Assessment of Necessity and Proportionality of Processing

Describe compliance and proportionality measures, in particular:

3.1 - What is your lawful basis for processing?

Personal data provided by potential relatives or obtained by the Director will be processed on the basis of Art 6.1.e (task carried out in the public interest or in the exercise of official authority). Art 6.1.e and 9.2g (reasons of substantial public interest) will be relied upon in relation to processing genetic data of potential relatives (generating DNA profiles and testing them).

Personal data provided by employees and contractors of an Office of the Director as well as FSI staff will be processed pursuant to Art 6b (contract). Genetic data (generating DNA profiles from elimination samples and testing them) will be processed under Article 6.1.e. Furthermore, 9.2g offers a further lawful basis in light of the fact that genetic data comes under special categories of personal data.

3.2 - Does the processing actually achieve your purpose?

Yes. As described above, where possible, remains will be identified and returned to family members. However, it may not be possible to identify all human remains. The success of a programme will depend on a number of factors including the quality of DNA that can be generated from the remains as well as the number of relatives participating. The condition of the interment of remains will also be a factor.

3.3 - Is there another way to achieve the same outcome?

No. The Government directed that a phased forensic-standard excavation, recovery, identification (if possible) and re-interment of the remains should be carried out at the full available site at Tuam. This legislation provides the legal basis for implementing that decision.

The Expert Technical Group, which was appointed to examine options for responding to the situation at Tuam, advised that the recovery of remains and subsequent use of DNA testing is the only possible way to identify remains under the circumstances. The implementation of a DNA identification programme needs to be underpinned by legislative provisions given the sensitive nature of personal and, even more importantly, genetic data.

3.4 - How will you prevent purpose/function creep?

Overall, data can only be processed in line with the legislation, which provides explicit guidance to a Director on implementing data processing activities, particularly in relation to genetic data.

An Advisory Board will provide guidance to a Director in performing relevant functions including managing an Identification Programme.

Furthermore, a Director will have to update the Minister and provide regular reports on the activity of the Office of the Director, including the implementation of an Identification Programme.

3.5 - How will you ensure data quality and data minimisation?

The legislation will underpin processing personal and genetic data. Only the minimum data necessary will be collected by a Director. Ministerial regulations will provide further guidance in relation to an Identification Programme, including the evidence required from eligible family members/relevant persons. A Director will only collect personal data where it is necessary to determine a person's eligibility to participate in a Programme. Where a person has submitted sufficient documentation, a Director will not seek further documentary evidence.

Only one biological sample will be taken from potential relatives and employees/contractors, with a second sample collected only if the first sample has proved insufficient. DNA profiles will only be generated for the purposes of establishing a familial link or establishing contamination of a sample. If the comparison of DNA profiles suggest a sufficient link, no more DNA profiles will be

generated from the sample of the relative(s) in question. A new type of DNA profile will only be generated from samples if the comparison of the first type of DNA profiles did not establish a familial link. In the same manner, where contamination is no longer a risk, elimination samples will be destroyed and DNA profiles be deleted.

Data will be only used for the purpose it was collected for. Documents submitted by relatives or obtained by a Director will only be used for the purpose of assessing a familial relationship with a deceased person and identifying remains. Biological samples will be only used to generate DNA profiles and such profiles can only be tested for the purpose of establishing a familial link or eliminating the effect of contamination of samples by employees and contractors or FSI personnel, as may be necessary.

3.6 - What information will you give individuals about the processing of their data (e.g. in the context of a Privacy Notice)?

An information campaign will be undertaken prior to the commencement of an Identification Programme. Information will also be given to each potential relative about an Identification Programme at the point of application. This will include information about taking and testing samples, the right to appoint nominees, the right to withdraw consent, notification about a potential familial link and destruction of samples and deleting DNA profiles.

Similarly, employees/contractors of the Director and FSI staff will receive detailed information about an Identification Programme, including the purpose of providing elimination samples, taking and testing of samples, destruction of samples and deletion of DNA profiles. .

A future Office of the Director will also be expected to develop a Privacy Notice.

3.7 - How will you help to support individual rights (e.g. to access/rectify their data)?

As outlined above, an information campaign will be undertaken prior to the commencement of an Identification Programme. Information will also be given to each potential relative about the Identification Programme at the point of application. It is intended that rights under GDPR will be explained to relatives by a Director's staff, in addition to the Privacy Notice provided. Since potential relatives will submit their own documents, access requests are less likely to arise but, where necessary, in the context of processing data, they will be facilitated e.g. regarding documents that the Director may obtain from other public bodies or a person who is holder, controller or processor of personal data.

3.8 - What measures do you take to ensure processors comply (e.g. contract arrangements)?

Such measures are to be developed by a future office of a Director. It is anticipated that a data sharing agreement will be developed between a Director and FSI. It is also foreseen that data processing will be covered in procurement contracts where a Director engages with contractors regarding activities that involve processing personal data.

3.9 - Are any international transfers envisaged? If so, how do you safeguard such transfers? What mechanisms do you intend to utilise in the event of transfers to third countries? Prior consultation required?

Potential relatives who live outside Ireland may wish to participate in an Identification Programme. They can send their records by post (e.g. birth certificates) but it is not envisaged that they can post their DNA samples.

For the purpose of analysis, DNA samples may be transferred to a laboratory in another country. This will be done with due regard to relevant European laws, applicable guidelines and codes of practice as well as court decisions, where appropriate. It is difficult to predict at this juncture but a

non-EU laboratory (e.g. UK) may have to be used in which case this will be communicated to data subjects.

Step 4: Consult with Stakeholders

Consider how to consult with relevant stakeholders:

4.1 - Describe when and how you will seek individuals' (data subjects) views or justify why it's not appropriate to do so. How would such consultations improve your understanding of the impact of the processing?

The proposed legislation was subject to pre-legislative scrutiny process, which allowed political representatives, relevant stakeholder organisation, experts and others to provide input into the legislation.

Furthermore, one of the key functions of a Director under the legislation is to engage with family members of deceased persons and former residents.

4.2 - Who do you need to involve within your organisation?

Colleagues from relevant units have been consulted in the development of the legislation.

4.3 - Do you need to ask your processors to assist?

It is not applicable to the legislation but it is something the Director may wish to consider.

4.4 - Do you plan to consult information security experts, or any other experts?

This will be an important task for a Director when establishing an Office and planning a programme of interventions in detail. More generally, relevant subject matter experts, including FSI, have been extensively consulted in the course of developing the legislation.

4.5 - What other stakeholders should be consulted (who may have a practical knowledge of the operations)? This may include external partners, to whom information might be disclosed.

Consultation with organisations such as Tusla and the Adoption Authority would be beneficial to an Office of a Director, given their experience of storing and processing historical data.

4.6 - How will stakeholder input be sought?

An Advisory Board will provide guidance and advice to a Director. The Board will comprise representatives of family members and residents as well as scientific experts.

The Director will engage with family members to update them about progress and will inform stakeholders more widely. These activities can draw on existing engagement with stakeholders that represent residents and family members associated with former Mother and Baby Home institutions as part of the implementation of the *Action Plan for Survivors and Former Residents of Mother and Baby and County Home Institutions*.

A Director will also regularly consult with its employees and contractors.

Steps 5 & 6: Risk Assessment - Identifying Privacy Risks and Evaluating Privacy Solutions

		Name of Project/Scheme/Service: Institutional Burials Bill 2022						Risk Register Owner: Peter Szlovak, DCEDIY	
Risk Type <small>(F – Financial) (S – Strategic) (O – Operational) (R – Reputational) (L – Legal) (Reg – Regulatory)</small>	Risk Description	Consequence	Risk Owner	Actions / Controls / Mitigations in place (provide details of how you currently manage the risk)	Assessment of Risk			Suggestions on additional Actions / Controls / Mitigations (to further reduce or limit the risk)	
					Likelihood <small>(1,2,3,4,5)</small>	Consequence <small>(1,2,3,4,5)</small>	Risk Score		
L	O	Unauthorised access to personal information related to the identification programme	People’s personal information is disclosed without permission	The Office of the Director	The legislation prohibits the disclosure of confidential information and prescribes an offence for violating this provision.	1	5	5	It is envisaged that the future organisation will put in place organisational and technical measures to reduce the likelihood of a breach e.g. Data Processing and Data Sharing agreements, record management system, training, policy.
L	O	Unauthorised access to genetic data and results of DNA profile comparison	People gain access to highly sensitive data of persons without sufficient legal basis	The Office of the Director	The legislation prohibits the disclosure of confidential information and also outlaws taking samples	1	5	5	It is envisaged that the future organisation will put in place organisational and technical measures and

					and generating DNA profiles for purposes other than a purpose authorised in the Act. The legislation further specifies that genetic data and personal information related to family members will be held in separate databases.				develop Data sharing agreement and Data processing clauses.
O	R	Lack of awareness about the Identification Programme and lack of clarity regarding the various processes and requirements associated with the Programme (e.g. regarding registering an interest and an objection)	People may not register an interest/objection; insufficient documentation creates challenges in processing notifications/applications; decision about registration or entry to the programme is not implemented consistently	The Office of the Director	Under the legislation an information campaign will have to be undertaken with a view to raising awareness about the Identification Programme and the opportunity to register an interest or objection. Ministerial regulations will provide details about evidence that applicants need to submit to establish eligibility to participate in the programme as well as details about the requirements and procedures concerning registering an objection	2	3	6	When the Office of the Director is established, training, guidelines and information materials will be developed.

					and other relevant information.				
O	R	Lack of sufficient awareness among participants about the data processing activities of an Identification Programme	People may be unaware of the details concerning the processing of personal and special categories of personal data	The Office of the Director	Under the legislation the Director has to provide detailed information about the Identification Programme to participants including the processing of personal data and the right to withdraw from a programme as well as the effect of such withdrawal.	1	4	4	It is envisaged that the future organisation will provide detailed information about the Identification Programme and data protection rights, including the effect of withdrawal from the programme.

NOTE – This Risk Assessment is not to be reflected on the DCEDIY Risk Register until data processing has been approved and commenced. Please also note that failure to adequately mitigate against a risk or risks will require DCEDIY consultation with the Data Protection Commission. See Appendix 2 for risk considerations.

Step 7: Document DPIA Actions/Outcomes

Item	Name/date	Notes
Actions to further reduce risk (see Step 8 below) approved by:	Historic Burials Legislation Unit	It is intended that this DPIA will be reviewed and updated by the future Director when an Office has been established
DPO advice provided:	Data Protection Officer	DPIA will need to be conducted on any new ICT system designed for this purpose
Summary of DPO advice: Constructive feedback was received.		
DPO advice accepted or overruled by:	Accepted	If overruled, you must explain your reasons
Explanation:		
Consultation responses reviewed by:		If your decision departs from individuals' views, you must explain your reasons
Explanation: The Department consulted closely with the Data Protection Commission pursuant to Article 36(4) of the GDPR and feedback received has been taken into account in the finalisation of this document. The Department will consult further with the DPC as necessary, including in relation to the development of Ministerial regulations.		
This DPIA will be kept under review by: Historical Burials Legislation Unit in conjunction with the future organisation to be established under the legislation		The DPO should also review ongoing compliance with DPIA