REPORT ON THE COLLECTION OF TUAM SURVIVORS' DNA

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15/04/2019

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SCHEDULE OF ABBREVIATIONS AND ACRONYMS

CCP	Code of Criminal Procedure
CJEU	Court of Justice of the European Union
CMC	Cuprija Medical Centre
ECHR	European Convention on Human Rights
ECtHR	European Court of Human Rights
ETG	Expert Technical Group
GDPR	General Data Protection Regulation
MADEKKI	Inspectorate of Quality Control for Medical Care and Working Capability
WP29	The Article 29 Working Party

PREFACE

On 13 February 2019, I was requested to examine whether establishing a voluntary scheme for the collection of DNA samples – with clear information to participants on their GDPR rights – would help vindicate any rights of family members under Article 8 ECHR which may be at issue in the uniquely complex circumstances that arise from the discovery of juvenile human remains at the site of the former Mother and Baby Home at Tuam. This request follows the Tuam Home Survivors' Network calling on the Government to begin collecting their DNA samples immediately.

I was provided with a period of eight weeks in which to carry out an analysis, and to provide a report to the Minister for Children and Youth Affairs, Dr Katherine Zappone TD ('the Minister').

The purpose of collecting samples would be to compare them against any DNA profiles which may be generated from juvenile human remains found at the site of the former Mother and Baby Home at Tuam and, if possible, to make positive identifications.

These issues will ultimately be addressed within bespoke legislation. However, the Minister has expressed sympathy to the concerns of survivors that their ages and health profiles introduce an element of significant urgency.

At the time of writing, it should be highlighted that it is not yet clear whether it will or will not be possible to generate DNA profiles from the juvenile human remains that are of such a quality that result in them being capable of yielding conclusive familial matches. However, survivors and relatives have expressed a concern that, given their age and health profiles, they may be unable to participate in any matching process that may take place in the future.

In the process of finalising this report, consultations have been held with the Data Protection Commission, the Department for Children and Youth Affairs and An Garda Síochána.

The Report seeks to consider what may be possible within the current legislative framework, with particular attention being given to each of the following Terms of Reference which were stipulated by the Minister:

- the collection of biological samples for comparison purposes;
- the extent to which any relevant family rights under Article 8 of the European Convention on Human Rights may apply; and
- how best to ensure that the rights of those who wish to give biological samples could be safeguarded in respect of sensitive personal data and informed consent.

Each of the aforementioned terms of reference will be addressed sequentially and according to the following framework:

- Collection of Biological Samples for Comparison Purposes within the Existing Legal Framework;
- ECHR Considerations;
- Data Privacy Considerations and Informed Consent.

1. EXECUTIVE SUMMARY

GENERAL LEGAL PRINCIPLES

The collection, retention and use of genetic material automatically engages the rights of the individuals involved under both the Constitution of Ireland and the European Convention on Human Rights (ECHR). From a constitutional perspective, the taking of samples will typically engage the right to privacy.[1] The use of any material obtained may also give rise to additional constitutional considerations in particular cases, including (potentially) the privacy or identity rights of other relatives or identifiable persons.

Similarly, the taking and use of samples has been found by the European Court of Human Rights (ECtHR) to constitute an interference with Article 8 of the ECHR.[2] It should be noted that the Court in *Marper* specifically drew a distinction between the taking of samples and their ongoing retention and usage, pointing out that they could give rise to different issues in different contexts. Furthermore, the ECtHR has held that Article 8 covers a person's biological identity such that an embryo created using a person's genetic material would engage the Article 8 entitlements of that person.[3]

This means that any programme which involves the collection, retention and (potentially) usage of genetic material must be designed so as to satisfy the requirements of the Irish Constitution and the ECHR. These are – at a very general level of abstraction – that the measures be rationally justifiable and/or proportionate in light of the objectives pursued.

In principle – and, again, speaking very generally – the objective of the proposal is likely to be regarded as constitutionally permissible and/or Convention-compliant. Moreover (and as I discuss in greater detail in Chapters 2, 3 and 4), an administrative scheme under which family members could voluntarily submit biological samples for later testing may be appropriate as a means of vindicating the rights of those persons who may wish to provide samples at this point in time in light of the age profile and health status of survivors.

[1] *Kennedy v. Ireland* [1987] IR 587.
[2] *Marper and S v. UK* [2008] ECHR 1581.
[3] *Parillo v. Italy* [2015] ECHR 755.

The key factor in justifying and/or defending any administrative scheme against a legal challenge is likely to be the specific detail of the procedures in accordance with which it is undertaken. These are likely to be critical in any assessment of the proportionality of the scheme and/or the extent to which it respects the rights of those involved.

It is also important to bear in mind that the fact that participation in any scheme would be voluntary is not necessarily sufficient to assuage all constitutional concerns. While it is possible for individuals to waive their constitutional rights, this must be done voluntarily and on the basis of full knowledge and consent.[4] The courts will not lightly assume that a waiver has taken place.[5] It will be necessary under any system to be able to demonstrate that the participants received full information prior to participation; and that they did so of their own free volition. Once again, this highlights the importance of clear and robust procedures in ensuring the legality of any proposed scheme.

The Minister has asked me to consider whether beginning to collect DNA samples in light of the age profile and health status of survivors may promote or vindicate Article 8 ECHR rights. This may be relevant to the justification of the scheme. The ECtHR has tended to construe Article 8 in a very broad and flexible manner as capable, in principle, of covering different family relationships. This means, in principle, that persons outside the immediate family kinship may have entitlements under Article 8 in particular cases.

However, the Court's focus has usually been on the existence and/or subsistence of some form of relationship between the parties in respect of whom Article 8 is said to apply. Given the lapse in time, there may not be such relationships in all, or even most, cases here. This means that the issue may more commonly be whether Article 8 applies to issues regarding the burial or exhumation of bodies. The ECtHR has, in this regard, held Article 8 (and Article 3) to apply where persons are seeking information and/or have concerns about the burial of immediate family members such as children or spouses.[6] This, again, arguably, relates to a situation where there was a sufficiently close family relationship in fact to merit the application of Article 8. By contrast, the English courts have held that questions concerning

[4] *G v. An Bord Uchtála* [1980] IR 32.
[5] *DPP v. M* [2018] IESC 21.
[6] *Pannullo and Forte v. France*, Application no. 37794/97, 30 October 2001; *Hadri-Vionnet v. Switzerland*, Application no 55525/00, 14 February 2008; *Girard v France*, Application no. 22590/04, 30 June 2011.

the burial or exhumation of deceased persons do not engage the Article 8 rights of blood relatives where there was no close family connection or personal relationship.[7]

In the present context, there is the consideration that the possibility of obtaining a positive identification is more remote in relationships other than parents and sibling or half-sibling. Taken together with the emphasis in the Strasbourg and UK case-law on Article 8 on the presence of a close personal relationship, this suggests that a European Convention on Human Rights compliant scheme is therefore likely to involve such a scheme applying only to first degree or second degree family relationships.

TERMS OF REFERENCE

Existing legal provisions

I now turn to a consideration of any statutory basis for the collection of biological samples for comparison purposes.

Section 48 of the Criminal Justice (Forensic Evidence and DNA Database System) Act 2014

The first question worthy of examination is whether section 48 of the Criminal Justice (Forensic Evidence and DNA Database System) Act 2014 (the 2014 Act) may provide a basis for the collection of biological samples for comparison purposes. This section provides as follows:

> (1) A sample may be taken under this section—
>
> (a) in accordance with subsection (5) in relation to a missing person who is missing in circumstances referred to in subsection (2), or
>
> (b) from a person who is a relative by blood of a missing person,
>
> for the purpose of generating a DNA profile in respect of the person concerned to be entered in the missing and unknown persons index of the DNA Database System to assist with finding or identifying the missing person.
>
> (2) A sample may be taken under this section for the purposes of the investigation by the Garda Síochána of the disappearance of a missing person if—
>
> (a) a member of the Garda Síochána not below the rank of inspector is satisfied that the circumstances of the disappearance so require, or

[7] See *R (Rudewicz) v. Secretary of State for Justice* [2013] QB 410; *dicta* in *R (Plantagent Alliance Ltd) v. Secretary of State for Justice* [2014] EWHC 1662.

(b) following a natural or other disaster, one or more persons are missing.

(3) A sample may be taken under this section only if a member of the Garda Síochána not below the rank of inspector authorises it to be taken.

(4) An authorisation under subsection (3) shall not be given unless the member of the Garda Síochána giving it believes that the taking of the sample concerned, the generation of a DNA profile from the sample in respect of the person concerned and the entry of the DNA profile in the missing and unknown persons index of the DNA Database System may assist with finding or identifying the missing person concerned.

(5) In the case of a missing person, a sample of biological material from which a DNA profile may be generated may be taken under this section from the clothing or other belongings of the person or from things reasonably believed to belong to, or to have been used by, the person or with which the person was reasonably believed to have been in contact.

Section 2 of the Act defines a missing person in the following terms:

> "missing person" means a person who, whether before or after the commencement of this section, is observed to be missing from his or her normal patterns of life, in relation to whom those persons who are likely to have heard from the person are unaware of the whereabouts of the person and that the circumstances of the person being missing raises concerns for his or her safety and well-being…

The first difficulty in applying this provision to the situation at hand is that there must be serious doubts as to whether the definition of 'missing person' could be said to cover the persons whose remains are, or may be, found in the site in Tuam. The definition identifies three criteria, all of which appear to be required to constitute a missing person, namely: (i) the person is observed to be missing from their own "normal patterns of life"; (ii) specific persons who are likely to have heard from the individual are unaware of their whereabouts; and (iii) there are "concerns" for safety and well-being.

None of these would seem to apply to persons who, almost automatically by virtue of their inclusion in the site, are understood to have been infants who have been deceased for at least a number of decades. Given the lapse of time, these individuals could not reasonably be said to have "normal patterns of life" from which they have been observed to be missing. Nor does it seem plausible to suggest that there are persons who would likely have heard from the person but who are unaware of their whereabouts. Finally, and perhaps most conclusively, the

definition appears to contemplate that there are 'concerns' in the sense that the person may be alive but where there are doubts, whereas the situation here is that the fate of the individuals in question is already known.

Even if the definition could be applied to these individuals, there are further difficulties arising from the restrictions imposed by section 48.

Subsection 4 requires that the Garda member authorising the taking of the sample be satisfied that the steps envisaged "may assist with finding or identifying the missing person concerned". The existence of such a belief is a statutory precondition to the exercise of the power under section 48. Given the unusual situation in the wake of the discovery of juvenile human remains at the site of the former Mother and Baby Home in Tuam, it cannot be assumed that the Garda member would automatically hold such a belief in each, or even most, cases.

In addition, section 48(1) makes clear that the power may only be exercised for the relatively narrow purpose of "generating a DNA profile in respect of the person concerned to be entered in the missing and unknown persons index of the DNA Database System to assist with finding or identifying the missing person". This is important not only to the initial taking of the sample but also to the use that may lawfully be made of it thereafter.

There are two distinct, but related, legal concerns in this regard. The first is the specific statutory question of whether the exercise of this power in an individual case to take a sample is intra vires the limits imposed by the Oireachtas. The second is that the purpose for which the sample is obtained imposes more general limitations on the use to which the sample may be subsequently put, both under the section itself and under general data protection principles. The sample could only be processed for purposes relating to that initial purpose; the information and consent given would have to be directed to that purpose; and the sample would likely have to be destroyed once that purpose had been accomplished.

In my view, there would be significant risks to making use of section 48 as a basis for the collection of samples. First, and perhaps most fundamentally, the persons whose remains are located at the site at Tuam would not seem to be "missing persons" under the definition used in the 2014 Act. Secondly, even if this difficulty could be addressed, it appears that the

retention and use of samples collected in respect of Tuam may not coincide precisely to the usage identified in section 48(1). This would create significant vulnerabilities under both normal statutory principles and more general data protection requirements.

Sections 27 to 28 of the Criminal Justice (Forensic Evidence and DNA Database System) Act 2014

I next give consideration to whether it may be possible to establish and operate a system pursuant to sections 27 and 28 of the 2014 Act. These allow for the collection of samples from volunteers in relation to the investigation of a particular offence, or the investigation of a particular incident that may have involved the commission of an offence.

At first glance, these sections appear somewhat more apposite given that they are directed towards "volunteers". Given it has been suggested in commentary since the identification of the site at Tuam that offences may have been committed, the purpose to which these sections are directed is, at least in principle, closer to that situation than to one of "missing persons".

However, the application of these sections is, once again, not without potential difficulty. First of all, despite the use of the term 'volunteer', section 27(1) appears to define a volunteer as being a person of whom a request is made by a Garda member or authorised person to provide a sample. The logic for this appears to relate to the requirement that the sample be taken for the purpose of an investigation. In other words, it is for An Garda Síochána (AGS) or authorised persons to identify and approach 'volunteers' who they believe may be relevant to an investigation.

This points to the additional difficulties that the more likely reading of the section is that there must be some form of investigation within the meaning of section 27(1)(a) or (b) in being at the time; and that the sample must relate to that investigation.

It is also possible that the reference to "a particular incident" could be construed narrowly as requiring a single incident, although this appears to me to be less likely in light of the provisions of section 18(a) of the Interpretation Act 2005 on singular and plural provisions.

It is unknown if an investigation into the 'incident' must be active or under contemplation at present. Even if one was in being, however, there may be doubts as to whether the taking of

samples to identify remains would be relevant to the offence being investigated. This would naturally depend on the offence at issue. It would not seem to necessarily follow, however, that identification of a specific set of remains would be relevant to the distinct question of whether criminal liability applies.

Thus, while sections 27 and 28 appear somewhat closer to what is envisaged here, there may be scope for divergences or tensions to arise between the framework provided therein, and the particular purpose of taking and holding samples under consideration here. This suggests that the use of these sections may also be susceptible to potential challenge.

POTENTIAL FOR CREATION OF AN INTERIM ADMINISTRATIVE SCHEME

There is no doubt that in the longer term, it is preferable that the process of collecting and matching DNA samples at the Tuam Mother and Baby Home should be underpinned by a robust statutory mechanism or framework. The question of whether the creation of an interim administrative scheme is legally possible is a question of constitutional law: does the executive branch enjoy the power to establish a scheme of this nature?

The Constitution is silent as to the extent of the executive power.[8] The Executive has been held to have certain inherent powers, some of which are possibly derived from royal prerogative powers.[9] For present purposes, the most relevant example of inherent executive power is that the superior courts have recognised that the Executive enjoys an inherent power to establish ex-gratia non-statutory schemes to implement desired policy objectives.[10] In the case of *C.A. and T.A. (a minor) v. Minister for Justice and Equality, Minister for Social Protection, the Attorney General and Ireland*,[11] the High Court considered a claim that the system of 'direct provision' was unlawful in the absence of enabling legislation.[12] In part, it was argued that the establishment of the scheme usurped the power of the Legislature. The

[8] Hogan, Whyte, Kenny, Walsh *Kelly: The Irish Constitution* (2018, 5th ed, Bloomsbury Professional) p. 164, p. 500.
[9] *Prendergast v. Higher Education Authority* [2010] 1 IR 490. Cahillane, 'The Prerogative and its Survival in Ireland: Dusty Antique or Positively Useful?' 1(2) (2010) Irish Journal of Legal Studies 1.
[10] See discussion of this in Casey, 'Underexplored Corners: Inherent Executive Power in the Irish Constitutional Order' (2017) 40(1) Dublin University Law Journal 1.
[11] [2014] IEHC 532.
[12] In the immigration context 'Direct provision' is a cashless provision of material support offered by the State to protection applicants in order to meet their basic needs

State argued that the direct provision scheme was a lawful use of inherent executive power under the Constitution, and in the course of legal argument pointed to a variety of other administrative schemes that existed in diverse fields.[13] In finding that the establishment of the direct provision scheme was a lawful exercise of executive power, Mac Eochaidh J. made the following helpful comments:

> The Constitution does not require that the legislature must establish principles and policies in order for the Government to exercise its executive powers. The Government may exercise executive powers independently of the legislature. In exercising its constitutional executive powers, the Government may not trespass upon the exclusive law making function of the legislature. If the Government establishes a scheme in pursuit of a policy which contains rules and conditions, though the rules may be regarded as a form of 'laws', this would not involve the executive usurping the law making function of the legislature within the meaning of Article 15 of the Constitution.[14]

He further commented that "The mere fact that 'direct provision' could have been placed on a legislative footing does not mean that this must happen."[15] Mac Eochaidh J. further observed that there were many executive schemes that operated with no statutory basis, and that the legitimacy of these had never been called into question. These included the system of primary school education, and the Criminal Injuries Compensation Tribunal. He also noted that the Irish Born Child Scheme had been approved by the Supreme Court in *Bode v. Minister for Justice*[16] as a valid use of inherent executive power.

The case-law on the executive power, scant though it is, strongly supports the existence of an inherent executive power to establish administrative schemes to achieve a policy end. Importantly, it should be noted that some emphasis has been laid on the fact that such schemes are usually *ex gratia* schemes which confer a benefit on given individuals,[17] rather than make determinations as to the legal rights of individuals. In the relevant sense, this would appear to apply to the proposed administrative scheme in the Tuam context. This scheme would not make any determination as to the rights and duties of individuals. It would, in a sense confer on them a benefit, i.e. inclusion in the DNA matching scheme. Most

[13] These included: Free Travel, Job Bridge, Work Placement Programme, Back to Education Allowance.
[14] §14.22.
[15] §14.25.
[16] [2008] 3 I.R. 663.
[17] See comments in *Bode* at p. 690.

crucially, the scheme would be entirely voluntary in nature, and also designed to exist only on a short-term or interim basis.

It seems therefore that an administrative scheme of this nature would likely be constitutionally permissible. The scheme would, of course, have to comply with other governing legal regimes, as explored in this report.

An appropriate administrative scheme

In general, there is therefore no inherent prohibition on the operation of an appropriate administrative scheme for the provision and analysis of genetic material on a voluntary basis. Anecdotal support for this might be seen in the existence of various commercial services involving DNA analysis. Nonetheless, there are certain considerations which must be borne in mind when seeking to establish such a scheme by the State.

First of all, it is necessary that any system clearly comply with existing law. There are several reasons for this. As creatures of public law, public bodies or entities do not have inherent legal capacities which means that their exercise of powers must have a specific legal basis.[18] This is reinforced in this particular context by the privacy and data protection rights that are engaged.

From a privacy perspective, any interference with Article 8 ECHR must be "prescribed by law".[19] This has been interpreted by the ECtHR as requiring that the law in question be clear and accessible, and that those subject to it are able to foresee how it may be applied to them.

Lawfulness of processing

The Strasbourg jurisprudence has also influenced the approach applied under EU law to privacy and data protection. Recital 41 of Regulation (EU) 2016/679 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (the GDPR) specifically re-states the requirement that:

[18] *Dellway Investments v. NAMA* [2011] 4 IR 1.
[19] *Malone v. the United Kingdom* (1985) 7 EHRR 14; *Kopp v. Switzerland* (1998) 27 EHRR 91.

> a legal basis or legislative measure should be clear and precise and its application should be foreseeable to persons subject to it, in accordance with the case-law of the Court of Justice of the European Union (the 'Court of Justice') and the European Court of Human Rights.

The Court of Justice of the European Union (CJEU) summarised the principle more generally in Case 362/14:[20]

> EU legislation involving interference with the fundamental rights guaranteed by Articles 7 and 8 of the Charter must, according to the Court's settled case-law, lay down clear and precise rules governing the scope and application of a measure and imposing minimum safeguards, so that the persons whose personal data is concerned have sufficient guarantees enabling their data to be effectively protected against the risk of abuse and against any unlawful access and use of that data.

In the specific context here, Article 6 of the GDPR permits the processing of personal data only where it has a valid legal basis. This states that:

> Processing shall be lawful only if and to the extent that at least one of the following applies:
>
> (a) the data subject has given consent to the processing of his or her personal data for one or more specific purposes;
> (b) processing is necessary for the performance of a contract to which the data subject is party or in order to take steps at the request of the data subject prior to entering into a contract;
> (c) processing is necessary for compliance with a legal obligation to which the controller is subject;
> (d) processing is necessary in order to protect the vital interests of the data subject or of another natural person;
> (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;
> (f) processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child.
>
> Point (f) of the first subparagraph shall not apply to processing carried out by public authorities in the performance of their tasks.

[20] *Schrems v. Data Protection Commissioner*, ECLI:EU:C:2015:650, at para. 91.

The most obvious bases for processing would appear to be those provided for by Article 6 (1)(a) and (e). However, it should be borne in mind in this regard that processing on the basis of point (e) is subject to additional regulation. Article 6(3) states that:

> The purpose of the processing shall be determined in that legal basis or, as regards the processing referred to in point (e) of paragraph 1, shall be necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.
>
> That legal basis may contain specific provisions to adapt the application of rules of this Regulation, inter alia: the general conditions governing the lawfulness of processing by the controller; the types of data which are subject to the processing; the data subjects concerned; the entities to, and the purposes for which, the personal data may be disclosed; the purpose limitation; storage periods; and processing operations and processing procedures, including measures to ensure lawful and fair processing such as those for other specific processing situations as provided for in Chapter IX.

This suggests that Article 6(1)(a) may provide a more robust basis for the processing envisaged in an appropriate administrative scheme.

Consent

Article 7 of the GDPR outlines the conditions for consent to be effective as a means of processing. It provides that:

> 1. Where processing is based on consent, the controller shall be able to demonstrate that the data subject has consented to processing of his or her personal data.
>
> 2. If the data subject's consent is given in the context of a written declaration which also concerns other matters, the request for consent shall be presented in a manner which is clearly distinguishable from the other matters, in an intelligible and easily accessible form, using clear and plain language. Any part of such a declaration which constitutes an infringement of this Regulation shall not be binding.
>
> 3. The data subject shall have the right to withdraw his or her consent at any time. The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal. Prior to giving consent, the data subject shall be informed thereof. It shall be as easy to withdraw as to give consent.

4. When assessing whether consent is freely given, utmost account shall be taken of whether, inter alia, the performance of a contract, including the provision of a service, is conditional on consent to the processing of personal data that is not necessary for the performance of that contract.

This gives effect to the principles identified in Recital 32 of the GDPR:

> Consent should be given by a clear affirmative act establishing a freely given, specific, informed and unambiguous indication of the data subject's agreement to the processing of personal data relating to him or her, such as by a written statement, including by electronic means, or an oral statement. This could include ticking a box when visiting an internet website, choosing technical settings for information society services or another statement or conduct which clearly indicates in this context the data subject's acceptance of the proposed processing of his or her personal data. Silence, pre-ticked boxes or inactivity should not therefore constitute consent. Consent should cover all processing activities carried out for the same purpose or purposes. When the processing has multiple purposes, consent should be given for all of them. If the data subject's consent is to be given following a request by electronic means, the request must be clear, concise and not unnecessarily disruptive to the use of the service for which it is provided.

There is a degree of overlap here between the specific requirements of the GDPR and the more general principles governing the conditions under which a constitutional right can be validly waived. This means, in practice, that full compliance with the GDPR requirements is likely to also assist in addressing any constitutional concerns that may arise from the operation of the voluntary scheme.

The GDPR imposes an obligation on the data controller to ensure that it is in a position to demonstrate that the data subject has given consent. Moreover, his/her consent should satisfy the Recital 32 objective that it be "a clear affirmative act establishing a freely given, specific, informed and unambiguous consent".

This means that it would be essential as part of any voluntary system to ensure that there is a clear documentary record of both the provision of formal written consent by participants but also of the steps taken to ensure that the written consent was specific, informed and freely given. It would seem prudent therefore, at a minimum, to ensure that any scheme would include the following measures:

- **The provision of a clear and accessible explanation of the scheme; the purpose for which the samples are being taken; and the uses to which they may be put.**

- **The inclusion of a clear statement as to any risks or adverse impact on participants that may arise from their participation in the scheme.**
- **Separate explanations of the steps and/or risks involved in the taking of samples; the retention of samples; and the use of those samples.**
- **A requirement for separate formal consent to the taking, retention and use of the samples.**
- **Confirmation that any person to whom the results are to be disclosed has consented to, and is willing to receive those results (given it may in some cases engage their own personal data and/or rights arising from genetic material and biological identity).**
- **An explanation that participants may withdraw from the scheme at any time.**
- **An explanation of how participants may withdraw their consent from the scheme (which must be relatively straightforward).**
- **An explanation of what will be done with the samples in the event that consent is withdrawn.**
- **A statement of the time for which the samples will be held and used. This does not necessarily require the identification of a specific period of time but should indicate the limits of the purpose for which they will be held.**
- **A statement of what will be done with the samples once the purpose of the processing has concluded.**
- **A statement of what will be done in the event that participants die.**
- **The appointment of a specific Data Protection Officer for the scheme; and the provision of information and contact details regarding how data protection principles are being applied and/or how participants can raise any concerns they may have.**
- **A statement of the rights of participants to access, correct or seek the deletion of their personal data, and how this can be done.**
- **The implementation of measures to ensure appropriate security of personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures; and an explanation of these.**

One issue which requires a degree of consideration is the use to which the results could be put. Because the samples (and any results) may include genetic material and/or biological information that relates to third parties, it is possible that certain usages of the material may also engage these third party rights. This is a complex question as it necessarily depends on the results of analysis in a particular case; and on the proposed use of the information obtained. In other contexts, this has been dealt with by way of a prohibition on the use or sharing of the information without the express consent of identifiable third parties. It may be that there would be difficulties with applying such an approach in this context. Nonetheless, this is a factor to be borne in mind at the point at which it becomes clear if analysis is feasible; and what the results of that analysis may be. If it is ultimately the case that the

analysis reveals no more than the identity of the deceased, then the risks in this regard may be relatively limited.

DISABILITY ACT 2005

The Disability Act 2005 contains a specific provision governing genetic testing, which it appears would have to be complied with in the case of DNA collection in the Tuam context. Section 42 of the Disability Act 2005, as amended, provides in relevant parts:

> (1) Genetic testing shall not be carried out on a person unless—
> (a) the testing is not prohibited by law, and
> (b) the consent of the person to the processing of any genetic data to be derived from the testing has been obtained in accordance with the Data Protection Regulation.
>
> …
>
> (3) A person shall not process genetic data unless all reasonable steps have been taken to provide the data subject with all appropriate information concerning—
> (a) the purpose and possible outcomes of the proposed processing, and
> (b) any potential implications for the health of the data subject which may become known as a result of the processing.

In effect, this section copper-fastens the protections already conferred by the GDPR and adds an additional requirement to provide information in respect of the purpose and possible outcomes of the proposed processing, as well as any potential health implications. In substance, it seems that these requirements are very similar to those already imposed by the data protection law regime, and which have been fully explored previously in this Report.

CONCLUSION

In conclusion, while the ECHR and the GDPR require that any measures engaging privacy and data protection rights be prescribed by law and have a legal basis, respectively, this has generally been broadly interpreted to include forms of legal authorisation other than legislation.[21] This is specifically acknowledged in the GDPR context in recital 45. While legislation clearly has certain advantages in terms of its generality, public accessibility and

[21] See, for example, Opinion 1/15, ECLI:EU:C:2017:592.

democratic authority, there is no reason, in principle, why an appropriate administrative scheme could not be established on the basis of other legal instruments. However, the fact that any system would remain subject to the requirements of clarity, accessibility and foreseeability already discussed means that it would not be possible for this to be done on an ad hoc basis. The details of the principles and procedures to be implemented would have to be comprehensively worked out prior to the establishment of an administrative scheme, fully publicised and implemented in a robust and transparent manner.

2. COLLECTION OF BIOLOGICAL SAMPLES FOR COMPARISON PURPOSES WITHIN THE EXISTING LEGAL FRAMEWORK

2.1 THE CURRENT STATUTORY FRAMEWORK

Part of the task that has been assigned to me under the Terms of Reference is to examine what may be possible under the current statutory framework.

It would appear that the only statutory provisions that could arguably be mobilised for the purpose of carrying out the proposed processes, and matching survivors' and/or relatives' DNA with those extracted from the remains exhumed at Tuam, are sections 27, 28 and 48 of the Criminal Justice (Forensic Evidence and DNA Database System) Act 2014.

This section of the Report therefore addresses whether these statutory provisions offer a possible mechanism for the intended purpose.

2.1.1 Section 48 of the Criminal Justice (Forensic Evidence and DNA Database System) Act 2014

The legislative purpose of the provision is most clearly articulated in subsections (1)-(2) of the main section:

> 48. (1) A sample may be taken under this section –
>
> (a) in accordance with subsection (5) in relation to a missing person who is missing in circumstances referred to in subsection (2), or
> (b) from a person who is a relative by blood of a missing person,
>
> for the purpose of generating a DNA profile in respect of the person concerned to be entered in the missing and unknown persons index of the DNA Database System to assist with finding or identifying the missing person.
>
> (2) A sample may be taken under this section for the purposes of the investigation by the Garda Síochána of the disappearance of a missing person if –
>
> (a) a member of the Garda Síochána not below the rank of inspector is satisfied that the circumstances of the disappearance so require, or

(b) following a natural or other disaster, one or more persons are missing.

While the provision provides a framework for the kind of collection of samples envisaged by survivors and relatives, there would appear to be several potential difficulties with its usage in this context.

The first difficulty in applying this provision to the situation at hand is that there may be doubts as to whether the definition of 'missing person' could be said to cover the persons whose remains are, or may be, found in the site in Tuam. The definition identifies at least three criteria, all of which appear to be required to constitute a missing person, namely: (i) the person is observed to be missing from their own "normal patterns of life"; (ii) specific persons who are likely to have heard from the individual are unaware of their whereabouts; and (iii) there are "concerns" for safety and well-being.

There must be doubts as to whether these criteria would be capable of being satisfied in all cases. This is particularly so given that the language used in the section may be read as implying that the conditions to be satisfied are contemporaneous or, at least, relatively recent. The reference to the missing persons as having "their normal patterns of life" from which they have been observed to be missing may imply, for example, that these are current or recent patterns. It may also strain the language of the section to suggest that there are persons who would be likely to have heard from the person but who are unaware of their whereabouts. This is because the section seems directed to persons who have recently heard from the person in question. Finally, the definition appears to contemplate that there are 'concerns' in the sense that the person may be alive but where there are doubts, whereas the situation here is that the fate of the individuals in question is already known.

Even if the definition could be applied to the deceased, there are further difficulties arising from the restrictions imposed by section 48.

Subsection 4 requires that the Garda member authorising the taking of the sample be satisfied that the steps envisaged "may assist with finding or identifying the missing person concerned". The existence of such a belief is a statutory precondition to the exercise of the power under section 48. Given the situation here, it cannot be assumed that the Garda member would automatically hold such a belief in each, or even most, cases.

In addition, section 48(1) makes clear that the power may only be exercised for the relatively narrow purpose of "generating a DNA profile in respect of the person concerned to be entered in the missing and unknown persons index of the DNA Database System to assist with finding or identifying the missing person". This is important not only to the initial taking of the sample but also to the use that may lawfully be made of it thereafter.

There are two distinct, but related, legal concerns in this regard. The first is the specific statutory question of whether the exercise of this power in an individual case to take a sample is intra vires the limits imposed by the Oireachtas. The second is that the purpose for which the sample is obtained imposes more general limitations on the use to which the sample may be subsequently put, both under the section itself and under general data protection principles. The sample could only be processed for purposes relating to that initial purpose; the information and consent given would have to be directed to that purpose; and the sample would likely have to be destroyed once that purpose had been accomplished.

This means that, while section 48 might be said to apply in some cases, there would be significant risks to making use of section 48 as the basis for a comprehensive scheme of collecting samples. The retention and use of samples collected in respect of Tuam may not coincide precisely to the usage identified in section 48(1). This would create significant vulnerabilities under both normal statutory principles and more general data protection requirements.

2.1.2 Sections 27 to 28 of the Criminal Justice (Forensic Evidence and DNA Database System) Act 2014

I next give consideration to whether it may be possible to establish and operate a system pursuant to sections 27 and 28 of the 2014 Act. These allow for the collection of samples from volunteers in relation to the investigation of a particular offence, or the investigation of a particular incident that may have involved the commission of an offence.

At first glance, these sections appear somewhat more apposite given that they are directed towards "volunteers". Given it has been suggested in commentary since the identification of the site at Tuam that offences may have been committed, the purpose to which these sections are directed is, at least in principle, closer to that situation than to one of "missing persons".

However, the application of these sections is, once again, not without potential difficulty. First of all, despite the use of the term 'volunteer', section 27(1) appears to define a volunteer as being a person of whom a request is made by a Garda member or authorised person to provide a sample. The logic for this appears to relate to the requirement that the sample be taken for the purpose of an investigation. In other words, it is for An Garda Síochána (AGS) or authorised persons to identify and approach 'volunteers' who they believe may be relevant to an investigation.

This points to the additional difficulties that the more likely reading of the section is that there must be some form of investigation within the meaning of section 27(1)(a) or (b) in being at the time; and that the sample must relate to that investigation.

It is also possible that the reference to "a particular incident" could be construed narrowly as requiring a single incident, although this appears to me to be less likely in light of the provisions of section 18(a) of the Interpretation Act 2005 on singular and plural provisions.

It is unknown if an investigation into the 'incident' must be active or under contemplation at present. Even if one was in being, however, there may be doubts as to whether the taking of samples to identify remains would be relevant to the offence being investigated. This would naturally depend on the offence at issue. It would not seem to necessarily follow, however, that identification of a specific set of remains would be relevant to the distinct question of whether criminal liability applies.

Thus, while sections 27 and 28 appear somewhat closer to what is envisaged here, there may be scope for divergences or tensions to arise between the framework provided therein, and the particular purpose of taking and holding samples under consideration here. This suggests that the use of these sections may also be susceptible to potential challenge.

2.1.2 Summary in relation to the current statutory framework

Clearly, the statutory framework under the 2014 Act was not developed with the kind of situation in mind engaged by the discovery of juvenile human remains at the site of the former Mother and Baby Home in Tuam. This means there are doubts over its applicability to at least some cases. Furthermore, the 2014 Act does not provide for an explicit mechanism

whereby information gleaned from a matching process may be disseminated to a relative or another individual when the data subject dies. This is a considerable vulnerability, especially in respect of the general principle that personal data or private information may only be used for the purpose for which it was obtained.

However, such a process may not be legally precluded. When a data subject dies, his/her data protection rights die with them; thus, it is arguable that An Garda Síochána may be able to provide information to those who make enquiries. Equally, however, the absence of a clear legal basis for the provision of information by An Garda Síochána means it cannot be assumed this could be done.

Pending the completion of bespoke legislation, there are several practical reasons to prefer the establishment of an administrative scheme to facilitate the process of collecting DNA samples immediately, not least of which is the age profile and health status of survivors. This process might enable the later matching between survivors/relatives and the remains at Tuam.

While preferable in the long-term, in the short-term it does not appear to be necessary that the process be underpinned by a statutory mechanism or framework, an issue discussed at section 2.2 of this report. It appears legally possible and permissible to collect, and would be desirable in the interests of justice, to store survivors and/or relatives' biological samples in the absence of any statutory framework existing.

Anecdotal support for this might be seen in the existence of various commercial services involving DNA analysis. Nonetheless, there are certain considerations which must be borne in mind when seeking to establish such a service provided by the State.

First of all, it is necessary that any system have a clear legal basis. There are several reasons for this. As creatures of public law, public bodies or entities do not have inherent legal capacities which means that their exercise of powers must have a specific legal basis.[22] This is reinforced in this particular context by the privacy and data protection rights that are engaged.

[22] *Dellway Investments v. NAMA* [2011] 4 IR 1

From a privacy perspective, any interference with Article 8 ECHR must be "prescribed by law".[23] This has been interpreted by the ECtHR as requiring that the law in question be clear and accessible, and that those subject to it are able to foresee how it may be applied to them.

The Strasbourg jurisprudence has also influenced the approach applied under EU law to privacy and data protection. Recital 41 of Regulation (EU) 2016/679 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (the GDPR) specifically re-states the requirement that:

> a legal basis or legislative measure should be clear and precise and its application should be foreseeable to persons subject to it, in accordance with the case-law of the Court of Justice of the European Union (the 'Court of Justice') and the European Court of Human Rights.

The Court of Justice of the European Union (CJEU) summarised the principle more generally in Case 362/14:[24]

> EU legislation involving interference with the fundamental rights guaranteed by Articles 7 and 8 of the Charter must, according to the Court's settled case-law, lay down clear and precise rules governing the scope and application of a measure and imposing minimum safeguards, so that the persons whose personal data is concerned have sufficient guarantees enabling their data to be effectively protected against the risk of abuse and against any unlawful access and use of that data.

This could (as is outlined in section 2.2 of this Report) be achieved through the establishment of an administrative scheme, as long as such a scheme is compliant with the provisions of the Data Protection Act 2018 and the GDPR, and the requirements of the Constitution and the ECHR. If such a scheme was to satisfy the criteria outlined below, there appears to be no reason why the State would be precluded from taking such action to fulfil the wishes of survivors and their relatives.

[23] *Malone v. the United Kingdom* (1985) 7 EHRR 14; *Kopp v. Switzerland* (1998) 27 EHRR 91.
[24] *Schrems v. Data Protection Commissioner*, ECLI:EU:C:2015:650, at para. 91.

2.2 POTENTIAL FOR CREATION OF AN INTERIM ADMINISTRATIVE SCHEME

There is no doubt that in the longer term, it is preferable that the process of collecting and matching DNA samples at the Tuam Mother and Baby Home should be underpinned by a robust statutory mechanism or framework. For present purposes, the question is whether it is possible for the Government to take measures to begin the collection process without a statutory basis, during the period when that statutory framework is being established. A non-statutory measure would be by its nature short-term or interim, and in the situation at Tuam would be designed to address the fact that the age profile of survivors and relatives has created a significant urgency in respect of the collection process. Given the risk that some of these people may die before the legislation is passed, time is clearly of the essence. The question of whether the creation of an interim administrative scheme is legally possible is a question of constitutional law: does the executive branch enjoy the power to establish a scheme of this nature? This Report does not purport to give a definitive view on that question, which is ultimately one for the Attorney General. However, the applicable constitutional principles are explored, in general terms.

As the authors of *Kelly: The Irish Constitution* comment, the Constitution is silent as to the extent of the executive power.[25] The Executive has been held to have certain inherent powers, some of which are possibly derived from royal prerogative powers.[26] For present purposes, the most relevant example of inherent executive power is that the superior courts have recognised that the Executive enjoys an inherent power to establish ex-gratia non-statutory schemes to implement desired policy objectives.[27] In the case of *C.A. and T.A. (a minor) v. Minister for Justice and Equality, Minister for Social Protection, the Attorney General and Ireland,*[28] the High Court considered a claim that the system of 'direct provision' was unlawful in the absence of enabling legislation.[29] In part, it was argued that the establishment of the scheme usurped the power of the Legislature. The State argued that the direct provision scheme was a lawful use of inherent executive power under the Constitution, and in the

[25] Hogan, Whyte, Kenny, Walsh *Kelly: The Irish Constitution* (2018, 5th ed, Bloomsbury Professional) p. 164, p. 500.
[26] *Prendergast v. Higher Education Authority* [2010] 1 IR 490. Cahillane, 'The Prerogative and its Survival in Ireland: Dusty Antique or Positively Useful?' 1(2) (2010) Irish Journal of Legal Studies 1.
[27] See discussion of this in Casey, 'Underexplored Corners: Inherent Executive Power in the Irish Constitutional Order' (2017) 40(1) Dublin University Law Journal 1.
[28] [2014] IEHC 532.
[29] In the immigration context 'Direct provision' is a cashless provision of material support offered by the State to protection applicants in order to meet their basic needs.

course of legal argument pointed to a variety of other administrative schemes that existed in diverse fields.[30] In finding that the establishment of the direct provision scheme was a lawful exercise of executive power, Mac Eochaidh J. made the following helpful comments:

> The Constitution does not require that the legislature must establish principles and policies in order for the Government to exercise its executive powers. The Government may exercise executive powers independently of the legislature. In exercising its constitutional executive powers, the Government may not trespass upon the exclusive law making function of the legislature. If the Government establishes a scheme in pursuit of a policy which contains rules and conditions, though the rules may be regarded as a form of 'laws', this would not involve the executive usurping the law making function of the legislature within the meaning of Article 15 of the Constitution.[31]

He further commented that "The mere fact that 'direct provision' could have been placed on a legislative footing does not mean that this must happen."[32] Mac Eochaidh J. further observed that there were many executive schemes that operated with no statutory basis, and that the legitimacy of these had never been called into question. These included the system of primary school education, and the Criminal Injuries Compensation Tribunal. He also noted that the Irish Born Child Scheme had been approved by the Supreme Court in *Bode v. Minister for Justice*[33] as a valid use of inherent executive power.

The case law on the executive power, scant though it is, strongly supports the existence of an inherent executive power to establish administrative schemes to achieve a policy end. Importantly, it should be noted that some emphasis has been laid on the fact that such schemes are usually *ex gratia* schemes which confer a benefit on given individuals,[34] rather than make determinations as to the legal rights of individuals. In the relevant sense, this would appear to apply to the proposed administrative scheme in the Tuam context. This scheme would not make any determination as to the rights and duties of individuals. It would, in a sense confer on them a benefit, i.e. inclusion in the DNA matching scheme. Most crucially, the scheme would be entirely voluntary in nature, and also designed to exist only on a short-term or interim basis.

[30] These included: Free Travel, Job Bridge, Work Placement Programme, Back to Education Allowance.
[31] §14.22.
[32] §14.25.
[33] [2008] 3 IR 663.
[34] See comments in *Bode* at p. 690.

It seems therefore that an administrative scheme of this nature would likely be constitutionally permissible. The scheme would, of course, have to comply with other governing legal regimes, as explored in this report.

2.3 CONCLUSIONS

- *The 2014 Act may provide a mechanism whereby the biological samples of survivors and/or relatives could be legally collected, stored and processed for the purpose of carrying out a DNA matching process with juvenile human remains exhumed at Tuam in some cases, if those cases fall within the criteria laid down in the Act. However, it seems likely that the 2014 Act would not necessarily apply in all cases. This suggests that it does not provide a suitable basis for a comprehensive scheme of collecting samples.*

- *An administrative scheme would be a preferable mechanism to collect DNA samples of survivors and/or relatives. While in the longer term a statutory scheme would undoubtedly be preferable, it would appear to be constitutionally permissible for an administrative scheme to be established on a short-term, interim basis.*

- *In circumstances where an administrative scheme is established, it will be necessary to seek the consent of the person who survivors and/or relatives wish for the information to be disseminated to, in order to retain their personal details so that they may be contacted in the future.*

3. ECHR CONSIDERATIONS

In examining whether the existing legislative framework in place within this jurisdiction permits the collection of DNA samples from survivors of the Tuam Mother and Baby Home and from their relatives, it is important to consider the extent to which any relevant family rights under Article 8 of the European Convention on Human Rights (ECHR) might apply. This section of the report therefore considers the parameters of Article 8, the rights protected therein and the duties that are placed upon the State arising therefrom. It also discusses whether a voluntary administrative scheme, if established to allow family members to voluntarily submit biological samples for later testing, would assist in vindicating the rights of family members under Article 8 that are at issue in the complex circumstances that arise from the discovery of juvenile human remains at the site of the former Mother and Baby Home at Tuam. A brief consideration of any further relevant ECHR rights that may also be engaged in the within circumstances is similarly considered below.

3.1 EUROPEAN CONVENTION ON HUMAN RIGHTS

The Convention for the Protection of Human Rights and Fundamental Freedoms, better known as the European Convention on Human Rights came into force in 1953. It was the first instrument to give effect to certain of the rights stated in the Universal Declaration of Human Rights and make them binding. Its contracting states are obliged to secure to everyone within their jurisdiction the rights and freedoms set out in section 1 of the ECHR. The European Court of Human Rights is tasked with enforcing the provisions of the ECHR and its judgments, in some cases, have broadened the interpretation of the Convention. In Ireland, the European Convention of Human Rights Act 2003 was introduced to give further effect to the ECHR in Irish law. The Act did not incorporate the Convention into Irish law, but rather requires Irish courts to interpret legislation in line with the Convention insofar as it is possible to do so. It also requires that certain public bodies perform their functions in a manner compatible with the Convention, unless precluded by law. The State, therefore, should ensure that its actions with respect to the within request from Tuam survivors comply with its obligations under the ECHR.

Section 1 of the ECHR contains the rights and freedoms that the Convention is designed to protect. Article 8 of the ECHR is of crucial importance for the present purposes, and it is necessary to set out in full its provisions:

> Article 8: **Right to respect for private and family life**
>
> 1. Everyone has the right to respect for his private and family life, his home and his correspondence.
>
> 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

3.2 ARTICLE 8 ECHR

The within Terms of Reference require consideration of the extent to which any relevant family rights under Article 8 ECHR may be engaged in light of the request by the Tuam Home Survivors' Network for the Government to begin collecting their DNA samples immediately. This first involves an examination of Article 8 ECHR and the rights of family members protected therein which arise in connection with the discovery of juvenile human remains at the site in Tuam. Next, the question arises as to whether these rights can be effectively exercised without positive familial identifications. Finally, it must be considered whether the right to identity, protected by Article 8, has a bearing on the question posed herein – and whether this right could potentially be extended to encompass a right to identify a relative. Article 8 is therefore the primary provision of consideration for the purposes of this report, however it is worth noting that the protections contained within Article 8 can operate at the same time as those contained in other articles, particularly Articles 2 and 3 ECHR, and this warrants some consideration. Furthermore, it is important to note that while Article 8 specifically guarantees the right to respect for an individual's private and family life, home and correspondence, its scope has been interpreted in a broad manner by the ECtHR, with rights being inferred from its provisions even where same are not expressly enumerated therein.

Considering the relevant rights under Article 8 that may apply, an evaluation of case-law of the ECtHR is set out below. In determining complaints as to whether Article 8 has been

breached, the ECtHR first considers whether the applicant's claim falls within the scope of Article 8 and the interests it is designed to protect. The Court then examines whether there has been an interference with that right or whether the State's positive obligations to protect that right has been engaged. This involves a consideration of the circumstances within which the State may curtail the enjoyment of a particular right as set out in Article 8.2 namely, where the interference is in accordance with law and necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

It is worth noting at the outset that while Article 8 is couched in negative terms, giving individuals protection against arbitrary interferences with their private and family life and mandating that the State refrain from such interference, the ECtHR has held that there may also be positive obligations placed upon the State to secure respect for private and family life. This may oblige the State to adopt measures designed to safeguard this right. This principle was first set out in the decision of *Marckx v. Belgium.*[35] In this case, the parents of a child born out of wedlock challenged the provisions of the Belgian Civil Code which detailed the process of establishing the maternal affiliation of an "illegitimate" child. Essentially, under Belgian law at that time, no legal bond between an unmarried mother and her child resulted from the mere fact of birth. Instead, the maternal affiliation of an "illegitimate" child was established by means of either a voluntary recognition by the mother or of legal proceedings taken for this purpose. Furthermore, in order to increase the rights of the child, for example for inheritance purposes, the parents were required to adopt their own "illegitimate" child. The parents therefore complained that their rights pursuant to Article 8 had been infringed.

The ECtHR duly held that the Belgian system infringed the right to private and family life by reducing inheritance rights for "illegitimate" children, finding that this Article made no distinction between the legitimate or "illegitimate" family. While the Court commented that the purpose of Article 8 is to protect the individual against arbitrary interference by the public authorities, it went on to state that Article 8 "…does not merely compel the State to abstain from such interference: in addition to this primarily negative undertaking, there may be positive obligations inherent in an effective 'respect' for family life." In this case, the

[35] (1979) 2 EHRR 330.

indictment was against Belgian law which was found to be wanting in respect of the family life of the applicants. This positive obligation means that the State, in its domestic legal system, determines the provisions applicable to certain family ties, including to those between an unmarried mother and her child and the State must act in a manner to enable those concerned to lead a normal family life. Article 8 demands the existence in domestic law of legal safeguards that enable a child to integrate with his or her family from the moment of birth. A law of the State that fails to satisfy this requirement violates Article 8.1, without the necessity to examine the provisions of Article 8.2.

In cases where a positive obligation is claimed, the Court considers whether the importance of the interest at issue requires the imposition of a positive obligation as sought by the applicant. The ECtHR in *Hämäläinen v. Finland*[36] considered certain factors as relevant in assessing the content of positive obligations on the State. Specifically, the Court stated that the importance of the interest at stake and whether 'fundamental values' or 'essential aspects' of private life are in issue are relevant, as well as the impact on an applicant of a discordance between the social reality and the law and the impact of the alleged positive obligation on the State concerned. In implementing their positive obligations, States enjoy a margin of appreciation, however that margin will be narrower where a particularly important facet of individuals' existence or identity is at stake.

Having regard to the site at Tuam and the identification of the juvenile human remains interred therein, the positive obligation inferred from Article 8 ECHR is of particular relevance. Given the rights at issue, discussed in full below, the question arises as to whether the State has a duty to take particular action to safeguard any potential positive familial identifications at Tuam – namely by collecting and storing, where possible, DNA samples from relatives and survivors of the Tuam Mother and Baby Home to enable such future identifications. It is arguable that key elements of private and family life are engaged by these circumstances and thus the State may be obliged to take such actions that are possible to ensure its compliance with its positive obligations under the Convention.

In the examination (below) of Article 8 ECHR, specific regard will be had to issues concerning the death and burial of family members and judgments given by the ECtHR

[36] [GC], Application no. 37359/09, ECHR 16 July 2014.

interpreting Article 8 and addressing this subject. The question examined is primarily whether there exists a right of family members to have the remains of their loved ones returned to them under the Convention. The existence of any such right should be considered in informing the State's response to the request by the Tuam Home Survivors' Network. In the relevant ECtHR decisions, it is clear that the rights of the family of the deceased are engaged and not those of the deceased themselves. These cases have involved challenges brought by individuals against a State who they claim failed to grant access to the remains of their family members or where excessive delays have occurred in the restitution of a body after an autopsy or following completion of a criminal investigation. Essentially, in its line of authorities, the ECtHR has inferred a right to bury family members into Article 8's protection for private and family life. There also exists a right of family members to be informed and provided with information surrounding the circumstances of their relative's death and/or burial, an additional entitlement that requires particular attention in assessing how to respond to the request to collect DNA samples from Tuam survivors and relatives forthwith. Furthermore, decisions of the ECtHR regarding the treatment of the body of deceased persons are considered, with a particular focus on the requirement for the consent of the deceased's next of kin if the body is to be exhumed or samples are to be taken therefrom.

Given the existence of family members' rights pursuant to Article 8, it will then be considered as to whether there is a positive obligation on the State to ensure that these rights are vindicated. The ability to exercise the right to bury one's family members and to be provided with information surrounding relatives' deaths is dependent upon knowledge as to whether or not the deceased is actually a family member. The question therefore is whether steps need to be taken proactively by the State to protect the future possibility of obtaining positive familial matches before time passes and the death of Tuam survivors or relatives precludes this from taking place or further complicates an already complex situation.

The applications considered below to the ECtHR have been brought in a variety of contexts and understandably, no case on its facts can be said to mirror the particular set of circumstances at issue in relation to the discovery of juvenile human remains at the site of the former Mother and Baby Home in Tuam. Nevertheless, comparisons can be drawn and it is necessary to examine each of the following cases to fully consider the applicable rights under ECHR law. It must be remembered that the rights recognised and vindicated therein are not absolute and a failure to return a dead body to the relatives for burial, or disclose where it was

buried for instance, may only constitute a violation of Article 8 if the interference with these rights cannot be justified by the State in question. A key question is whether sufficient justification is given and the necessity and proportionality of the interference concerned.

3.2.1 Returning body to family member – delay between death and burial

In a number of cases that have come before the ECtHR, complaints have been made concerning the return of a deceased's body to his or her family members. Specifically, the length of time between death and the burial of the deceased is a pertinent issue. This warrants consideration bearing in mind that those interred in the Tuam site have not as of yet been returned to their family members for a respectful and appropriate burial. The proximity of family relationships is also likely to be relevant in this regard. The cases set out below concern immediate family members. While immediate family relationships may arise in some instances in relation to the Tuam excavation, this will not necessarily be the case in all situations. It is possible to envisage the Irish courts drawing a line between the rights of immediate family members and the interests of more distant relatives. This would seem to be consistent with the approach adopted by the ECtHR in the majority of cases decided by it. In the present context, there is also the consideration that the possibility of obtaining a positive identification is more remote in relationships other than parents and sibling or half-sibling. Taken together with the emphasis in the Strasbourg and UK case-law on Article 8 on the presence of a close personal relationship, this suggests that a European Convention on Human Rights compliant scheme is therefore likely to involve such a scheme applying only to first degree or second degree family relationships.

3.2.1.1 Pannullo and Forte v. France[37]

In June 1996, the daughter of Italian parents had died following a postoperative check-up in France at age four. Investigations were carried out by French authorities into the cause of her death and an examination took place into her diagnosis and treatment. These investigations caused a delay in the return of her body to her parents. An autopsy had been carried out in July 1996, but the body was not returned to her parents until February 1997. Medical evidence demonstrated that there was no necessity to keep the body for investigative purposes after the autopsy had been completed. Furthermore, the forensic scientist carrying

[37] Application no. 37794/97, ECHR 2001-X.

out an expert report had indicated to the investigating judge following the autopsy that the necessary samples had been taken and the body could be repatriated. Despite this notification, the body was still not released. It was therefore claimed by her parents that the delay constituted an unjustified interference with their right to respect for their private and family life pursuant to Article 8 ECHR. On behalf of France, the delay was not disputed and it was accepted that it constituted an interference with the parent's Article 8 rights, but it was argued that the various formalities carried out in the release of the body had pursued a legitimate aim of preventing crime and therefore Article 8 was not breached. The Court noted:

> …[W]hile the essential object of Article 8 is to protect the individual against arbitrary interference by the public authorities, there may in addition be positive obligations inherent in effective "respect" for family life. In both contexts regard must be had to the fair balance that has to be struck between the competing interests of the individual and the community as a whole, and in both contexts the State is recognised as enjoying a certain margin of appreciation.[38]

It found that the interference with the applicants' rights was in accordance with law and pursued the legitimate aim of preventing crime. The question here therefore was whether the interference was necessary in a democratic society. In this regard, the Court took account of the fact that more than seven months passed between the child's death and the issuance of the burial certificate. While it determined that the deceased's body was required for the autopsy, it was clear that her body should have been returned to her parents immediately after the autopsy. Having regard to the circumstances of the case and the tragedy for the parents of losing their child, the Court concluded that the French authorities failed to strike a fair balance between the applicant's right to respect for private and family life and the legitimate aim pursued. The Court thus held that there had been a violation of Article 8 ECHR.

This case makes it clear that the unjustified delay in the restitution of a body after an autopsy may constitute an interference with both the private life and family life of surviving family members.

[38] Ibid, at para. 35.

3.2.1.2 Girard v. France[39]

In this case, the applicants were two French nationals whose daughter had disappeared in November 1997. More than a year and a half later, she was found murdered. In an action against French authorities, relying on Article 2 of the Convention, the right to life, they argued that there had been a failure to properly investigate their daughter's disappearance. They further argued that the delay in returning samples taken from the deceased's body constituted an interference with their Article 8 rights.

The Court found that an extended delay in returning samples taken from the applicants' daughter's body by police, which prevented the applicants from burying her in a timely manner, violated Article 8. It placed weight on the delay of over four months that elapsed between the decision of the authorities to return the samples to the applicants and the actual return of the samples, similar to the unnecessary delay at issue in *Pannullo and Forte* demonstrated above. Furthermore, the Court held that there had been a violation of Article 2 ECHR due to the lack of an effective investigation into the deceased's disappearance. This case essentially recognises that under Article 8 – there exists a right to bury one's relatives – and demonstrates the link that may occur between Articles 2 and 8 in certain situations.

3.2.2 Right to know the fate of a family member – information surrounding circumstances of death

The ECtHR has held that the Article 8 protection of private and family life covers the right to bury family members. Individuals have challenged the State's failure to grant access to the remains of deceased family members in a wide range of contexts. Following the death of a loved one, it is understandable that his/her relatives will seek information concerning the circumstances of his/her passing. Where a family member is missing, his/her relatives will usually seek to obtain the truth of his/her fate. There are various reasons for seeking and ascertaining these details. It may assist in securing the return of remains for burial and commemoration purposes and enable a death certificate to be obtained. Information and investigations surrounding the death or disappearance of a relative may explain what happened, restoring the human dignity of the deceased, or ultimately leading to answers, accountability and criminal justice proceedings. On a larger scale, the provision of such

[39] Application no. 22590/04, 30 June 2011.

information to the public itself may promote transparency and prevent similar situations from arising again. The right to know the fate of a family member has been at issue in certain ECtHR decisions, as set out below.

3.2.2.1 Hadri-Vionnet v. Switzerland [40]

The case concerned the conditions under which the municipal authorities conducted the burial of the applicant's stillborn child without consulting her on the matter. In this case, the applicant gave birth to a stillborn baby while she was residing in a centre for asylum seekers in Switzerland. She and the child's father decided that they did not wish to see the child's body. An autopsy was then performed on the body and the baby was buried in a communal grave for stillborn babies. This burial took place without the parents being present and without a ceremony. The applicant mother challenged the manner in which this burial occurred, arguing that the burial took place without her knowledge in a communal grave and that she had not been entitled to attend. She contended that this was an infringement of her Article 8 rights under the Convention.

First, the ECtHR found that Article 8 was applicable in these circumstances. It thus found that the State's failure to inform the mother about the location and time of the burial of her still-born son was not authorised by law and violated her rights under Article 8. This arguably demonstrates that knowledge is crucial – namely, that a family member of a deceased has the right to know where the deceased is buried and the failure to provide information regarding a burial may be in breach of Article 8 ECHR.

3.2.2.2 Marić v. Croatia[41]

In *Marić v. Croatia*, the ECtHR found again that the disposal of the body in a manner which left the parents with no information as to the whereabouts of the remains breached the parents Article 8 rights. The Court relied on its previous decisions as clearly establishing that Article 8 was engaged by the applicant's complaint that he was prevented from knowing where his child was buried. However, it might also be noted that the Court described the case as one where:

[40] Application no. 55525/00, 14 February 2008.
[41] Application no. 50132/12.

> it is not a question of whether the applicant had the right to a particular type of ceremony or to choose the exact location of the child's place of rest, as could be understood from the Government's arguments, but whether there has been an interference with the applicant's rights under Article 8 by the body of his stillborn child being disposed of as clinical waste.

It is clear that the Court in this case was responding to the Croatian government's arguments rather than making a positive decision on the scope of the Article 8 obligation. It does, however, draw attention to the fact that the Court's Article 8 case law thus far has been concerned with negative interferences on the part of the State with the right of family members to the return or disposal of bodies, or to information about their disposal. The Court does not yet appear to have considered whether Article 8 imposes a more extensive positive obligation on the part of State authorities to ensure that a burial takes place in the particular manner desired by the family.

3.2.2.3 Zorica Jovanović v. Serbia[42]

A similar concern regarding being informed of the circumstances of a family member's death arose in the case of *Zorica Jovanović v. Serbia.* In this case, in October 1983, the applicant gave birth to a healthy child in the Cuprija Medical Centre (CMC), a State-run hospital. A few days after his birth, the applicant's son was taken to a separate room for new-born babies as was standard procedure. The following day, the applicant was informed by a doctor that her son had died. She was told that an autopsy would be performed on his body in Belgrade, thus his body could not be released to his parents at that stage. His body was never returned to the applicant.

From 2001 onwards, the Serbian media began reporting extensively on numerous cases similar to that of the applicant's where new-born babies had "gone missing" following their alleged deaths in hospital wards. The applicant requested information regarding her son's death – seeking all relevant documentation from the CMC, requesting information from the Municipality of Cuprija and lodging a criminal complaint against the medical staff of the CMC for her son's "abduction". She was informed by the CMC that her son's death had been from an unknown cause and that no other information was available because its archives had been flooded and many documents had been destroyed. The Municipality informed her that

[42] Application no. 21794/08, ECHR 2013.

her son's birth was registered in their records, but his death was not. The criminal complaint was rejected as unsubstantiated as "there was evidence that the applicant's son had died on 31 October 1983". The body of the applicant's son was never released to her, nor was she ever provided with an autopsy report or informed as to when and where he was allegedly buried.

It is worth noting that, in light of the hundreds of similar cases to that of the applicant, an Investigating Committee was established in Serbia. The findings of the Committee concluded that there had been serious shortcomings in the legislation in place at the relevant times and in the procedures in place; that the situation justified the parents' concerns as to what really happened to their children; and that a concerted effort should be made on the part of all government bodies to provide parents with adequate redress. An Ombudsman report similarly found that there were no coherent procedures in place at the time; that the autopsy reports were usually incomplete, inconclusive and of highly dubious veracity; and that it could not rule out that the babies in question were indeed removed from their family unlawfully. In response, the Parliament adopted the findings of the Committee and new procedures were put in place in Serbia in 2003 regarding the burial of new-born babies who died in hospital, setting out a detailed procedure to prevent any unlawful removal of babies from hospital wards.

In its judgment, the Court noted that the applicant's son allegedly died or went missing on 31 October 1983, whilst the Convention came into force in Serbia in March 2004. Nevertheless, the Court emphasised that it was claimed that the respondent State continued to fail to provide the applicant with any definitive and/or credible information as to the fate of her son. In these circumstances, the Court determined that the applicant's complaint related to a continuing situation and the Court was competent to examine the complaint in so far as it related to the respondent State's alleged failure to fulfil its procedural obligations under the ECHR as of March 2004. It could, however, consider the facts prior to ratification in so far as they could be considered to have created a continuous situation extending beyond that date.

With regard to "family life" the Court stated that the mutual enjoyment by a parent and child of each other's company constitutes a fundamental element of "family life" within the meaning of Article 8. It noted that the essential object of Article 8 is to protect the individual against arbitrary interference by public authorities, but that there may also be positive

obligations inherent in this provision extending to the effectiveness of any investigating procedures relating to one's family life.

The Court determined that the failure of the hospital to provide information to the applicant regarding the death of her infant son and the subsequent disappearance of his body violated Article 8 and its respect for private and family life. Although the child had died in 1983, it found that there had been an ongoing failure of the State to provide the applicant with information surrounding what had occurred to her son. The Court noted that the amended legislation only improved the position for the future and effectively offered nothing to those parents who endured the ordeal in this case. It concluded that the applicant suffered a continuing violation of Article 8 of the Convention due to the respondent's continuing failure to provide her with credible information as to the fate of her son.

The two decisions (discussed above) of the ECtHR demonstrate that under the Convention, family members of a deceased person have a right to information regarding the fate of their loved ones – whether this means being informed of the burial time, autopsy results or the location of his or her last resting place. A State's failure to provide such information may violate Article 8 where it is in breach of the positive obligation upon it to have in place effective investigative procedures even where the death occurred prior to the coming into force of the ECHR in the State in question, as long as there was a continued failure post the coming into force of the ECHR to provide the relevant information. While there are differences between the situation in *Zorica Jovanović* and Tuam, the decision in *Zorica Jovanović* may be of potential relevance given that it is likely that the deaths of many of the juveniles interred in the Tuam site occurred prior to the coming into force of the ECHR in Ireland, but the discovery of unrecorded burials only took place in recent years.

It is clear from the foregoing that the Article 8 rights of immediate family members are engaged surrounding issues of their loved ones' burial. Whether these rights extend to other relatives, however, is questionable. In this regard, it should be noted that the English courts have held that questions concerning the burial or exhumation of deceased persons do not necessarily engage the Article 8 rights of all blood relatives. In *R (Rudewicz) v. Secretary of State for Justice*,[43] the Court of Appeal held that the claimant's Article 8 rights were not

[43] [2013] QB 410; [2012] 3 WLR 901.

affected by a decision to exhume a deceased relative. Although she was the deceased's closest living relative, she had never met him or had a close family connection to him. While the exhumation might offend her religious feelings or beliefs, Lord Neuberger MR (as he then was) held that this was different from impacting on her family or private life.

At a further historical remove, the Article 8 rights of blood relatives were also briefly discussed in *R (Plantagent Alliance Ltd) v. Secretary of State for Justice*.[44] This was a challenge by a descendant of Richard III to decisions concerning his exhumation and proposed re-burial. Ultimately, the Article 8 arguments were not pursued at trial, an approach described by the Divisional Court as sensible given that they were "doomed to fail".

3.2.2.4 Lozovyye v Russia[45]

This case concerned a murder victim who had been buried before his parents had been informed of his death. The applicants' son had been killed in St. Petersburg on 1 December 2005. On 18 January 2006, the investigator of the district prosecutor's office in St. Petersburg asked the head of the district police to identify relatives of the deceased and summons them to the prosecutor's office for the purpose of granting them victim status in the criminal case against the suspect charged with murder. A week later, the applicants' son was buried under his full name in St Petersburg. On 30 January 2006, the investigator concluded it was impossible to identify the relatives of the deceased and assigned the status of victim in the case to a representative of the municipal authorities. The following day, police officials informed the investigator that operative measures undertaken by them to identify the deceased's relatives had not produced any results. On 2 February 2006, the applicants contacted the investigator and informed her of their intention to come to St. Petersburg and take part in the criminal proceedings. Despite this notification, she sent the criminal case for trial and only some time later were the applicants invited to take part in the criminal proceedings in the capacity of victims. On 14 February 2006, the applicants were allowed to exhume their son's remains and two days later they buried him in Belomorsk.

In 2007, the applicants lodged an action against the Prosecutor General's Office seeking compensation. They argued that as a result of the investigator's failure to promptly notify

[44] [2014] EWHC 1662.
[45] Application no. 4587/09, [2018] ECHR 361.

them of their son's death, they had suffered pecuniary damage, having been forced to pay for exhumation and transport of their son's remains, but also non-pecuniary damage, having been unaware of their son's whereabouts for a long time, unable to say goodbye to him, unable to provide him with a decent burial and being forced to identify disfigured remains after exhumation. In 2008, the District Court in Moscow dismissed the claim, finding that the investigator had not committed any unlawful actions and this was upheld by the Moscow City Court. The applicants complained to the ECtHR.

In considering the application, the Court reiterated that everyone had a right to access to information relating to their private and/or family life under Article 8 ECHR, and that a person's right to attend the funeral of a member of his family fell under Article 8. It noted that the applicants in the present case argued that they had not been properly notified of their son's death and thus had been deprived of an opportunity to take part in his funeral. In the light of its case-law on an applicant's right to information concerning his or her private and family life, taken together with the case-law on the applicability of Article 8 to an individual's ability to attend the funeral of a deceased member of the family, the Court held that the applicants' right to respect for their private and family lives was affected by the failure of the State to inform them, or even to take steps to inform them, of the death before their son was buried.

The Court commented that the substance of the applicants' complaint was not that the State acted in a certain way but that it failed to act, and it therefore approached its consideration of the case from the perspective of a positive obligation on the respondent State under Article 8. It held that where the authorities, but not other family members, are aware of a death, there is an obligation on the relevant authorities to at least undertake reasonable steps to ensure that surviving members of the family are informed. Having regard to the legal framework in place under Russian law, the Court considered that the relevant domestic law and practice lacked clarity, but that was not sufficient in itself to find a violation of Article 8. On the other hand, it concluded that the authorities had not acted with reasonable diligence to comply with the aforementioned positive obligation, given the information that was available to the domestic authorities in order to identify, locate and inform the deceased's parents. Accordingly, the Court held that there had been a violation of Article 8 in this case.

This decision is important as it indicates clearly the positive obligation upon State authorities to undertake reasonable steps to ensure surviving family members are informed of a death of their relative.

3.2.3 Treatment of body – samples, exhumation and consent

In certain ECtHR cases, the treatment of a deceased's body is at issue – particularly in relation to the removal of bodily materials and samples from same for certain purposes, but also in relation to exhumation. This raises the issue of consent and whether permission must be sought from the deceased's family. Across all cultures, it is a common belief that the dead should be treated with respect. This is demonstrated in the criminal legislation of many States, which provide that mutilation of a corpse is an offence. In relation to the use of tissue or organs from a deceased person for donation or other purposes, the domestic law of most countries will specifically set out the circumstances in which this may take place. In Ireland, for example, at present there is an opt-in/explicit consent position with regard to organ donation. If a person wishes to become an organ donor after his/her death, potential donors are advised to inform his/her next of kin of his/her intentions and to carry an organ donor card. Next of kin are always asked for consent in order for a donation to proceed and consent is never presumed, even if a donor card has been signed.[46]

3.2.3.1 Petrova v. Latvia[47]

In this case, the applicant's son sustained serious injuries in a car accident in May 2002. He died in hospital a few days later. Immediately following his death, a laparotomy was performed on the body, in the course of which the kidneys and the spleen were removed for organ transplantation purposes. The applicant had not visited the hospital, but claimed that she was in permanent contact with the doctors there during her son's stay. She said that she had not been informed that his condition was deteriorating, had not been asked whether her son had consented to being an organ donor and had not been asked whether she would consent to organ transplantation in the absence of any wishes expressed by her son. She

[46] In July 2017, the Government approved the preparation of the General Scheme and Heads of a Human Tissue Bill, providing for an opt-out system of consent for organ donation in Ireland. Publication is still awaited, although it was expected early this year.
[47] Application no. 4605/05, 24 June 2014, [2014] ECHR 805.

claimed that the removal of her son's organs without her consent constituted an interference with her private and family life. The State claimed that the hospital did not have any information on record providing the contact details of any relative – thus there was no contact with the applicant whatsoever when her son was in hospital. It argued that the "presumed consent system" in place in Latvia permitted interference with an individual's right to private life under Article 8 ECHR and that in this case, the organ removal had been carried out in accordance with the domestic law.

At that time in Latvia, the relevant law provided that every person with legal capacity was entitled to consent or object in writing to the use of his or her body after death. A person was required to apply to the Office of Citizenship and Migration Affairs to exercise the right to consent or object. Only such refusal or consent as was recorded in the Population Register had legal effect. The procedure which the State institutions had to follow to request and receive the relevant information from the Population Register, however, had not been adopted at the time of the applicant's son's death. The law also provided that the organs and tissues of a deceased person could not be used against his or her wishes as expressed during his or her lifetime. In the absence of express wishes, the organs could be used if none of the closest relatives objected. It went on to state that the organs could be removed if he or she had not objected to such removal during his or her lifetime and if the closest relatives had not prohibited it. A stamp on a person's passport added before 31 December 2001 denoting objection or consent to the use of his or her body after death had legal effect until a new passport was issued or an application to the Office of Citizenship was submitted. The domestic law was later amended in 2004.

At a domestic level, the applicant made numerous complaints and in response, the Inspectorate of Quality Control for Medical Care and Working Capability (the MADEKKI), carried out an investigation. It concluded that the hospital complied with the relevant domestic law in taking the decision to remove organs and carrying out the surgery. The MADEKKI noted that there was no information at its disposal as to whether or not there had been a stamp on the deceased's passport signifying an objection to the use of his body tissues and organs. As the applicant had not been informed about the imminent removal of her son's organs, it determined that she neither consented nor refused. It was further concluded by a prosecutor considering the criminal complaint that the domestic law required consent from

parents or guardians only in cases where organs were removed from a deceased child's body for transplantation purposes.

The ECtHR, in considering the case, determined that the removal by the hospital of the deceased's organs without informing his mother and without seeking her consent was not carried out in accordance with law and violated her rights to private life under Article 8 ECHR. It noted that Article 8's purpose is to protect the individual against arbitrary interference by public authorities. Interferences may be justified as necessary in a democratic society if proportionate and they pursue a legitimate aim. This requires the domestic law to be formulated with sufficient precision to afford adequate legal protection against arbitrariness and it must indicate with sufficient clarity the scope of discretion conferred on the appropriate authorities. In this case, the dispute between the parties was not with regard to the content of the Latvian law – which expressly provided the deceased's closest relatives with a right to express their wishes on organ removal following the death - but how this right was to be exercised. The applicant contended that the domestic authorities had not fulfilled their duty to provide conditions whereby her wishes could be expressed. The State, on the other hand, claimed the relatives involved were expected to take positive steps if they wished to veto any organ removal. It was concluded by the Court that the law was not sufficiently clear as regards the implementation of this right. At no time when the applicant's son was still alive, was a procedure in place for the State institution to follow in order to establish that person's own views on organ transplantation, nor was there a legal duty on State institutions to inform the closest relatives about imminent organ removal. It stated that it was unclear how the claimed "presumed consent system" operated in practice in the circumstances in which the applicant found herself whereby she had certain rights, but was not informed as to how and when these rights might have to be exercised. The Court thus found that the applicable Latvian law was not formulated with sufficient precision or afforded adequate legal protection against arbitrariness. The interference with the applicant's Article 8 rights was not in accordance with law and a violation of Article 8 was held to have had occurred.

On the same reasoning, the Court also upheld the applicant's complaint that she had been subjected to inhuman and degrading treatment contrary to Article 3 ECHR on account of the fact that the removal of her son's organs had been carried out without his prior consent or the consent of the applicant.

3.2.3.2 Elberte v. Latvia[48]

In 2001, the applicant's husband had died in hospital following a car accident. His body was transported from the hospital to the State Centre for Forensic Medical Examination in Riga. To establish the cause of death, an autopsy was carried out. Following the autopsy, tissue was removed from his body – the outer layer of the meninges - by a forensic expert who stated that he had verified that there was no stamp on the deceased's passport denoting his objection to the use of his body tissue. The applicant argued that the expert could not have verified that there was no stamp on her husband's passport as that passport had been in their home at the time.

The applicant only became aware that tissue had been removed from her husband's body two years later, when police informed her that a criminal inquiry had been opened into the illegal removal of organs and tissue for supply to a pharmaceutical company in Germany. There was in existence an agreement between the Forensic Centre and the German company to provide organs and tissue for scientific research. Under the agreement, experts carrying out tissue removal were to comply with domestic law and were to verify whether the potential donor had objected to the removal of organs or tissues by checking his/her passport for the presence of the stamp. If relatives objected to the removal, their wishes were to be respected. Experts, however, did not attempt to contact relatives to establish their wishes. Ultimately, the criminal inquiry was discontinued. In this decision, it was held that the experts did not have any legal obligation to inform anyone about his/her right to consent to or refuse organ or tissue removal. While the domestic law provided for the right of the closest relatives to object to the removal of material from deceased persons, it did not place an obligation on experts to explain these rights to the relatives.

Reiterating the principle of clarity as set out in *Petrova,* the ECtHR held that Article 8 ECHR had been violated in this case. The domestic law was not formulated with sufficient precision to enable relatives to exercise their rights to object to the removal of bodily material from their family member. In this case, tissue was removed from the deceased without the knowledge and consent of his spouse. This occurred due to the lack of clarity in the domestic

[48] Application no. 61243/08, ECHR 2015.

law and the absence of legal safeguards against arbitrariness. The ECtHR therefore held that Article 8 had been violated.

3.2.3.4 Estate of Kresten Filtenborg Mortensen v. Denmark[49]

The case concerned the removal of DNA from the body of a deceased for the purposes of a paternity suit. It was claimed by two brothers that the deceased was their biological father. Following other testing, the City Court decided that his body was to be exhumed for the purpose of taking DNA samples – this being the only remaining option to establish paternity. The estate of the deceased, represented by his legitimate son, appealed against the decision and the case ultimately was considered by the Supreme Court of Denmark. The Supreme Court permitted the taking of biological material from the corpse despite the fact that the relevant domestic legislation did not contain any specific rules on forensic genetic testing of deceased persons.

In the challenge to the ECtHR, the deceased's estate complained that the exhumation of the corpse for the purposes of taking DNA samples constituted a breach of Article 8 ECHR as same was not "in accordance with law".

In considering this case, the Court emphasised that the applicant for the purposes of these proceedings was "the estate of KFM". It was complained that the Supreme Court's decision violated "the rights of the estate of KFM". While the concept of "private life" is a broad term, the Court stated that it would stretch the reasoning developed in case-law too far to hold that the proposed testing on the deceased in this case constituted an interference with the Article 8 rights of the deceased's estate. In cases such as *Pannullo and Forte* (discussed earlier), the Convention was relied upon by individuals who were alive when they lodged their complaint with the Court who maintained that their right to respect for private or family life had been breached, as opposed to the deceased person's right to respect for private or family life. The ECtHR stated:

> In the present case the individual in question, namely KFM, was deceased when the alleged violation took place and hence when his estate, on his behalf, lodged the complaint with the Court alleging an interference with his right, or rather his corpse's right, to respect for private life. In such circumstances, the Court is not prepared to

[49] Application no. 1338/03, ECHR 2006-V.

> conclude that there was an interference with KFM's right to respect for private life within the meaning of Article 8.1 of the Convention.

While the representative for the estate, the legitimate son, did not make a claim in his own right as a family member of the deceased, submissions were made to the Court that the exhumation of the corpse also constituted an intrusion of that son's privacy rights. On the facts of this case, however, the Court rejected this assertion on the grounds that there was no evidence that the son complained at any point during the domestic proceedings that his rights had been violated. This submission was therefore inadmissible due to the non-exhaustion of domestic remedies.

These cases demonstrate that in terms of pursuing any claim for violation of Convention rights, it is the family members alone who are capable of asserting these rights. The deceased no longer possess human rights and they are not capable of asserting same. This approach is similarly demonstrated in the Council of Europe's Additional Protocol on Transplantation of Organs and Tissues of Human Origin.[50] Pursuant to Article 18, "Respect for the human body", it is provided that during removal of organs and/or tissues, the human body must be treated with respect and all reasonable measures must be taken to restore the appearance of the corpse. The Explanatory Comment to Article 18 states; "A dead body is not legally regarded as a person, but nonetheless should be treated with respect."

3.2.3.5 Solska and Rybicka v. Poland[51]

This recent decision concerned the exhumation of remains of deceased persons, in the context of criminal proceedings, against the wishes of their families. The case arose out of a plane crash which occurred in April 2010. The aircraft in question carried a Polish State delegation including the President of Poland. It crashed killing all ninety-six people on board. In 2016, a prosecutor of the State Prosecutor's Office decided to appoint a team of international and forensic experts with a view to carrying out autopsies on the bodies of eighty-three victims of the crash (the bodies of nine victims had already been exhumed and four victims had been cremated). For this purpose, the prosecutor ordered that the bodies be exhumed.

[50] Adopted 24 January 2002, entered into force 1 May 2006; See Comment to Article 18, Additional Protocol on Transplantation of Organs and Tissues of Human Origin.
[51] Application no. 30491/17 and 31083/17, judgment of 20 September 2018.

The applicants in the case were the widows of two of the victims of the crash. They objected to the exhumation of their husbands' bodies and lodged interlocutory appeals against the prosecutor's decision. The Warsaw Regional Court held that as Article 210 of the Code of Criminal Procedure ("the CCP") did not provide for judicial review of a prosecutor's decision to exhume a body under that Article, it was constitutionally and conventionally deficient and referred a legal question to the Constitutional Court. The proceedings before it were suspended until the Constitutional Court had issued a decision on the matter. The applicants' attempt to obtain an injunction from the civil courts was unsuccessful and the exhumations took place in 2018. In their case to the ECtHR, the applicants claimed that their Article 8 rights had been violated.

Until this case, the Court had not specifically addressed the issue of the applicability of Article 8 to the exhumation of a deceased person against the will of his or her family members in the context of criminal proceedings. The Court considered whether the right to respect for the memory of a late relative, which was recognised under Polish law, should be considered part of family life. The ECtHR noted that Article 8 rights predominately relate to relationships between living human beings, however it had regard to its previous decisions surrounding issues relating to the way in which the body of a deceased relative was treated and the ability to attend the burial and pay respects at the grave of a relative, which all came within the scope of the right to respect for family life. The Court thus held that the facts of this case fell within the parameters of Article 8.

It then considered whether the exhumation of the applicants' husbands constituted an interference with their right to respect for private and family life. The Court noted that this involved balancing the requirements of an effective investigation against protection for the right to family life of the parties concerned and that there may be circumstances in which an exhumation would be justified, despite opposition by the family. The relevant Polish law allowed the prosecutor to issue an order for exhumation without requiring him to assess whether the aims of the investigation could be attained through less intrusive means or to evaluate the possible implications of the impugned measures on the family life of the applicants. The prosecutor's decision was not amenable to appeal before a criminal court or any other form of adequate scrutiny before an independent authority. The Court thus concluded that Polish law did not provide sufficient safeguards against arbitrariness with regard to a prosecutorial decision ordering exhumation and it did not provide for a

mechanism to review the proportionality of the restrictions on the relevant Article 8 rights of the persons concerned. It held that the applicants had therefore been deprived of the minimum degree of protection to which they were entitled and a violation of their Article 8 rights had occurred.

This case is important as it makes clear that Article 8 is engaged in circumstances where State authorities seek to exhume the body of a deceased, without the consent of the deceased's family members where the relevant domestic law fails to provide sufficient safeguards against arbitrariness with regard to the authority's decision to exhume. It is a recent decision which again is illustrative of the rights vested in family members of a deceased person concerning the treatment of his or her body.

3.2.4 Specific requests regarding burial

3.2.4.1 Elli Poluhas Dödsbo v. Sweden[52]

In this case, the ashes of the applicant's husband were buried in a family grave in Fagersta, Sweden, where the family had been living for some time. Years later, the applicant moved to be closer to her children. She thus requested that the cemetery authorities allow the transfer of her husband's urn to her family plot in Stockholm. She submitted that her children agreed to the removal, that she had no connection to Fagersta any longer and that she was sure her husband would not have objected to the transfer. Her request was refused by authorities in deference to the notion of a "peaceful rest" under the Funeral Act 1990 and her appeals were also refused. The relevant domestic law provided that when a person dies, his or her wishes concerning cremation and burial should, as far as possible, be followed. Where a dispute arises between survivors, it is for the county administrative board to decide. Once remains or ashes have been buried, moving them from one place to another is in principle not allowed unless permission is granted if special reasons exist. These provisions were based on respect for the sanctity of the grave. This requires that the provisions regarding the removal of remains and ashes be restrictive. A deceased's grave should be left in peace and may only be disturbed in special circumstances.

[52] Application no. 61564/00, ECHR 2006-I.

The applicant therefore complained that the refusal to allow her to transfer the urn containing her husband's ashes to her family burial plot in Stockholm was in breach of Article 8 ECHR. It was not disputed by the State that the refusal to grant permission to remove the urn from one burial place to another involved an interference with the applicant's private life, but it was argued that the interference was in accordance with law, that it served legitimate aims and was justified under Article 8.2.

As to the legitimate aims, the Government emphasised that the principle of the sanctity of graves had a long-standing tradition and was founded on respect of the deceased. Thus, the strict approach taken by its law, and by the public authorities in applying the law, served to prevent disorder and to protect morals in society at large. It also submitted that the restrictive approach was necessary to prevent conflicts arising amongst relatives and that the living were entitled to be assured that, after death, their remains would be treated with respect. Regarding the issue of necessity, Sweden submitted that States should be afforded a wide margin of appreciation in cases of this kind, where the authorities had to balance the interests of the person requesting the removal with society's role in ensuring graves are not disturbed. In this case, there were no indications that the husband had not been buried in accordance with his wishes; he was buried in the region where he had lived and worked for twenty-five years; the burial site was a family grave, large enough for his entire family; and there was no obstacle to the applicant having her final resting place in the same cemetery as that of her husband.

The ECtHR acknowledged that the applicant's Article 8 right to private life was engaged. It stated that the concepts of "private and family life" are broad terms not susceptible to exhaustive definition and it noted the findings of the Commission that an applicant's wish to have his ashes spread over his own land fell within the sphere of private life in *X v. Germany.*[53] It found, however, that the State's refusal to transfer an urn from one burial plot to another did not violate Article 8. The Court held that the decision to refuse to transfer the remains was made with due consideration to the interests of the deceased's wife and fell within the margin of appreciation available in such cases, finding that, in such an important and sensitive issue, States should be afforded a wide margin of appreciation.

[53] Commission decision of 10 March 1981, Application no. 8741/79.

3.2.5 Application of Article 8 principles

It is clear from the foregoing body of case law that Article 8 ECHR is of particular relevance when considering the rights of family members and survivors of the Tuam Mother and Baby Home. The existence and protection of these rights should inform the Government's response to the request to immediately commence the collection of DNA samples. Article 8 has been broadly interpreted by the ECtHR, providing family members of deceased persons with a substantial number of rights capable of assertion. While these rights are not absolute, and may be proportionately interfered with, their existence is of considerable importance and the State should be careful to ensure no illegitimate infringement of such rights. Family members possess the right to have their loved one's body returned to them. Moreover, relatives have a right to know the fate of their family members, including information surrounding the death and/or burial of their loved ones. A failure to provide relatives with definite and/or credible information may fall foul of the positive obligation under Article 8, even where the death occurred before the Convention came into force in the relevant country, where the failure to provide information continues following the coming into force of the ECHR. It is also of note, that where samples are sought to be taken from a corpse or a body exhumed, the consent of the family member is a relevant concern and should be borne in mind in any approach taken.

Irish authorities are required to carry out their functions in a manner compatible with the ECHR and Article 8 rights in particular must be positively vindicated. Regard should be given to the distress and anguish of family members seeking information surrounding the death and/or burial of their loved ones. Nonetheless, it should also be borne in mind that there may be limits to the information which can or must be provided for the purposes of complying with Article 8. Furthermore, any Article 8 ECHR right should be considered having regard to the extreme delicacy of any exhumation and further investigation at the Tuam site, as determined by the Expert Technical Group. The report of the ETG states that: "There are a number of factors that make this situation unique: The forensic requirement of the site; The 'significant' quantities of juvenile remains; The commingled or intermixed state of the remains; The position of the remains within subsurface chambers, with limited access." The report[54] concludes that the comingled state of the remains renders identification

[54] Report of the Expert Technical Group, December 2017, (i).

"particularly challenging". Moreover, the ETG states there is a "risk of destruction to human remains" that raises ethical issues.

3.2.5.1 Effective invocation of Article 8 rights

It is clear from the above examination of Article 8 that the relatives of those deceased juveniles interred at Tuam possess ECHR rights that they may assert and that require protection. Whether family members are able to effectively invoke those rights will ultimately depend on the collection of DNA profiles from the juvenile human remains interred at the site and matching these profiles with those of relatives and survivors of the Mother and Baby Home to make positive identifications. As indicated by the ETG, it is not clear yet whether it will be possible to generate good quality DNA profiles from the juvenile human remains capable of yielding conclusive matches. This will only be ascertained in time following forensic excavation of the site and bespoke legislation is awaited in this regard. It would, however, appear to be possible to obtain DNA samples from prospective relatives of the deceased at this juncture - at least physically - prior to the establishment of any comprehensive statutory scheme introduced for this purpose. It must be borne in mind that if the DNA samples of survivors and relatives are not collected forthwith, given their age profile and health status, the concern arises that future matches will not be possible at all in certain cases. From a European Convention on Human Rights perspective therefore, it is desirable that the State take action to prevent such a situation from arising and to ensure that relatives of those interred in Tuam are capable of effectively asserting their Article 8 rights into the future.

The ability of family members to effectively invoke their Article 8 rights is contingent on positive family identifications being made. An appropriate administrative scheme, if established to allow family members to voluntarily submit their biological samples for later testing, would assist in vindicating these rights of family members under Article 8 ECHR. The establishment of such a scheme, once donors give full, free and informed consent on an entirely voluntarily basis for the specific purpose of comparing samples with any future samples extracted from the site at Tuam, may be a possible solution to ensure that family members of those interred at Tuam are capable of exercising their Article 8 rights in these particularly complex circumstances.

It is interesting to note the existence of online and Irish providers which allow for such voluntary DNA testing and which are in operation within the State at present. There are a number of such providers which advertise and promote the ability to "uncover ethnic origins" and "find new relatives". This includes myheritage.com, findmypast.ie, ancestry.com and easydna.ie. These companies operate by providing home DNA test kits, which are sent to customers, who then provide a sample of their DNA (saliva). Samples are returned to the company who carry out tests thereon to uncover family origins – not only geographically – but also by linking with relatives online, often distant cousins.

There appears to be a compelling justification to establish an appropriate administrative scheme rendering it permissible to collect Tuam survivors DNA samples on a voluntary basis once privacy and GDPR concerns are addressed. This would assist in ensuring they are capable of asserting their family rights at a later date, if a family connection is made.

3.2.5.2 How far do the relevant family rights extend pursuant to Article 8?

It is clear from the above examination of ECtHR jurisprudence that it is the family members who assert their rights under the Convention. They are not asserting the rights of the deceased, but their own as relatives. It is even questionable whether the deceased possess any human rights as, realistically due to their death, they are not capable of asserting same. This issue was considered by Rosenblatt in relation to the investigation of mass graves in *International Forensic Investigations and the Human Rights of the Dead.*[55] He states:

> … [H]uman rights for the dead are philosophically unworkable and irreconcilable with the practical limitations of forensic work; therefore, we should not think of the dead as having human rights. However, this conclusion does not end discussion about what forensic investigators do for dead bodies. Rather, it makes room for a modest but rich sense of how exhumation can restore the identity, physical location, and care that have been denied to victims of atrocity.

In this regard, therefore, the rights of relatives are of paramount importance. The next question that necessarily arises is how far these Article 8 rights of family members can extend. Are only immediate family members eligible to assert their rights under Article 8

[55] *Human Rights Quarterly*, Volume 32, Number 4, November 2010, pp. 921-950 (Article) published by The Johns Hopkins University Press.

concerning the remains of their loved ones, or is the net cast more widely to include extended family members?

It is clear that the case law considered in the above discussion concerns immediate family relationships only. In particular, the relationship between parents and children is at issue therein. This is clearly the familial relationship with the closest connection that is protected by Article 8. It can be said, therefore, without doubt that the rights of parents of any children who were buried at the site in Tuam will be engaged by the ECHR.

The rights of other close family members, for instance as between siblings and between aunts/uncles and nieces/nephews, are less clear. While these important familial relationships were not raised or at issue in the context of the abovementioned ECtHR case law concerning burial rights or the right to know the fate of a loved one, they have been protected in decisions on other subjects in which Article 8 has been engaged. Family life has been held to exist between siblings[56], aunts/uncles and nieces/nephews[57], and between near relatives, for instance those between grandparents and grandchildren, since such relatives may play a considerable part in family life.[58] Furthermore, the traditional approach of the ECtHR is that close relationships short of family life generally fall within the scope of private life. This was illustrated in the case of *Znamenskaya v. Russia.*[59] In this case, the applicant complained under Article 8 that the domestic courts had not considered her claim to establish her stillborn child's descent from her late partner. The primary issue was the applicant's ability to obtain recognition of Mr G. as the biological father of the stillborn child, notwithstanding the legal presumption that her husband was the father of the child born within three hundred days of the dissolution of the marriage. In considering the applicability of Article 8 to this case, the Court stated;

> The existence or non-existence of "family life" for the purposes of Article 8 is essentially a question of fact depending upon the real existence in practice of close personal ties (see *K. and T. v. Finland* [GC], no. 25702/94, § 150, ECHR 2001-VII). It is obvious that in the instant case no such personal ties could have developed because the child was stillborn and because its biological father had been separated

[56] *Moustaquim v. Belgium*, 18 February 1991, Series A no.193; *Mustafa and Armağan Akın v. Turkey*, Application no. 4696/03, 6 April 2010.
[57] *Boyle v. the United Kingdom*, 28 February 1994, Series A no. 282-B.
[58] *Marckx v. Belgium*, 13 June 1979, Series A no. 31; *Price v. the United Kingdom*, Application no. 12402/86, Commission decision of 9 March 1988, DR 55.
[59] *Znamenskaya v. Russia*, Application no. 77785/01, 2 June 2005.

> from the applicant before its birth and died shortly thereafter. However, it has also been the Convention organs' traditional approach to accept that close relationships short of "family life" would generally fall within the scope of "private life" (see, for example, *Wakefield v. the United Kingdom*, no. 15817/89, Commission decision of 1 October 1990 [relationship between a prisoner and his fiancée]; *X. and Y. v. the United Kingdom*, no. 9369/81, Commission decision of 3 May 1983 [same-sex relationship]; and *X. v. Switzerland*, no. 8257/78, Commission decision of 10 July 1978 [relationship between a foster mother and the child she had looked after]). Bearing in mind that the applicant must have developed a strong bond with the embryo whom she had almost brought to full term and that she expressed the desire to give him a name and bury him, the establishment of his descent undoubtedly affected her "private life", the respect for which is also guaranteed by Article 8. That provision is therefore applicable in the present case.

Having regard to the general findings of the ECtHR concerning family rights applicable to other close family relationships aside from that between parent and child, it is likely that the types of relationships envisaged above are capable of protection arising out of the circumstances at Tuam. It is unlikely, however, that the abovementioned rights are applicable to more extended relatives of deceased persons. In this regard, as stated at section 3.2.2.3 of this report, the English courts have held that questions concerning the burial or exhumation of deceased persons do not necessarily engage the Article 8 rights of blood relatives. In *R (Rudewicz) v. Secretary of State for Justice*,[60] the Court of Appeal held that the claimant's Article 8 rights were not affected by a decision to exhume a deceased relative. As stated earlier, the claimant in this case was the deceased's first cousin once removed. Although she was his closest living relative, she had never met him or had a close family connection to him. The Court of Appeal held that her family or private life was not impacted in this case. It stated that while the situation may have been different if there had been a close personal relationship, or even a close familial relationship between the deceased and the claimant, it was difficult to see how her family life or private life was engaged on the facts of the case where she was a distant relative of the deceased and they had never met.

3.2.6 Right to identity

Another body of ECtHR case law arising out of Article 8 also warrants consideration in light of the issues raised in the Terms of Reference. This concerns an individual's right to identity. The right of access to personal information and to discover one's origins are rights that have previously been held by the ECtHR to be protected pursuant to Article 8, often balanced against the duty of confidentiality to other persons. These rights have primarily arisen in

[60] [2012] 3 WLR 901.

circumstances where an individual is seeking information concerning his or her biological parents. Birth, and in particular the circumstances in which a child is born, forms part of a child's, and subsequently the adult's, private life guaranteed by Article 8 of the ECHR. Similarly, details of vital relevance to an individual's personal development are protected by Article 8 ECHR, including the identity of one's parents, one's origins and aspects of one's childhood and early development.

With regard to the situation at Tuam, it is likely that different familial relationships may be established between survivors/relatives and the juvenile remains discovered therein. A question arises, therefore, as to whether the Article 8 right to identity extends to encompass a right to identify one's relatives, the identity of relatives being part of a person's own identity and therefore deserving of protection for similar reasons. Certain ECtHR decisions on this issue warrant consideration.

3.2.6.1 Gaskin v. the United Kingdom[61]

This decision concerned an individual's application for access to case records made by the local authority during the applicant's period in care. The applicant had spent the majority of his childhood in the care of Liverpool City Council.

In considering whether Article 8 ECHR applied in the circumstances of this case, the Court held that the records related to the applicant's "private and family life" in such a way that the question of his access thereto fell within the ambit of Article 8. The Court then considered whether Article 8 had been violated. It held that persons in the situation of the applicant have a vital interest in receiving the information necessary to know and to understand their childhood and early development. On the other hand, it noted that confidentiality of public records is of importance for receiving objective and reliable information and such confidentiality can be necessary for the protection of third parties. While the British system, which then made access to records dependent on the consent of the contributor, could in principle be compatible with the obligations under Article 8, the Court considered that under such a system the interests of the individual seeking access to records relating to his private and family life must be secured when a contributor to the records either is not available or improperly refuses consent. Such a system is only in conformity with the principle of

[61] Application no. 10454/83, judgment of 7 July 1989, (1989) 12 EHRR 36.

proportionality if it provides that an independent authority finally decides whether access has to be granted in cases where a contributor fails to answer or withholds consent. In this case therefore, the ECtHR held that denying the applicant access to his file was a breach of Article 8 in the absence of an independent and impartial authority to determine the merits of the applicant's claims. The ECtHR stated as follows:

> In the opinion of the Commission, the file provided a substitute record for the memories and experience of the parents of the child who is not in care. It no doubt contained information concerning highly personal aspects of the applicant's childhood, development and history and thus could constitute his principal source of information about his past and formative years. Consequently, lack of access hereto did raise issues under Article 8.[62]

3.2.6.2 Mikulic v Croatia[63]

In this case, the ECtHR recognised the importance to a child of information about his or her identity. It held that matters of relevance to personal development include details of a person's identity as a human being and the vital interest protected by the Convention in obtaining information necessary to discover the truth concerning important aspects of one's personal identity, such as the identity of one's parents. The ECtHR held that a child had a right to identify her father through DNA testing.

The applicant complained that the procedure in place in Croatia to establish her paternity was of such lengthy duration that her rights to private and family life were violated. Relying on Article 8, she claimed that the domestic courts had been inefficient in deciding her paternity claim and had therefore left her uncertain as to her personal identity. In determining whether Article 8 was applicable to this case, the Court noted its previous decisions which held that the notion of "family life" in Article 8 is not confined solely to marriage-based relationships but may also encompass other *de facto* "family ties" where sufficient constancy is present. In this case, however, the Court noted that no family tie had been established between the applicant and her alleged father. It reiterated, however, that Article 8 protects not only "family" but also "private" life. The ECtHR held as follows:

> Private life, in the Court's view, includes a person's physical and psychological

[62] Para. 36. See also *Segerstedt-Wiberg v. Sweden* (2007) 44 EHRR 2, which deals with access to a police register.
[63] Application no. 53176/99, judgment of 7 February 2002.

integrity and can sometimes embrace aspects of an individual's physical and social identity.

Referencing *Gaskin v. the United Kingdom,* the ECtHR noted that it had previously held that **"**respect for private life requires that everyone should be able to establish details of their identity as individual human beings and that an individual's entitlement to such information is of importance because of its formative implications for his or her personality."[64] In this case, as the applicant was a child born out of wedlock who was seeking, by means of judicial proceedings, to establish who her natural father was, the Court held that there was a direct link between the establishment of paternity and the applicant's private life. It thus held that the facts of this case fell within the ambit of Article 8.

Considering the Croatian system, the Court held that there had been a violation of Article 8 in this case. It noted that in the Croatian system, there was no means of compelling the alleged father to comply with a court order for DNA tests to be carried out. While in principle, this may be considered to be compatible with the obligations deriving from Article 8, taking into account the State's margin of appreciation, however under such a system, the interests of the individual seeking the establishment of paternity must be secured when paternity cannot be established by means of DNA testing. The lack of any procedural measure to compel the alleged father to comply with the court order would only be in conformity with the principle of proportionality if it provided alternative means enabling an independent authority to determine the paternity claim speedily. No such procedure was available to the applicant in the present case.

Furthermore, the Court found that the procedure available did not strike a fair balance between the right of the applicant to have her uncertainty as to her personal identity eliminated without unnecessary delay and that of her supposed father not to undergo DNA tests. It considered that the protection of the interests involved were not proportionate. Accordingly, it found that the inefficiency of the domestic courts had left the applicant in a state of prolonged uncertainty as to her personal identity. It therefore held that the Croatian authorities failed to secure to the applicant the "respect" for her private life to which she is entitled under the ECHR.

[64] Ibid at para. 54

3.2.6.3 Odièvre v France[65]

In *Odièvre v France*, the Court declined to find that the provision under French law of a system of anonymous births which did not permit an applicant to obtain information about her mother was contrary to Article 8. The applicant in this case was an adopted person seeking the release of information identifying her natural mother. She was blocked in her application by the French authorities and laws and she claimed that her right to information concerning her personal history pursuant to Article 8 ECHR was breached in this case.

The Court noted that although the objective of Article 8 is to protect the individual against arbitrary interference by public authorities, it does not merely compel the State to abstain from such interference. As the natural mother had expressly reserved her right to confidentiality, the ECtHR held, by a majority of ten votes to seven, that the Parisian Child Welfare Authority's refusal to release this information to the applicant was not contrary to the ECHR, on the grounds that France had a pressing reason to respect the privacy of the natural mother. The Court found that the circumstances of the parties in *Mikulic* and *Gaskin* were different to that of the applicant in this case, distinguishing between the issue of access about one's origins and identity of one's natural parents and that of access to a case record concerning a child in care or to evidence of alleged paternity.

There are a number of specific aspects of the proceedings in this case that call into question the extent to which it can be directly applied elsewhere. First of all, this was a case, for example, where the mother made a positive request – as she was entitled to under law to have her identity kept secret. As the Court noted, the relevant legal regime here was one – which the Court made clear had a long history in France – of anonymous births. The submissions of the French government placed particular emphasis on the value of the anonymous birth system in encouraging women in distress not to have abortions and/or to give birth in favourable conditions, rather than alone with the attendant risk that they may not tend to the child's needs. Indeed, the Court specifically drew attention to this in its reasoning.

There was also a general interest at stake, as the French legislature had consistently sought to protect the mother's and child's health during pregnancy and birth and to avoid abortions, in particular illegal abortions, and children being abandoned other than under the proper

[65] Application no. 42326/98, [2004] 38 EHRR 43.

procedure. The right to respect for life, a higher-ranking value guaranteed by the ECHR, was thus one of the aims pursued by the French system.

Thirdly, the Court was also influenced in that case by the impending enactment of reforms to the French system which proposed, inter alia, the abolition of the parents' right to request confidentiality.

This interpretation of *Odièvre* as a decision at least in part based on its own particular facts is supported by the subsequent decision of the ECtHR in *Godelli v Italy*.[66] Here, the ECtHR was called on to consider the Italian regime in respect of the provision of adoption information. In that case, the applicant was abandoned at birth by her birth mother who did not consent to being named on the birth certificate. The Italian family courts denied the applicant access to information about her origins because her mother, at the time of the applicant's birth, had not agreed to have her identity disclosed. The applicant complained that Italy had failed to guarantee respect for her private life on account of its legal system, which imposed a blanket ban on revealing any information about the birth mother where the latter had requested the non-disclosure of her identity and which, above all, prohibited the communication of non-identifying information about the mother. The Court held this to be in violation of Article 8 of the ECHR. Unlike in *Odièvre*, the applicant's request for information about her origins was totally and definitively refused, without any balancing of the competing interests or prospect of a remedy. The Court identified and summarised the critical differences between the two systems as follows:

> [U]nlike the French system examined in Odièvre, Italian law does not attempt to strike any balance between the competing rights and interests at stake. In the absence of any machinery enabling the applicant's right to find out her origins to be balanced against the mother's interests in remaining anonymous, blind preference is inevitably given to the latter.

3.2.6.4 Jäggi v Switzerland[67]

Other judgments of the ECtHR demonstrate a departure from the restrictive approach in *Odièvre* and the Court has placed an increased emphasis on the right to identity. In *Jäggi v Switzerland*, the ECtHR stated that the right to identity was an integral part of the right to

[66] Application no. 33783/09; 25 September 2012.
[67] Application no. 58757/00, 13 July 2006.

private and family life, with the Court stating that "persons seeking to establish the identity of their ascendants have a vital interest" protected by the ECHR.[68] It held that there had been a violation of Article 8 of the ECHR on account of the fact that it had been impossible for the applicant to obtain a DNA analysis of the mortal remains of his putative biological father.

3.2.6.5 Mifsud v. Malta[69]

In this case, the applicant complained about an order made against him to provide a genetic sample in the context of paternity proceedings. The Maltese law in question made it mandatory to provide a genetic sample in paternity proceedings. The applicant complained that this order had been imposed on him contrary to his will.

In its judgment, delivered in January 2019, the Court noted that a DNA test is the scientific method available for accurately determining paternity and its probative value substantially outweighs any other evidence presented by parties to prove or disprove biological paternity. In assessing whether the Maltese law was in accordance with the relevant ECHR requirements, the Court noted that the legitimate aim was of particular importance. In this case, the impugned action had been aimed at fulfilling the State's positive obligations arising under Article 8 concerning the applicant's putative daughter. The ECtHR also noted that while the Maltese law appeared to be mandatory, in practice, it was not convinced that a court would order such a test without regard to any other consideration such as whether a prima facie case had been made out. Similarly, once an order had been made, the individual concerned should be able to appeal against such an order. In this case, it noted that it was only after fully fledged constitutional proceedings undertaken at the applicant's request that the DNA test was ordered. The order to undergo the test, therefore, had not been made on the basis of its mandatory nature.

The ECtHR therefore determined that the decision-making process within the Maltese courts had been fair overall and had provided the applicant with the requisite protection of his interests safeguarded by Article 8. It concluded that the domestic courts had struck a fair balance between the interest of the applicant's putative daughter to have paternity established and that of the applicant not to undergo the DNA test. No violation of Article 8 was found in this case. The Court stated:

[68] Ibid., at para. 38.
[69] Application no. 62257/15, 29 January 2019 [Section III].

> While the essential object of Article 8 is to protect the individual against arbitrary action by the public authorities, there may in addition be positive obligations inherent in effective "respect" for private or family life. These positive obligations may involve the adoption of measures designed to secure respect for private life even in the sphere of the relations of individuals between themselves (see *Mikulić*, cited above, § 57 and *S.H. and Others v. Austria* [GC], no. 57813/00, § 87, ECHR 2011). Further, respect for private life requires that everyone should be able to establish details of their identity as individual human beings and that an individual's entitlement to such information is of importance because of its formative implications for his or her personality. This includes obtaining the information needed to uncover the truth concerning important aspects of one's personal identity, such as the identity of one's parents (see, for example, *Călin and Others v. Romania*, nos. 25057/11 and 2 others, § 83, 19 July 2016, with further references).[70]

This case is helpful in that it restates that Article 8 protects the right of each person to establish details of their identity as individuals and that an individual is entitled to such information "because of its formative implications for his or her personality".

It is clear from the foregoing that the ECtHR has therefore recognised the right to obtain information in order to discover one's origins and the identity of one's parents as an integral part of identity protected under the right to private and family life. The jurisprudence of the Court makes it clear that cases concerning the parental status of individuals fall under the ambit of private and family life within Article 8. This may have a bearing concerning the situation at Tuam, in particular in circumstances where the parental status of individuals is at issue and information concerning a parent/child relationship is sought. Whether this extends to a general right to identify one's relatives is questionable however.

3.3 OTHER RELEVANT ECHR RIGHTS

While the Terms of Reference require specific consideration of the extent to which any relevant family rights under Article 8 ECHR may be engaged in light of the request by the Tuam Home Survivors' Network to begin collecting their DNA samples immediately, other ECHR rights may also be applicable in the circumstances under consideration. Article 2 ECHR (which protects the right to life) is particularly relevant and requires brief consideration in that it justifies the collection of DNA samples from the Tuam Home Survivors' Network and gives it a human rights promoting objective.

[70] Ibid., at para. 56.

In relation to Ireland, while the European Convention on Human Rights Act was only introduced in 2003, the Convention itself was signed and ratified in this jurisdiction in 1953, entering into force on 3 September 1953. The deaths which occurred at the Tuam Mother and Baby Home are estimated to have occurred in the period between 1925 – 1960. The majority of that period thus pre-dates the entry into force of the Convention in Ireland in 1953 and the adoption of the Convention itself in 1950, although the remainder of that period post-dates Ireland's ratification of the Convention. Nonetheless, the presence of the juvenile human remains interred at Tuam was confirmed in 2017. In light of the very recent evidence of juvenile human remains at the site of the former Mother and Baby Home at Tuam, therefore, arguably the duty placed upon the State is triggered in the present circumstances.[71] This has presumably informed in some respects the Government's decision to fully excavate the site at Tuam. Article 2 considerations may also now inform the specific query raised in the within Terms of Reference, particularly with regard to the position of relatives in respect of this duty to investigate as discussed below.

3.3.1 Edwards v. the United Kingdom[72]

It has been held that relatives of the deceased should be involved in any investigation to a sufficient degree to safeguard their legitimate interests. This was made clear in the decision of the ECtHR in *Edwards v. the United Kingdom*.

It is submitted that in light of the positive obligations under Article 2 ECHR and the requirement to ensure relatives of the deceased are involved in the investigation to a sufficient degree to safeguard their legitimate interests, there would appear to be an obligation on the State to take necessary action to protect the interests of relatives in such investigations. Having regard to the circumstances at issue in the Tuam Mother and Baby Home, this duty arguably could extend to safeguarding the interests of relatives by "banking" their DNA now to protect the possibility of making positive matches in the future between the remains found at Tuam and surviving relatives. Such action would thereby protect the legitimate interests of relatives in the investigation of the site at Tuam and enable their related

[71] Note, however, the unsettled position in the UK. In *Re McKerr* [2004] UKHL 12, the House of Lords held that an obligation to initiate an investigation under Article 2 only applied to deaths occurring after the Human Rights Act 1988 came into force in 2000. This, however, was called into question in subsequent decisions and the current position is unclear.
[72] Application no. 46477/99, [2002] ECHR 303.

ECHR rights to be later vindicated – that is, their right to bury their family member, know their fate and be provided with any additional information that emerges surrounding their death.

With regard to the Terms of Reference herein, it is possible to argue that to ensure an effective investigation of the site at Tuam, which will involve forensic-standard excavation and exhumation, identifications of those remains interred is necessitated, where scientifically possible. Identification may only be possible if familial matches are made. Yet, such conclusive familial matches may be entirely out of reach if the DNA of Tuam survivors is not gathered immediately, given their age profile and health status. Thus, it is possible to contend that to effectively investigate the site in Tuam and to safeguard the Article 2 rights of family members, advance collection of DNA samples by the State may be desirable by virtue of its ECHR obligations.

3.4 SUMMARY OF ECHR CONSIDERATIONS

The Terms of Reference have requested consideration of the extent to which the existing legislative framework permits the collection of DNA samples from survivors of the Tuam Mother and Baby Home and from their relatives, with particular reference to the extent to which any relevant family rights under Article 8 of the European Convention on Human Rights might apply in these circumstances.

As indicated in the above analysis, Article 8 is of paramount importance with regard to the query raised therein. It has been interpreted broadly and held to involve positive obligations placed upon the State in order to protect those rights. Furthermore, the European Convention of Human Rights Act 2003 requires Irish courts to interpret legislation in line with the Convention insofar as it is possible to do so and requires that certain public bodies perform their functions in a manner compatible with the Convention.

The foregoing body of case-law indicates that Article 8 ECHR is of particular relevance when considering the rights of family members and survivors of the Tuam Mother and Baby Home. It provides family members of deceased persons with a substantial number of rights capable of assertion – such as the right to have their loved one’s body returned to them and a right to know the fate of their family members, including information surrounding the death and/or

burial of their loved ones. A failure to provide relatives with definite and/or credible information may fall foul of the positive obligation under Article 8, even where the death occurred before the Convention came into force in the relevant country, where the failure to provide information continues following the coming into force of the ECHR.

It is clear from the above examination of ECtHR jurisprudence that it is the family members who assert their rights under the Convention, and not those of the deceased. The case-law considered concerns only the relationship between parents and children. This is clearly the familial relationship with the closest connection that is protected by Article 8. It can be said, therefore, that the rights of parents of any children who were buried at the site in Tuam may be engaged by the Convention. The rights of other close family members, for instance as between siblings and between aunts/uncles and nieces/nephews, are less clear. While these important familial relationships were not raised or at issue in the context of the abovementioned ECtHR case law concerning burial rights or the right to know the fate of a loved one, they have been protected in decisions on other subjects in which Article 8 has been engaged. Family life has been held to exist between siblings[73], aunts/uncles and nieces/nephews[74], as well as between near relatives, for instance those between grandparents and grandchildren, since such relatives may play a considerable part in family life.[75] It is unlikely, however, that the abovementioned rights are applicable to more extended relatives of deceased persons.

Under Article 8, the ECtHR has also recognised the right to obtain information in order to discover one's origins and the identity of one's parents as an integral part of identity protected under the right to private and family life. The jurisprudence of the Court makes it clear that cases concerning the parental status of individuals fall under the ambit of private and family life within Article 8. This may have a bearing concerning the situation at Tuam, in particular in circumstances where the parental status of individuals is at issue and information concerning a parent/child relationship is sought. Whether this extends to a general right to identify one's relatives is questionable however.

[73] *Moustaquim v. Belgium*, 18 February 1991, Series A no. 193; *Mustafa and Armağan Akın v. Turkey*, Application no. 4696/03, 6 April 2010.
[74] *Boyle v. the United Kingdom*, 28 February 1994, Series A no. 282-B.
[75] *Marckx v. Belgium*, 13 June 1979, Series A no. 31; *Price v. the United Kingdom*, Application no. 12402/86, Commission decision of 9 March 1988, DR 55.

In the present context, there is also the consideration that the possibility of obtaining a positive identification is more remote in relationships other than parents and sibling or half-sibling. Taken together with the emphasis in the Strasbourg and UK case-law on Article 8 on the presence of a close personal relationship, this suggests that a European Convention on Human Rights compliant scheme is therefore likely to involve such a scheme applying only to first degree or second degree family relationships.

In light of the aforementioned ECHR rights which arise in favour of family members of those interred at the Tuam site, the question arises as to whether the family members are able to effectively invoke those rights. This will ultimately depend on the collection of DNA profiles from the juvenile human remains interred at the site and matching these profiles with those of relatives and survivors of the Mother and Baby Home to make positive identifications. While it is not clear yet whether it will be possible to generate good quality DNA profiles from the juvenile human remains capable of yielding conclusive matches, it is possible to obtain DNA samples from prospective relatives of the deceased at this juncture. If the DNA samples of survivors and relatives are not collected forthwith, given their age profile and health status, the concern arises that future matches will not be possible at all in certain cases.

From a European Convention on Human Rights perspective therefore, I believe it desirable that the State take action to prevent such a situation from arising and to ensure that relatives of those interred in Tuam are capable of effectively asserting their ECHR rights into the future. This will protect the possibility of future positive familial identifications, and ultimately safeguard the rights of those family members, once identified. An appropriate administrative scheme, if established to allow family members to voluntarily submit biological samples for later testing, would assist in vindicating the rights of family members under Articles 8 ECHR and represent the type of positive action required of the State under its ECHR obligations.

3.5 CONCLUSIONS

- *The rights of family members of those interred at Tuam arise pursuant to Article 8 of the European Convention on Human Rights. These ECHR rights are interpreted broadly by the ECtHR and have been held to also involve positive obligations placed upon the State in order to protect those rights.*

- *Article 8 ECHR provides family members of deceased persons with a substantial number of rights capable of assertion – such as the right to have their loved one's body returned to them and a right to know the fate of their family members, including information surrounding the death and/or burial of their loved ones. A right to personal information is arguably also capable of assertion in certain more limited circumstances by particular family members where the parental status of individuals is at issue and information concerning a parent/child relationship is sought. Whether this extends to a general right to identify one's relatives is questionable however.*

- *In the present context, there is also the consideration that the possibility of obtaining a positive identification is more remote in relationships other than parents and sibling or half-sibling. Taken together with the emphasis in the Strasbourg and UK case-law on Article 8 on the presence of a close personal relationship, this suggests that a European Convention on Human Rights compliant scheme is therefore likely to involve such a scheme applying only to first degree or second degree family relationships.*

- *To enable family members to effectively invoke their rights and ensure such rights are vindicated by the State, positive familial identifications, where possible, must be made. If DNA samples of survivors and relatives are not collected, given their age profile and health status, the concern arises that future matches will not be possible at all in certain cases.*

- *From a European Convention on Human Rights perspective therefore, there may be an obligation on the State to ensure that relatives of those interred in Tuam are capable of effectively asserting their ECHR rights into the future.*

- *An appropriate administrative scheme, if established to allow family members to voluntarily submit biological samples for later testing, would assist in vindicating the rights of family members under Article 8 ECHR.*

4 DATA PRIVACY CONSIDERATIONS AND INFORMED CONSENT

If a voluntary administrative scheme is established to facilitate the lawful collection of DNA samples from survivors of the Tuam Mother and Baby Home, and their relatives, it will be necessary to ensure that consent is provided,[76] and that the task of data collection, storage, and processing is compliant with national, regional, and international legal instruments, principally the GDPR and the Data Protection Act 2018, and the obligations that flow from same. The obtaining of clear and informed consent will also be important to ensuring that the scheme is consistent with the Constitution's protection of the right to privacy.

This portion of the Report therefore identifies the various different ways that consent has been defined in this jurisdiction, as well as by regional judicial bodies. It recommends that the definition set down by Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (more commonly known as the 'General Data Protection Regulation' or 'GDPR'), be adopted for the purpose of any administrative scheme that might be established. It also sets out the stringent requirements that must be satisfied in order for data to be stored and collected on the basis of consent, and examines the way in which those requirements could be met in the context of the collection and storage of biological samples from survivors of the Tuam Mother and Baby Home and/or their relatives.

4.1 DEFINITION OF CONSENT

To be legally viable and indeed, practically legitimate, it will be vitally important that the task of ascertaining and obtaining an individual's consent to participate in an administrative scheme is underpinned by a clear legal definition of the term and concept of consent. It will be necessary to have regard to the approach taken in various different forums and judicial bodies, including the Superior Courts in this jurisdiction, the ECtHR, and the CJEU.

[76] Data Protection Act 2018, section 36(1)(a).

4.1.1 Constitutional Law

In this jurisdiction, it has been established by the Supreme Court that for an individual to lawfully consent to surrender constitutional rights, they must express their willingness to do so in a fully-informed, and free manner.[77] The necessity to ensure that consent to the abdication of rights is first, fully informed, and second, free, has been endorsed in several subsequent judgments of the Superior Courts. For example, the aforementioned definition has been adopted with regard to the consent that is necessary in order to lawfully put one's child up for adoption;[78] to marry;[79] and to convey one's interest in a family home to an individual other than his/her spouse.[80] The courts have emphasised that they will not lightly assume that a waiver of constitutional rights has taken place.[81]

MacGrath J. explored the concept of consent in the context of adoption in his recent judgment, *The Adoption Authority of Ireland v. The Child and Family Agency, FT, GT, and KR (A Minor).*[82] MacGrath J. acknowledged the well-established principles that, where consent is required, it must be real and not merely apparent. It is not sufficient for a person whose consent is required for adoption merely to state, in writing, that he or she has consented. It must be shown, as stipulated in *G v. An Bord Uchtála,*[83] that consent is full, free and informed – it must be given with as full as possible an understanding of the consequences.

While MacGrath J.'s exploration was in a different context, it is instructive in terms of the lengths that will need to be gone to in ensuring that any consent to collect a biological sample(s) and/or to disseminate information in relation to matching samples, is robust. Laffoy J.'s analysis of the concept, also in the context of adoption, provides further indication of how the process of seeking consent in cases involving constitutional rights is to be approached in this jurisdiction. The learned Judge has stated as follows:

[77] *G v. An Bord Uchtála* [1980] IR 32, 74.
[78] *The Adoption Authority of Ireland v. The Child and Family Agency, FT, GT, and KR (A Minor)* [2018] IEHC 632, 17.
[79] *N v. K* [1985] IR 733, 742.
[80] *Bank of Ireland v. Smyth* [1995] 2 IR 459, 468.
[81] *DPP v. M* [2018] IESC 21.
[82] [2018] IEHC 632.
[83] [1980] IR 32, 74.

> The true test is whether in the circumstances which prevail at the time she makes her decision, that decision reflects her will or the will of somebody else.[84]

4.1.2 ECHR

Organs of the State are also bound to perform their functions in a manner that is compatible with its obligations under the ECHR.[85]

Article 8 of the European Convention on Human Rights ('Article 8'), the provisions of which are outlined in an earlier chapter of this report, provides for the right to respect for private and family life.

It transpires from the jurisprudence of the European Court of Human Rights in relation to Article 8 that it extends to the areas of informational privacy and data protection. While those terms do not usually emanate from the Court's case-law it has, on numerous occasions confirmed that Article 8 protects individuals against the storing and processing of data or information pertaining to their private life without their consent. The Court's case-law in this area is predominantly influenced by the Data Protection Convention.[86]

The European Court of Human Rights has previously drawn a distinction in, for example, the case of *Van der Velden v. The Netherlands*,[87] when addressing issues of criminal procedure, between the retention of finger prints on the one hand and the retention of cellular samples and DNA profiles on the other hand. This is in view of the stronger potential for future use of the personal information contained in the latter.

Both categories of personal information – fingerprints and DNA profiles – have been found by the Court to fall within the scope of Article 8, as a consequence of being directly relevant to the identification of the individual concerned.[88] With regard to cellular samples and DNA profiles, the basis upon which they have been found to fall within the scope of Article 8 has

[84] *DG and MG v. An Bord Uchtála* HC 23 May 1996, 22.
[85] European Convention on Human Rights Act 2003, section 3.
[86] Council of Europe Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data CETS No. 108.
[87] Application Number 29514/05, (ECtHR, 7 December 2006).
[88] *S and Marper v. the United Kingdom*, Application Numbers 20562/04 and 30566/04 (ECtHR, 4 December 2008), 23-25.

been most clearly articulated in a passage from the European Court of Human Rights judgment in *S and Marper v. the United Kingdom*,[89] in which it was stated:

> 70. In *Van der Velden*, the Court considered that, given the use to which cellular material in particular could conceivably be put in the future, the systematic retention of that material was sufficiently intrusive to disclose interference with the right to respect for private life (see *Van der Velden* cited above). The Government criticised that conclusion on the ground that it is speculated on the theoretical future use of samples and that there was no such interference at present.
>
> 71. The Court maintains its view that an individual's concern about the possible future use of private information retained by the authorities is legitimate and relevant to a determination of the issue of whether there has been an interference. Indeed, bearing in mind the rapid pace of developments in the field of genetics and information technology, the Court cannot discount the possibility that in the future the private-life interests bound up with genetic information may be adversely affected in novel ways or in a manner which cannot be anticipated with precision today.
>
> 72. Legitimate concerns about the conceivable use of cellular material in the future are not, however, the only element to be taken into account in the determination of the present issue. In addition to the highly personal nature of cellular samples, the Court notes that they contain much sensitive information about an individual, including information about his or her health. Moreover, samples contain unique genetic codes of great relevance to both the individual and his relatives [...]
>
> 73. Given the nature and the amount of personal information contained in cellular samples, their retention per se must be regarded as interfering with the right to respect for the private lives of the individuals concerned. That only a limited part of this information is actually extracted or used by the authorities through DNA profiling and that no immediate detriment is caused in a particular case does not change this conclusion [...]

In addition, it would not be a prerequisite to Article 8 being engaged that the DNA samples actually be used, rather according to the judgment in *Amann v. Switzerland*, the mere storing of such private personal information by a state authority is sufficient to constitute an interference with Article 8 where consent has not been obtained.[90]

[89] Application Numbers 20562/04 and 30566/04 (ECtHR, 4 December 2008).
[90] Application Number 27798/95 (ECtHR, 16 February 2000), 20.

4.1.3 General Data Protection Regulation

Under European Union Law genetic data, including DNA, is treated as personal data.[91] A clear and concise definition is provided by the GDPR, which states:

> "Consent" of the data subject means any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her.[92]

Recital 32 of the GDPR clarifies the process by which consent should be sought:

> Consent should be given by a clear affirmative act establishing a freely given, specific, informed and unambiguous indication of the data subject's agreement to the processing of personal data relating to him or her, such as by a written statement, including by electronic means, or an oral statement. This could include ticking a box when visiting an internet website, choosing technical settings for information society services or another statement or conduct which clearly indicates in this context the data subject's acceptance of the proposed processing of his or her personal data. Silence, pre-ticked boxes or inactivity should not therefore constitute consent. Consent should cover all processing activities carried out for the same purpose or purposes. When the processing has multiple purposes, consent should be given for all of them. If the data subject's consent is to be given following a request by electronic means, the request must be clear, concise and not unnecessarily disruptive to the use of the service for which it is provided.[93]

It is clear therefore that the GDPR, similarly to the position previously adopted by the Superior Courts of this jurisdiction as well as the ECtHR, requires affirmative consent for data processing. It mandates that in order for consent of a data subject to satisfy the provisions of the GDPR, it must be:

- Freely given;
- Specific;
- Informed; and
- Unambiguous.

[91] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, recitals 23 and 34.
[92] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 4(11).
[93] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, recital 32.

This definition of consent is, while similar, arguably even more exacting than that which has been stipulated by the Irish Superior Courts in terms of what must be satisfied for a lawful abandonment of constitutional rights to occur. In that instance, as already stated, consent must be provided in a fully-informed and free manner. It is therefore recommended that the definition set down by the GDPR be adopted in respect of any scheme that may be established in order to collect, store and process the biological samples of survivors of the Tuam Mother and Baby Home, and/or their relatives.

4.2 THE LEGAL BASIS FOR COLLECTING, STORING, AND PROCESSING DATA

The processing of a citizen's data, to include DNA samples, is lawful only if and to the extent that one of the following applies:

(a) the data subject has given consent to the processing of his or her personal data for one or more specific purposes;

(b) processing is necessary for the performance of a contract to which the data subject is party or in order to take steps at the request of the data subject prior to entering into a contract;

(c) processing is necessary for compliance with a legal obligation to which the controller is the subject;

(d) processing is necessary in order to protect the vital interests of the data subject or of another natural person;

(e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;

(f) processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child.[94]

It should be emphasised that consent is not always the primary or most desirable means of legitimising and/or legalising the processing of personal data. In addition, it might appear, *prima facie*, that given the nature of the task and, in particular, its association with the

[94] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 6(1).

excavation of the site at the Tuam Mother and Baby Home, that it be covered by Article 6(1)(e) of the GDPR (above), in that an administrative scheme could be classified as being in the public interest. However, in the absence of a bespoke legislative mechanism, such an interpretation would be misconstrued. Article 6(1)(e) must be read in light of Article 6(3), which reiterates that processing of data under the former provision must be laid down by law.

In the absence of bespoke legislation providing stringent statutory requirements, there would be scope for uncertainty as to whether adequate safeguards to process and/or store data under the public interest heading provided for by Article 6(1)(e) of the GDPR were present. Thus, for the avoidance of doubt, any administrative scheme could only operate on the basis of consent, as provided for by Article 6(1)(a).

4.3 CONSENT IN THE GDPR AND THE DATA PROTECTION ACT 2018

On 27th April 2016, the European Commission published the GDPR. The GDPR radically changed the scope of data protection across European Union Member States, including in this jurisdiction. The legal basis for the text is Article 16 of the Treaty on the Functioning of the European Union.[95]

The GDPR seeks to protect individuals' personal data as an overarching, fundamental human right. The GDPR consists of 99 Articles, and 173 Recitals; the Recitals seek to outline the rationale underlying the provisions of the GDPR and provide insight as to how the Articles should be interpreted.

The Data Protection Act 2018 entered into force on 25th May 2018. The objectives of the Act are to *inter alia* give effect to the limited areas of flexibility permitted under the GDPR and to transpose the Directive into Irish Law.

Consent is one of the six lawful bases to process personal data.[96] The State must always consider whether consent is the appropriate lawful ground for the processing of personal data.

[95] Consolidated Version of the Treaty on the Functioning of the European Union [2016] C115/47.
[96] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 6.

In this case, consent is deemed the most appropriate ground upon which to collect, store, and process the biological samples of survivors and/or their relatives.

This subsection of the Report seeks to identify the various characteristics that a legally valid consent must contain under the GDPR, and examines those characteristics in the context of collecting, storing, and processing survivors' personal data, and/or that of their relatives.

4.3.1 Freely Given Consent

It is important that the prospective data controller/processing authority, is cognisant of the parameters set down by Recital 43 of the GDPR, which provides:

> In order to ensure that consent is freely given, consent should not provide a valid legal ground for the processing of personal data in a specific case where there is a clear imbalance between the data subject and the controller, in particular where the controller is a public authority and it is therefore unlikely that consent was freely given in all the circumstances of the specific situation. Consent is presumed not to be freely given if it does not allow separate consent to be given to different personal data processing operations despite it being appropriate in the individual case, or if the performance of a contract, including the provision of a service, is dependent on the consent despite such consent not being necessary for such performance.[97]

While it is of vital importance that protective measures, as outlined below, are put in place to minimise the impact of an imbalance of power between the data processor and applicants to the Scheme, the aforesaid provision does not preclude the State from processing data on the basis of consent.[98] Rather, the consent should be characterised by each of the following in order to be valid:

- The data subject should be provided with a real choice;
- Consent should not be compelled;
- Negative consequences should not flow from a refusal of consent.

To ensure that there is a real choice for data subjects, it is desirable that it be made clear to applicants that any administrative scheme that is established is only a temporary measure pending the enactment of bespoke legislation. It should be open to Tuam survivors and/or

[97] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, recital 34.
[98] Article 29 Data Protection Working Party, *Article 29 Working Party Guidelines on consent under Regulation 2016/679* (WP259rev.01 2017), 7.

relatives to await the introduction of legislation before participating in a DNA matching process.

Any scheme established should be publicised, and direct contact should be made by the administrator of the Scheme with survivors' support groups to build awareness of their entitlement to apply. Such action should be taken as soon as a scheme is established. However, to ensure consent is not compelled, the Department should await a proactive expression of interest by each individual applicant, and should provide detailed information in relation to each area of consent at the earliest possible stage, and ideally, immediately after receiving an expression of interest or application to the Scheme.

A failure to consent to all or any aspect of the Scheme should not result in any adverse consequences for a survivor or relative. It is imperative that an earlier refusal of consent should not preclude a prospective applicant from applying to the Scheme again and/or providing consent at a later date. It is also essential that a prospective applicant is not precluded from applying to any scheme or body established on foot of bespoke legislation which is enacted, as a result of failing or refusing to consent to an administrative scheme that is set up in the interim. It is advised that this be clearly communicated to each prospective applicant from the outset, and in the absence of being provided with this information, they should not yet be treated as being fully informed applicants.

Finally, to ensure any application to the Scheme is truly free, it is recommended that there should not be a deadline set by which time an application should be submitted in order to be admitted to the Scheme. It is advised that the State should accept rolling applications up until the enactment and commencement of bespoke legislation. This approach could seek to ensure that undue pressure is not ultimately placed on an applicant to consent in a timeframe that does not allow him/her to give full consideration to each and every aspect of the Scheme that he/she is consenting to. Similarly, it is recommended that there should not be an arbitrary cut off point based on, for example, age or illness, that precludes an individual from applying to the Scheme. Such an approach could, ultimately lead to a successful legal challenge based on the irrationality of an exclusion.

4.3.2 Specific Consent

It is important to note that the DNA of applicants to the Scheme is, as genetic data,[99] considered to be a special category of personal data[100].[101] This renders the requirement to ensure specificity in seeking consent all the more stringent.

The Article 29 Working Party ('WP29') was an advisory body made up of representatives from the data protection authority of each member state, the European Data Protection Supervisor, and the European Commission.[102] Prior to being replaced by the European Data Protection Board under the GDPR, it published a useful guidance document. This guidance, in light of the sparse amount of case-law that has emanated from the CJEU since the GDPR became enforceable last May, provides a useful interpretative tool.

WP29 has indicated, in relation to the question of how the concept of specific consent should be determined:

> If the controller is relying on Article 6(1a), data subjects must always give consent for a specific processing purpose. In line with the concept of purpose limitation, and Article 5(1b) and recital 32, consent may cover different operations, as long as these operations serve the same purpose. It goes without saying that specific consent can only be obtained when data subjects are specifically informed about the intended purposes of data use concerning them.[103]

However, while this purposive limitation may permit, for example, for the data controller/processing authority to use whatever technical matching process is necessary to achieve the purpose of comparing the DNA of a scheme participant with that of remains exhumed at the Tuam site, this does not negate the requirement to provide granular detail to

[99] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, recital 34.
[100] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 9
[101] Data Protection Act 2018, section 2.
[102] Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data [1995] L281/131, article 29.
[103] Article 29 Data Protection Working Party, *Article 29 Working Party Guidelines on consent under Regulation 2016/679* (WP259rev.01 2017), 12.

the data subject when seeking his/her consent.[104] Treating an applicant's initial application to the Scheme as providing implicit consent to collect and store his/her DNA sample(s) would not be compliant with Article 4(11) of the GDPR. Nor would it be sufficient to rely upon one indication of consent to enable a variety of processing activities. In order to be in compliance with Article 7(2) of the GDPR,[105] and ensure the data privacy rights of scheme participants are protected, the DNA samples collected must only be extracted and stored in order to carry out the matching process prescribed.

It is recommended that information in respect of the Scheme be presented in an accessible and clear format, and both Article 12 of the GDPR and section 73(3)(b) of the Data Protection Act 2018 require that it be detailed in plain language.[106] While the language used to inform participants must be accurate, it should not be overly technical, and should be, '[...] easy to understand.'[107]

It is advisable that the adequacy or clarity of the language used is not determined only by those with technical knowledge and expertise. To ensure that any scheme established is accessible to all, and that, for example, disabilities and/or learning difficulties do not act as a barrier, it is recommended that before formally establishing an administrative scheme, and prior to distributing consent forms, that the scheme administrator seeks advice and guidance on Plain English editing.

To ensure that the consent given is as robust as possible, each applicant to the Scheme should be provided with comprehensive information which could take the form of questions on the scheme followed by answers that are legally accurate and which provide clarity.

[104] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, recital 32.
[105] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 7(2).
[106] Data Protection Act 2018, section 73(3)(b).
[107] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, recital 39.

Under common law, while it is rebuttable, capacity is to be presumed;[108] this is also the position adopted in the recently enacted, but not yet commenced, Assistant Decision-Making (Capacity) Act 2015.[109] This presumption should apply to each participant in the Scheme, as far as obtaining his/her consent is concerned. However in some instances, for example, where an applicant suffers from an intellectual disability or due to age has difficulty understanding or communicating his/her wishes, it may be necessary to engage the assistance of a next of kin or an advocate.

It is recommended that explicit consent of applicants to an administrative scheme be obtained in the clearest possible terms. While granular detail is desirable, it should also be concise, so as not to confuse a survivor and/or relative. Jay et al, provide:

> Whilst a communication with a data subject in relation to their rights is required to be concise under art.12 and also Recitals 39 and 58, this may prove a challenge in the light of the expanded list of information that must be specified in a notice and data controllers will need to balance the requirements of transparency and being concise when drafting.[110]

It is advised that consent be sought in a detailed yet concise manner in relation to, for example -

(i) The method by which a DNA sample will be collected, including but not necessarily limited to:

- The time, date, and location that DNA will be collected;
- The body, institution and/or individual that will be responsible for extracting the DNA sample;
- The mechanism that will be used in order to extract a DNA sample, including the equipment that will be used and/or any interference with the participant's bodily autonomy that might be required;
- The part of the participant's body that the sample will be extracted from;
- The collection of necessary and supplementary information, for example, *inter alia* the participant's date of birth, address, and contact details. If it is deemed necessary to retain a next of kin's contact details, it will also be necessary to obtain their consent to store personal data.

[108] See for example, *HSE v. B* [2017] ILRM 54; *HSE v. TM* [2016] IEHC 593.
[109] Assistant Decision-Making (Capacity) Act 2015, section 8(2).
[110] Jay, Bapat and Townsend, 'Transparency and Procedural Rules for the Individual Rights' in Rosemary Jay (ed.), *Guide to the General Data Protection Regulation: A Companion to Data Protection Law and Practice* (4th edn., Sweet and Maxwell 2017), 218.

(ii) The storage of DNA samples as distinct from the collection of those DNA samples, including but not necessarily limited to:

- By whom any DNA sample(s) will be stored;
- The process by which a category of individual and/or body may gain access to DNA sample(s);
- The body or bodies, and/or categories of individual that will have knowledge of the fact that a participant's data is being stored.

(iii) The storage of DNA samples following the participant's death (this issue is dealt with in more detail below):

- The permission to retain data pending a matching process taking place;
- The retention of DNA sample(s) in circumstances where it is not possible to match it/them with remains exhumed from the site at Tuam, for the purpose of carrying out a future matching process, technological advancement permitting.

4.3.3 Transparency and Informed Consent

Every data subject has the right to be informed.[111] Without providing detailed, up to date, and clear information to prospective scheme applicants, the State runs the risk of obtaining consent that is not informed, and thus, legally invalid.

One of the guiding principles set down by Article 5 of the GDPR is that personal data must be processed in a transparent, as well as a lawful and fair, manner. Thus, providing information to a prospective data subject prior to the collection, processing and/or storage of his/her personal data is advised to ensure compliance with the provisions of the GDPR and the Data Protection Act 2018.

W29 has outlined that, if "the controller does not provide accessible information, user control becomes illusory and consent will be an invalid basis for processing." It also provides useful guidance with regard to what it claims are the minimum content requirements for consent to be informed. These include:

(i) the controller's identity,
(ii) the purpose of each of the processing operations for which consent is sought,
(iii) what (type of) data will be collected and used,
(iv) the existence of the right to withdraw consent,

[111] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, articles 13-14.

(v) information about the use of the data for decisions based solely on automated processing, including profiling in accordance with Article 22(2) [...][112]

The question of whether consent is informed for the purposes of the GDPR, is intrinsically linked with the matter of whether it is specific.[113] The Data Protection Commissioner has clearly articulated the threshold of requirements that should be fulfilled before consent can be deemed, informed, in line with Article 13 of the GDPR.[114] These are as follows:

> 1. Identity and contact details of the data controller (and where applicable, the controller's representative);
>
> 2. Contact details of the Data Protection Officer (person with responsibility for data protection matters within the organisation);
>
> 3. Purpose(s) of the processing and the lawful basis for the processing;
>
> 4. Where processing is based on the legitimate interests of the controller or a third party, the legitimate interests of the controller;
>
> 5. Any other recipient(s) of the personal data;
>
> 6. Where applicable, details of any intended transfers to a third country (non-EU member state) or international organisation and details of adequacy decisions and safeguards;
>
> 7. The retention period (how long an organisation holds onto data) or, if that is not possible, the criteria used to determine the retention period;
>
> 8. The existence of the following rights –
>
> - Right of access
> - Right of rectification
> - Right to erasure
> - Right to restrict processing
> - Right to data portability
> - Right to object –
>
> and to request these from the data controller.
>
> 9. Where processing is based on consent, the right to withdraw consent at any time, without affecting the lawfulness of processing based on consent before its withdrawal;

[112] Article 29 Data Protection Working Party, *Article 29 Working Party Guidelines on consent under Regulation 2016/679* (WP259rev.01 2017), 13.
[113] Rohan Massey, 'A thorough analysis of the notion of consent in the General Data Protection Regulation', (2018) 29(4) Entertainment Law Review 106-111.
[114] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 13.

> 10. The right to lodge a complaint with a supervisory authority;
>
> 11. Whether the provision of personal data is a statutory or contractual requirement, necessary to enter into a contract, an obligation and the possible consequence of failing to provide the personal data;
>
> 12. The existence of any automated decision making processes that will be applied to the data, including profiling, and meaningful information about how decisions are made, the significance and the consequences of processing.[115]

It would not be possible, and indeed, it is not legally necessary to provide granular detail in relation to the identity of each and every government servant or agent who may be involved in the collection, processing or storage of a given biological sample. The term 'controller' is defined as meaning:

> ...the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data; where the purposes and means of such processing are determined by Union or Member State law, the controller or the specific criteria for its nomination may be provided for by Union or Member State law...[116]

Survivors and/or relatives participating in the Scheme will therefore need to be informed, prior to the collection of biological samples, of the public authority or authorities that will be responsible for the collection; storage; and processing of the data.[117] Recommendations in respect of whom and/or what agency should be responsible for administering and/or overseeing the Scheme are outlined elsewhere in this Report.

If a diverse range of agencies undertake different elements of the process, for example, if one agency will extract the biological sample, while another agency will be responsible for the storage of data pending the matching process, it is recommended that this be detailed to each scheme participant.

In addition, if there is a change of circumstances; for example, if the authority responsible for storing the data changes, it is recommended that the participant in the Scheme be informed

[115] Data Protection Commissioner, *Rights of individuals under the General Data Protection Regulation,* (2018) 5, available at: http://gdprandyou.ie/wp-content/uploads/2018/03/Rights-of-Individuals-under-the-General-Data-Protection-Regulation.pdf, accessed 6 March 2019.
[116] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 4(7).
[117] Data Protection Act 2018, section 71(3)(a).

before such change is affected and be provided with a real and meaningful opportunity to withdraw consent.

4.3.4 Communicating Information to Prospective Data Subjects and Seeking Unambiguous Consent

Neither the Data Protection Act 2018 nor the GDPR specify the form in which information must be communicated in order to ensure that consent is informed. The requirements that must be fulfilled have previously been rehearsed, and are predominantly set out in Recital 32 and Article 7(2) of the GDPR. The latter provides:

> If the data subject's consent is given in the context of a written declaration which also concerns other matters, the request for consent shall be presented in a manner which is clearly distinguishable from other matters, in an intelligible and easily accessible form, using clear and plain language. Any part of such a declaration which constitutes an infringement of this Regulation shall not be binding.[118]

It is recommended that any administrative scheme that is established is underpinned by written consent. While the presentation and wording of such written consent is yet to be formulated and would, in any event, require the input of the various professionals who would be involved in collecting, processing and storing the samples (for example, scientists and/or members of An Garda Síochána), it is vitally important that specific consent is sought.

It is advised that the indication of consent be so unambiguous as to meet the threshold set out under Article 9 of the GDPR, in respect of 'special categories of personal data'. WP29 prescribes:

> The term explicit refers to the way consent is expressed by the data subject. It means that the data subject must give an express statement of consent. An obvious way to make sure consent is explicit would be to expressly confirm consent in a written statement. Where appropriate, the controller could make sure the written statement is signed by the data subject, in order to remove all possible doubt and potential lack of evidence in the future.[119]

[118] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 7(2).
[119] Article 29 Data Protection Working Party, *Article 29 Working Party Guidelines on consent under Regulation 2016/679* (WP259rev.01 2017), 18.

It is recommended in the first instance that, the opportunity to have a biological sample collected for the purpose of a matching process should be publicised. It would also be advisable that survivors/relatives be required to provide a proactive expression of interest, as referenced above. They should be able to do so in writing to a designated address and/or online through a secure website.

At the point of expressing interest, it is recommended that they be provided with a package of information, enclosing consent forms. The information and consent forms could be provided in hard copy format and accessible online, to ensure that each prospective applicant has the greatest opportunity possible to access, analyse, and discuss the information provided to him/her should he/she deem it necessary to do so. WP29 has outlined:

> Perhaps the most literal way to fulfil the criterion of a "written statement" is to make sure a data subject writes in a letter or types an email to the controller explaining what exactly he/she agrees to. However, this is often not realistic. Written statements can come in many shapes and sizes that could be compliant with the GDPR.

The use of pre-ticked or opt-out boxes is precluded under Article 7(2) of the GDPR. Thus, to ensure that granular consent is given, it is recommended that a detailed explanation be provided in relation to each processing activity (as outlined above).

In addition, to ensure the consent is as proactive and unambiguous an expression as possible, it is advised that a detailed explanation be provided and read before a prospective data subject signs a declaration that indicates his/her clear understanding of what he/she is consenting to.

The written statement of consent should, where feasible, be completed as close in time to the collection of the DNA sample as possible.

4.3.5 Purpose Limitation

It is absolutely essential to recognise that the purpose of data processing plays a pivotal role in determining the lawfulness of the controller's and/or processor's activities. Thus, it is recommended two things are achieved before the data of Tuam survivors and/or their relatives is collected, stored, and/or processed. First, the purpose of the collection, storage and/or processing of biological samples should be definitively identified and articulated.

Second, the purpose of an administrative scheme and the activities associated with it should be clearly communicated in unambiguous terms before any action is taken to collect, store and/or process an applicant's data.

Not only must the data processing activities be aligned to the purpose of an administrative scheme, it should be a requirement to ensure lawful retention of biological samples that storage is tied to the clearly stated purpose of the scheme. It is imperative that every storage and processing activity is justified by the stated purpose of an administrative scheme; the biological samples collected on foot of the Scheme may not be lawfully processed and information in relation to those samples cannot lawfully be disseminated unless underpinned by the purpose for which the scheme was established.[120] Castro-Edwards clearly articulates the position:

> The crucial point is that the purpose (or purposes) for which personal data are to be processed must be specified to the data subject. Any further purposes for which personal data may be processed that are not specified explicitly in the transparency language are likely to fall outside the principle.
>
> Where personal data is collected and processed for one purpose, it may only be processed for a further purpose if that processing is compatible with the first purpose …[121]

The right to erasure is enshrined in section 92 of the Data Protection Act 2018 and Article 17 of the GDPR. Applicants to the scheme should be made aware of this right, particularly in circumstances where the retention of the subject's personal data is no longer necessary in relation to the purpose for which it was processed. Paul Voigt and Axel von dem Bussche state:

> This provision applies to data that has initially been collected and processed lawfully. Erasure can be obtained for those data that are no longer necessary for the *purpose* of processing or where the purpose ceases to exist. However, in case the data concerned is necessary for realising another purpose of processing that partially

[120] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 5(1)(b).
[121] Castro-Edwards, *EU General Data Protection Regulation, A Guide to the New Law* (The Law Society of England and Wales, 2017), 23.

> overlaps with or is compatible with the eliminated purpose, erasure does not need to take place.[122]

Furthermore, it is recommended that an aspect of the consent sought and obtained from an applicant to a scheme should stipulate that data will be retained until a matching process successfully occurs, or until consent is withdrawn, whichever occurs first. This will not be a live issue if the scheme participant dies prior to there having been a successful matching process. However, it may be an issue if, for example, a matching process is attempted but because of a lack of technological advancement it is not possible to successfully match the scheme participant's DNA with that of remains at Tuam. In those circumstances, and where the scheme participant remains alive, it would be necessary for him/her to consent to the retention of his/her data even if an initial matching attempt is unsuccessful or inconclusive.

4.4 WITHDRAWAL OF CONSENT

4.4.1 Condition of Consent

It is a central component of a valid consent that the data subject be provided with a right to withdraw consent at any time he/she chooses; he/she must also be informed of his/her right to withdraw his/her consent prior to being deemed as having provided lawful consent. Article 7(3) of the GDPR provides:

> The data subject shall have the right to withdraw his or her consent at any time. The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal. Prior to giving consent, the data subject shall be informed thereof. It shall be as easy to withdraw as to give consent.

It is therefore advised that prospective data subjects are made aware of their right to withdraw consent at any time, and it is recommended that this be done prior to or at the same time as communicating the different elements of the scheme that will require collection, processing and storage of data. It is advisable that a declaration to the effect that the data subject understands his/her right to withdraw consent at any time by the means prescribed should be included as an element of the consent form.

[122]Voigt and von dem Bussche, *The EU General Data Protection Regulation (GDPR)* (Springer International, 2017), 156-157.

In light of the fact it is recommended that consent be sought in a granular way, and in light of the nature of any administrative scheme that could be established, it is anticipated that withdrawing consent should in fact be easier than providing consent in this given instance. This is the case because, if a data subject withdraws consent in respect of one of the processing activities that underpins the scheme, this will consequently result in his/her place in a scheme becoming somewhat defunct.

A withdrawal of consent in respect of the Scheme as a whole should be treated as withdrawal of consent in relation to each and every storage or processing activity that had previously been consented to.

4.4.2 Method of Withdrawal

Participants in the scheme – survivors and/or their relatives – should be able to withdraw consent in writing or by sending an email to a designated email address. The email address should be provided to them at the earliest possible stage and certainly prior to their biological samples being collected. This email address should be continually monitored.

4.5 CONSENT OF THE NOMINEE

It must be acknowledged that there are several reasons that survivors of the Tuam Mother and Baby Home have called for biological samples to be collected and stored at this time. One of the grounds upon which these requests have been made relate to survivors' and relatives' concerns that they will be deceased prior to remains being exhumed from the site at Tuam, and/or before bespoke legislation is enacted and commenced, resulting in a matching process becoming impossible.

Therefore, a necessary feature of the Scheme will be that an applicant will have to nominate an individual to whom information gleaned from the DNA matching process will be disseminated to. Considerations in relation to the appropriate class of individuals that could be nominated have been dealt with in a separate section of this Report, which deal with rights falling under Article 8 of the ECHR.

However, one issue that falls for consideration under this section is the matter of a nominated person having to consent in order to participate in the process. This brings with it, separate considerations in relation to those individuals.

4.5.1 Storage of Nominees' Personal Data

While they would not strictly be an applicant to the Scheme, it will be legally and practically necessary that a nominated person be informed and consent to being nominated to receive the information which could be gleaned from the DNA matching process.

It will clearly be necessary to retain personal details of the nominated person in order to be able to successfully identify and communicate results to him/her at a later stage. Such details may include, for example, his/her date of birth, PPS number, correspondence address, email address, and/or telephone number.

It should be a requirement, prior to deeming an application as complete, that a nominated person's consent be sought on the same basis as outlined earlier in this subsection. That consent should address, but may not necessarily be limited to:

- Consent for the State to collect and store personal details (such as those outlined above) for the purpose of communicating DNA matching results, only in circumstances where an applicant dies prior to the process taking place;

- Consent to that personal information being destroyed in a prescribed manner after the process is carried out;

- Consent to retain the personal information until such time that technological developments allow the DNA matching process to successfully take place; if it is not possible to do so at the current time.

4.5.2 Withdrawal of Consent by a Nominated Person

It is necessary to highlight that the principles which apply to scheme participants in relation to the right to withdraw consent, are also applicable to individuals nominated to receive information in relation to the matching process upon a participant's death.

If the nominated person withdraws his or her consent for a data controller to store, for example, his/her personal contact details for the purpose of disseminating information in relation to the DNA matching process, the data controller will have no option but to relinquish that data.

The resulting consequence would be that the State would not be in a position to disseminate information in relation to the matching process. If this was to occur during the lifetime of a participant, it could be easily remedied. However, if a nominee was to withdraw consent following a participant's death it would not be possible to.

Thus, it is recommended, in an attempt to minimise this risk that applicants to a scheme be provided with an opportunity to put forward two nominees. This information could be provided in rank order.

4.6 DATA PROTECTION AND DECEASED PERSONS

An unfortunate reality that will characterise any proposed administrative scheme will be the possibility of applicants – survivors and/or relatives – dying prior to bespoke legislation coming into place. It is therefore necessary to consider the impact of a scheme participant's death.

4.6.1 Implications of a data subject's death

Data protection rights do not survive beyond a data subject's death, and the GDPR explicitly stipulates that it does not have any applicability to the data of deceased persons. The GDPR states:

> This Regulation does not apply to the personal data of deceased persons. Member States may provide for rules regarding the processing of personal data of deceased persons.[123]

[123] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, recital 27.

In this jurisdiction, the Data Protection Act 2018 also makes no provision for data protection rights pertaining to deceased persons.

4.7 OTHER LEGAL AND ETHICAL CONSIDERATIONS

4.7.1 The Role of the Data Protection Officer

Article 37(1)(a) of the GDPR clearly stipulates that where processing is carried out by a public authority, as it will in this particular instance, the controller must designate a data protection officer.[124] In line with the obligations placed on a data protection officer by Article 39 of the GDPR, it is recommended that the data protection officer assigned to the institution or agency that will ultimately serve as the data controller be provided with an opportunity to fully review every aspect of any administrative scheme and, in particular, the wording and nature of the consent that will be sought from each applicant.

Article 39(1)(b) of the GDPR provides that one of the tasks of a data protection officer is to ensure compliance with the provisions of the Regulation.[125] It is therefore advisable that the relevant data protection officer be provided with as fulsome an opportunity as possible to make recommendations, and provide advice with regard to all aspects of an administrative scheme. It is recommended that prior to the implementation of an administrative scheme, the relevant data protection officer's opinion and advice should be fully considered, and implemented where appropriate.

4.7.2 Consent in respect of an administrative scheme and the impact of bespoke legislation

The necessity for an administrative scheme is clear and legitimate – the concerns of survivors and relatives that their deaths may prevent a biological link being made between them and the remains exhumed from the site at Tuam. This Report finds, as already outlined, that there

[124] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 37(1)(a).
[125] Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC [2016] L119/1, article 39(1)(b).

does not appear to be a legal impediment to such a scheme being established, and in the interests of justice, it is desirable that an appropriate administrative scheme should be set up.

However, it is also important that any administrative scheme that is established is no more than a temporary measure. It cannot be the permanent solution.

It is of vital importance that in tandem with an administrative scheme being established and it then carrying out its work, that the State is actively working towards enacting bespoke legislation that will create a statutory mechanism for the collection, storage and processing of survivors' and relatives' DNA samples, for the purpose of carrying out a matching process with the exhumed remains from Tuam.

An administrative scheme that fulfils the requirements set out above would offer sufficiently stringent protections for participants and nominees, and is desirable at this time. However, to ensure consistency and permanency of the arrangement and to provide statutory protection, the introduction of legislation will be necessary at a later date.

It is envisaged that any temporary administrative scheme that is established should eventually be subsumed into bespoke legislation; this must also form an element of the consent obtained from participants and nominees.

4.7.3 Administration of the Scheme

The situation that has arisen on foot of the Tuam Survivors Network calling for DNA storage and matching processes to take place cannot in any way be compared or conflated with the border crisis that has recently arisen in the United States of America. However, the public reaction to the US Government's announcement of its intentions to use DNA tests in respect of family reunification is demonstrative of the sensitivity associated with processing such personal data, as well as the difficulties and problems that arise on foot of inconsistent media reporting.[126]

[126] Farahany, Chodavadia, Katsanis, 'Ethical Guidelines for DNA Testing in Migrant Family Reunification', (2019) 19(2) The American Journal of Bioethics 4-7.

It is therefore imperative that the State clearly communicates with survivors and relatives predominantly, but also to the media and general public.

While it will be solely a matter for the Department to determine what institution or agency is responsible for each aspect of the Scheme, in the process of compiling this report, consultation has been had with the Data Protection Commission and An Garda Síochána.

In establishing an administrative scheme, it is recommended that the State be cognisant of the cultural and historical connotations that may be associated with An Garda Síochána storing or processing the biological samples of individuals who have, for example, not been charged with a crime.

In addition, individuals may have a concern, however unfounded that concern may be, that their data could be used for the purpose of updating the Garda Pulse system.

It is therefore recommended that while An Garda Síochána should be responsible for the collection of the biological sample, given that it is the institution with the expertise and facilities to be able to do so (on foot of section 48 of the 2014 Act), it is advised that it should not be the institution responsible for the storage or processing of that data. When an application is made to an administrative scheme, the local garda station (or the nearest garda station with suitable facilities) could be designated for the collection of the biological sample.

The storage and processing of the data should be a scientific exercise that is carried out separately under the auspices of a government department.

4.8 SUMMARY OF DATA PRIVACY CONSIDERATIONS

The GDPR provides that consent is a lawful basis for the collection, storage and processing of personal data. Thus, in this particular case, biological samples may be legally obtained, retained and processed where those activities are underpinned by the consent of survivors and/or relatives.

There is no reason why such activities could not occur in the absence of a bespoke legislative mechanism. This conclusion has been reached not only on foot of a comprehensive analysis of the relevant legal provisions, but also following a consultation with the Data Protection Commission. For consent to be valid, in line with the provisions of the GDPR and the Data Protection Act 2018, it must be freely given; specific; informed and unambiguous.

4.9 CONCLUSIONS

The definition of consent set down by the GDPR should be adopted for the purpose of any administrative scheme that might be established.

It is clear that the GDPR, similarly to the position previously adopted by the Superior Courts of this jurisdiction as well as the ECtHR, requires affirmative consent for data processing. It mandates that in order for consent of a data subject to satisfy the provisions of the GDPR, it must be:

- *Freely given;*
- *Specific;*
- *Informed; and*
- *Unambiguous.*

The consent should be characterised by each of the following in order to be valid:

- *The data subject should be provided with a real choice;*
- *Consent should not be compelled;*
- *Negative consequences should not flow from a refusal of consent.*

It will be essential that the adequacy or clarity of the language used is not determined only by those with technical knowledge and expertise. It will be necessary to ensure that any scheme established is accessible to all, and that, for example, disabilities and/or learning difficulties do not act as a barrier. It is therefore recommended that before formally establishing an administrative scheme, and prior to distributing consent forms, that the scheme administrator seeks advice and guidance on Plain English editing.

In summary, the following GDPR requirements should be incorporated in any administrative scheme established:

- *There should be clarity for participants about how the data will be processed at all stages. This includes obtaining the data, analysing it, disclosing results, and storage.*

- *There are obligations around the security of storage, the length of time it is retained for and what will be done with it when the process it was collected for is exhausted.*

- *There are also the various procedural entitlements of data subjects in Chapter 3 of the GDPR such as the right to access the information held and/or to seek to have it erased. Whoever is the data controller for the scheme will have to have some system in place for dealing with such requests and should ensure data subjects know what that system is.*

- *In terms of publicity, the requirement is for information on how the scheme works to be clear and accessible. This does not mean it has to be widely publicised as long as participants in the scheme are able to know and/or find out how it is regulated.*

5. THE DISABILITY ACT 2005

5.1 GENETIC TESTING

The Disability Act 2005 contains a specific provision governing genetic testing, which it appears would have to be complied with in the case of DNA collection in the Tuam context. Section 42 of the Disability Act 2005, as amended, provides in relevant parts:

> (1) Genetic testing shall not be carried out on a person unless—
>
> (a) the testing is not prohibited by law, and
>
> (b) the consent of the person to the processing of any genetic data to be derived from the testing has been obtained in accordance with the Data Protection Regulation.
>
> …
>
> (3) A person shall not process genetic data unless all reasonable steps have been taken to provide the data subject with all appropriate information concerning—
>
> (a) the purpose and possible outcomes of the proposed processing, and
>
> (b) any potential implications for the health of the data subject which may become known as a result of the processing.

In effect, this section copper-fastens the protections already conferred by the GDPR and adds an additional requirement to provide information in respect of the purpose and possible outcomes of the proposed processing, as well as any potential health implications. In substance, it seems that these requirements are very similar to those already imposed by the data protection law regime, and which have been fully explored previously in this Report.

5.2 CONCLUSION

- *The proposed administrative scheme will need to comply with the requirements of the Disability Act 2005.*