



# L&RS Note

## The Ethics of Confidentiality: the use of sensitive information

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### Abstract

This Note examines the various considerations around confidentiality in light of the publication of the [Retention of Records Bill 2019](#). This Note should be read in conjunction with the [Bill Digest on Retention of Records 2019](#). It considers the rationale for confidentiality within the medical sphere, the criminal justice field, academic research and journalism. It examines the justifications for maintaining confidentiality and the protections afforded to participants within each area. It highlights the chilling effects disclosure of records can have and the social harm it can cause.



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## Introduction

This Note is intended as an accompaniment to the [Bill Digest on Retention of Records Bill 2019](#). The Bill intends to provide for the retention of records belonging to the Commission of Inquiry into Child Abuse<sup>1</sup>, the Residential Institutions Redress Board<sup>2</sup> and the Residential Institutions Redress Review Committee<sup>3</sup> (the 'relevant bodies'). The purpose of retention is to assign these records as Departmental records so they can be transferred to the National Archives for a sealing period of 75 years, after which time they will be made available for public inspection. Under current legislation the relevant bodies are prohibited from disclosing any information provided to them, subject to regulations. Unauthorised disclosure currently constitutes a criminal offence. Current legislative provisions also provide for the relevant bodies' records to be destroyed when their work is complete. The proposed legislation aims to remove these restrictions. It also revokes the protections of anonymity given to those that attended the Confidential Committee to tell their story of institutional child abuse. It would also result in the making public of uncontested evidence, such as allegations of abuse against individuals who would not have had the opportunity to contest it. Finally, it places a restriction on any Freedom of Information requests being made on the documents by persons who gave evidence to the relevant bodies. This means that an individual cannot access his or her personal records until they are made publically available in 75 years time. The Bill also dis-applies the current protections dealing with confidential information under the Archives Act.

This Note examines responses to confidentiality within the medical field, the criminal justice field and the academic and journalistic field. It considers how confidentiality is necessary in certain areas in order to preserve confidence in that profession. It also sets out the limited exceptions where disclosure is necessary in the interests of the wider public. A balance must be struck whereby research should cause minimal social harm and participants should not be worse off as a result.

## Medical Ethics and confidentiality

Patient confidentiality is protected by professional codes such as the [Medical Council's guide on professional conduct and ethics](#)<sup>4</sup> as well as laws such as the right to privacy under the Irish Constitution and the [European Convention on Human Rights](#) (ECHR). The right to confidentiality is not absolute however and scenarios where the medical professional may qualify the right hinge on concerns about protecting the well-being of the patient or protecting others from harm. Where

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<sup>1</sup> The main functions of the Commission were to report on the abuse of children in various institutions and to provide, to those who were resident in the institutions during the relevant period, an opportunity to describe the abuse they suffered.

<sup>2</sup> The Redress Board was set up to make awards to persons who, as children, were abused while resident in industrial schools, reformatories and other institutions subject to state regulation or inspection. Once the relevant persons made applications it was the function of the Redress Board to determine whether the applicant was entitled to an award

<sup>3</sup> The functions of the Review Committee are to review decisions and awards made by the Redress Board by having regard to any evidence or reports submitted to that Board.

<sup>4</sup> 8<sup>th</sup> edition (2016).

disclosure is considered, the medical practitioner must be clear about the purpose of the disclosure; whether or not the patient consents to it and if there is any other legal basis for disclosing the information.<sup>5</sup> A practitioner must also be satisfied that:

- a) Anonymisation has been considered and is definitely not an option;
- b) The minimum information is being disclosed to the minimum amount of people;
- c) The person to whom the information is disclosed knows that it is confidential and they have their own duty of confidentiality.<sup>6</sup>

Patient consent is considered an integral part of the disclosure process, even where it is to the patient's relatives or close friends. The Medical Council instruct that anonymisation and coding should be used whenever possible, before disclosing the records to anyone outside of the health care team.<sup>7</sup> Where a disclosure is required by law or is in the public interest the patient should be informed of the intended disclosure. A disclosure in the public interest is where the disclosure may protect the patient, other identifiable people or the community more widely. Before such a disclosure is made, the practitioner should be satisfied that any harm experienced by the patient is outweighed by the benefits that are likely to arise.

Taking these standards into consideration, the retention and disclosure of Commission of Inquiry into Child Abuse records could raise some questions about the appropriateness of retention. Comparing rationales for disclosure, in the medical sphere it is to protect the well-being and safety of both the patient and others; in the press release announcing the publication of the [General Scheme of the Bill](#) these highly sensitive records are retained and later made public for the purpose of posterity and to ensure that future generations will understand what happened.

**Anonymisation of the data, the minimum information needed and consent of the individuals who gave information are not standards provided for in the Bill.**

### Public interest value in confidentiality

Hogan puts forward the idea that, the [Freedom of Information Act 1997](#) allows some access to medical records held by public bodies; there is no overarching legislation which effectively outlines the parameters of a doctor's duty of confidentiality.<sup>8</sup> She outlines, however, that one of the major principles underlying this duty is that it is beneficial to the individual and the wider public when medical records remain confidential. Due to the sensitive and personal nature of information shared with a doctor, there is a genuine risk that sharing of such information with colleagues, spouses or relatives could deter them from divulging important information, or from seeking medical treatment. This could have implications for the wider public and undermine trust placed in the medical profession. Confidentiality is therefore important to protect public health.<sup>9</sup>

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<sup>5</sup> Medical Council, "[Guide to Professional Conduct and Ethics for Registered Medical Practitioners](#)" (May 2016) pp.25-26.

<sup>6</sup> *Ibid.*

<sup>7</sup> *Ibid.*

<sup>8</sup> Hogan, H., "[The Duty of Confidentiality in Irish Medical Law: Individualistic and Communitarian Rationales](#)" (2017) 20(1) *Trinity College Law Review* pp.53-63.

<sup>9</sup> *Ibid.*

In the 2008 European Court of Human Rights (ECtHR) case [I v Finland](#), the applicant instituted civil proceedings against the District Health Authority.<sup>10</sup> She worked as a nurse in a public hospital and was also receiving treatment there for HIV. It soon became apparent that her colleagues were aware of her illness because all hospital staff had access to the patient register. She made a claim for pecuniary<sup>11</sup> and non-pecuniary damages for the alleged failure to keep her patient records confidential. She made her claim under [Article 8 of the European Convention](#) which states that: “Everyone has the right to respect for his private and family life, his home and his correspondence”. The ECtHR found in favour of the applicant and awarded damages on the grounds that there had been a violation of Art. 8. In reaching its decision the court stated that:

*“Although the object of Article 8 is essentially that of protecting the individual against arbitrary interference by the public authorities, it 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 private or family life... These obligations may involve the adoption of measures designed to secure respect for private life.”*

It was recognised by the court that the need for sufficient guarantees is particularly important when processing highly intimate and sensitive data. They added that “it is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general”. Commentary points out that this case highlights how the law is clear in this respect; that only relevant personnel involved in the treatment of the patient should have access to the patient’s records and the State is obliged to adopt practical and effective measures designed to secure respect for private life in this regard.<sup>12</sup>

When considering this with regards to the Commission of Inquiry records, the step taken to ensure the privacy of individuals is protected is the 75 year guarantee and the expectation that they will be deceased by the time the records are made public. While this will most likely be the case, they may have extended family that will still be alive. There is potential that this future disclosure, of privately obtained information, could deter others from disclosing information to other Commissions of Investigation or even undermine the trust placed in them in the future.

### Where the patient is deceased

According to the Medical Council, a patient’s information remains confidential even after death. Where it is unclear whether the patient consented, the practitioner is directed to consider how the disclosure might affect the deceased’s family or carers, the effect it may have on the deceased’s reputation and the purpose of the disclosure.<sup>13</sup>

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<sup>10</sup> (2009) 48 E.H.R.R. 31

<sup>11</sup> Pecuniary damages are damages that can be estimated in and compensated by money; not merely the loss of money or saleable property or rights, but all such loss, deprivation, or injury as can be made the subject of calculation and of recompense in money. Source [The Law Dictionary](#).

<sup>12</sup> Sheikh, A. “[Confidentiality and Privacy of Patient Information and Records: A Need for Vigilance in Accessing, Storing and Discussing Patient Information](#)” (2010) 16(1) *Medico-legal Journal of Ireland* pp.2-6.

<sup>13</sup> *Ibid*, p.27.

A case brought before the [Office of the Information Commissioner](#) in 2003 involved an access request for medical records held by Cork University Hospital.<sup>14</sup> The request was placed by Mrs. X regarding her late brother who had passed away. In refusing the request the Irish Southern Health Board presented the following arguments:

- i. The doctor-patient relationship is inherently private and based on confidence;
- ii. It is reasonable to assume that a deceased's person's right to confidentiality remains after death;
- iii. If there is a public perception that records will be released after death it may deter patients from providing all the necessary medical information required;
- iv. Once records are released under FOI there are no restrictions on how they may be used.<sup>15</sup>

On appeal to the Information Commissioner, the applicant's rights were upheld and Mrs X was granted access to the medical records based on the following reasons:

- i. All of the deceased's siblings agree to the records being transferred to Mrs X;
- ii. The deceased had named one of his sibling's as his next of kin and personal carer in the hospital admission records, therefore indicating he trusted her in relation to matters concerning him;
- iii. The deceased had a strong relationship with all his siblings and they visited him regularly until he passed away;
- iv. There was nothing in the records that could be deemed as unusually sensitive;
- v. The deceased's GP approved of the release of the records to Mrs X.

It was also pointed out that while the Board argued that [section 28\(1\)](#) of the FOI Act 1997 applied, which allows for refusal to grant access where disclosure involves personal information of a deceased person; the Board failed to also refer to [section 28\(6\)](#) which permits the Minister to make regulations for the granting of a request where the person about whom the records relate is deceased and the requester is a specified person within the regulations.<sup>16</sup>

In 2009 [S.I. no. 387 of 2009](#) (the 2009 Regulations) updated section 28(6) of the 1997 FOI Act in relation to access to posthumous information. It sets out the three categories of persons who can make an access request in relation to a deceased person's medical records:

- 1) Personal representatives acting in the course of administration of the deceased's estate;
- 2) A person on whom a particular function has been conferred by law, either as a personal representative or a trustee; access will only be granted to such individuals insofar as they are performing the function specified;
- 3) Spouses and next of kin.

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<sup>14</sup> The Information Commissioner's Office carries out independent reviews of decisions taken by public bodies on Freedom of Information requests.

<sup>15</sup> The Irish Hospice Foundation, "[Ethical Framework for End of Life Care: Study Session 7: the Ethics of Confidentiality](#)" (2013)

<sup>16</sup> Information Commissioner, [Mrs X and the Southern Health Board Case 020561](#) (17 July 2003).



[Guidance Notes](#)<sup>17</sup> drawn up by the Minister for Finance,<sup>18</sup> pursuant to the 2009 regulations, provide further clarity on how the matter of public interest should be dealt with. It provides a list of considerations which the decision maker should have regard to:

- Confidentiality as set out in section 28(1) of the Act;
- Whether the deceased would have consented to the release of the records while they were alive;
- Is there any reference in their will indicating consent to the release of records;
- Would the release damage the good name of the deceased person;
- The nature of the relationship between the requester and the deceased person, particularly prior to death;
- The nature of the records to be released;
- Can the requester source the information they seek through another source?

In terms of retention and disclosure of documents proposed under the Bill, it must also be considered that some of the individuals who told their story to the Confidential Committee might now be deceased. **Reflecting on the obligations outlined above, consideration should therefore be given to how the disclosure would affect the family of the deceased in 75 years time and the effect it would have on the reputation and good name of the individual involved. Also, because the documents contain such sensitive information, scrutiny of other forms or methods for ensuring this chapter of history is not forgotten could be examined.**

## The Retention of Fingerprint data

In the UK [Chapter 1 of Part 1 of the Protection of Freedoms Act 2012](#) introduced a regime governing the destruction, retention and use of fingerprints, footwear impressions and DNA samples. The old regime was set out under [section 64 of the Police and Criminal Evidence Act 1984](#) (PACE 1984), and was subsequently repealed by the 2012 Act and replaced by sections [63D-63U](#). When PACE 1984 was originally enacted it did not make any specific provision for retention and use of biometric data in relation to persons convicted of an offence. It did, however, make provision for fingerprints and DNA samples, taken from persons who were not prosecuted, or prosecuted but acquitted, to have their data destroyed as soon as practicable.<sup>19</sup> A series of amendments made to PACE 1984<sup>20</sup> resulted in a position whereby the police can indefinitely retain fingerprints, footwear impressions and DNA samples, irrespective of whether the person is prosecuted or acquitted. The use of the data is confined to purposes related to the prevention and detection of crime, the investigation of a crime, the conduct of a prosecution or the identification of a deceased person. The wide power to take and retain such data of persons not charged or not convicted of any offence gave rise to considerable debate and was challenged by way of judicial

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<sup>17</sup> Minister for Finance, "[Guidance Note on: Access to records by parents/guardians. Access to records relating to deceased persons under section 28\(6\) of the Freedom of Information Act 1997](#)" (2009).

<sup>18</sup> The Minister for Finance in 2009 was Brian Lenihan.

<sup>19</sup> Section 64 PACE 1984, as originally enacted.

<sup>20</sup> Amendments were made by the following legislation: [Criminal Justice and Public Order Act 1994](#), [Criminal Justice and Police Act 2001](#), [Criminal Justice Act 2003](#) and [Serious Organised Crime and Police Act 2005](#).

review in 2002. In the case of [S v United Kingdom](#)<sup>21</sup> the applicant was a juvenile who had been arrested and charged with attempted robbery and was subsequently acquitted following trial. The applicant had fingerprint and DNA samples taken after arrest. Following acquittal, requests for the police to destroy the evidence taken was refused. The majority of the House of Lords determined that the retention and storage of fingerprints, DNA profiles and samples did not interfere with the appellant's right to private life and so Article 8(1) of the ECHR was not engaged. They added that retention could be justified under Article 8(2) as it was clearly directed towards a legitimate purpose and any interference with private life was modest. The policy of the police to retain the samples was lawful because it was aimed at the prevention and investigation of crime and the prosecution of offences. The case was appealed to the ECtHR. In that court's view:<sup>22</sup>

*"The mere retention and storing of personal data by public authorities, however obtained, are to be regarded as having direct impact on the private-life interest of an individual concerned, irrespective of whether subsequent use is made of the data."*

With regard to the retention of cellular samples in particular, the Court noted that the nature and amount of personal information contained in them must be regarded as an interference with the right to respect for private life. It was found that the law on retention therefore failed to strike a fair balance between competing public and private interests. According to Cape the case of [S v United Kingdom](#)<sup>23</sup> highlights how both the risk of stigmatisation and the importance of the presumption of innocence in relation to the retention of such material need to be justified by evidence that serves a legitimate purpose.<sup>24</sup>

For the purposes of the *Retention of Records Bill 2019*, it is worth considering if disclosure for the purpose of posterity could be equated with the standard set out in the above scenario, which is for the purpose of crime prevention and detection. In addition, while the disclosure will be legitimised through legislative provision, it would still need to strike a fair balance between public and private interests, which could pose difficulty, given the sensitive nature of the information provided and the unproven allegations of abuse detailed therein.<sup>25</sup>

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<sup>21</sup> (2009) 48 E.H.R.R. 50.

<sup>22</sup> *Ibid*, p.1169 at 121.

<sup>23</sup> (2009) 48 EHRR 50.

<sup>24</sup> Cape, E. (2013), "The Protection of Freedoms Act 2012: the retention and use of biometric data provisions" *Criminal Law Review* 23.

<sup>25</sup> The Commission to Inquire into Child Abuse contains the uncontested evidence of those who were resident in the institutions examined and reported being abused as children. The confidential committee report contains accounts on physical, sexual and emotional abuse, as well as neglect by religious and lay adults. In excess of 800 individuals were identified as carrying out physical and/or sexual abuse on the witnesses interviewed during their time in the institutions. Commission to Inquire into Child Abuse, [Report-Commission to Inquire into Child Abuse Executive Summary](#) (Stationary Office; Dublin, 2009).



## Academic and Journalistic Research

Examples of demands for disclosure on academic and journalistic research, which were gathered through guarantees of confidentiality, provide helpful comparatives. In the Boston College Tapes case, discussed below, we see how confidentiality around sensitive oral history data relating to the Northern Ireland Troubles was breached and the significant impacts this had for the researchers and their participants. It shows how contracts of confidentiality can be overridden by the law of the land and the 'chilling effect' this can potentially have for future research. It highlights the need for full disclosure around potential exemptions to confidentiality before the data is gathered.

### The "Boston College Tapes" Case

In 2001, researchers sponsored by Boston College began to compile an oral history of "The Troubles" in Northern Ireland. The research, entitled 'The Boston Project' hoped to gain insight into the thought processes of individuals who became personally involved in the conflict of the Troubles by compiling the testimonies of loyalists and republicans. The interviewee's participation was contingent upon a strict guarantee of confidentiality until after their death.<sup>26</sup> Ed Moloney, a journalist and writer, became the project's director and entered into a contract with Boston College which required him to ensure that the interviewers and interviewees signed and adhered to a strict confidentiality agreement. The agreement prohibited all participants from disclosing the existence and scope of the project without the permission of Boston College. The contract also mandated that the interviewers use a coding system when documenting their research to protect the anonymity of the participants.<sup>27</sup> Interviewees also signed 'donation agreements' which transferred possession and absolute title to their interview recordings and transcripts to Boston College upon their deaths. The following clause was contained in the donation agreement:<sup>28</sup>

*Access to the tapes and transcripts shall be restricted until after my death except in those cases where I have provided prior written approval for their use following consultation with the Burns Librarian, Boston College. Due to the sensitivity of the content, the ultimate power of release shall rest with me. After my death, the Burns Librarian of Boston College may exercise such power exclusively."*

However, that confidentiality was put in jeopardy when the US Attorney General served two sets of subpoenas on Boston College to supply them with the transcripts and tapes from some of the interviews, pursuant to a request from the UK government issued under a mutual legal assistance treaty (MLAT).<sup>29</sup> British police sought the interviews as part of investigations into alleged terrorist offences stretching back to 40 years ago.<sup>30</sup> The access request involved an International Letter of

<sup>26</sup> O'Doherty, M. "[Why our oral history isn't worth the paper it's written on if Boston College case succeeds](#)" *Belfast Telegraph*, 15 November 2017.

<sup>27</sup> Steffen, *supra* note 49, p.329.

<sup>28</sup> Steffen, *supra* note 49, p.330.

<sup>29</sup> Mutual legal assistance treaties allow for the state parties to exchange evidence and information about criminal matters

<sup>30</sup> Erwin, A., "[Attempt to access former IRA man's Boston College tapes 'replete with errors' court told](#)" *Irish Times* 16 January 2018.

Request (ILOR) setting out alleged offences being probed, including a bomb explosion at a rugby venue in Belfast in 1976 and membership of a proscribed organisation. Media reports indicate that, although the tapes were released and flown from America, they remain under seal within the court until the legal challenge is determined.<sup>31</sup> Boston College and the individuals involved in the project challenged the subpoena, asserting an academic privilege that would allow them to protect confidential information from compelled disclosure.<sup>32</sup>

In an article exploring academic privilege in the Boston College tapes case, Steffen argues that academic confidentiality agreements are essential for two reasons. Firstly, when individuals are encouraged to share their life experiences in a safe, academic environment, it enhances society's knowledge and awareness. Accordingly, if researchers cannot promise anonymity to their participants who need it, then participants will be hesitant to participate in studies and researchers will never be able to gather true and accurate information to disseminate to the public.<sup>33</sup> Secondly, the safety of researchers and their sources hinges on their ability to enter into and enforce confidentiality agreements. Steffen asserts that research participants put themselves at risk when they share experiences regarding controversial and dangerous topics.<sup>34</sup>

Commentary by Palys and Lowman on the Boston tapes case points out that Boston College's pledge of confidentiality to the researchers and participants only extended as far as American law allowed.<sup>35</sup> This meant that the donation agreements, which the participants signed at the start, misinformed them in a fundamental way about the scope of confidentiality they could expect. The donor agreement specified that no transcript or tape would be released until after the participant's death; however, following the subpoenas Boston College began to ship the data to the UK. Palys and Lowman identify that releasing the transcripts would not just jeopardise the safety of the participants but also, potentially, other living individuals who were identified in the material.<sup>36</sup> As a result, the authors argue that academic institutions are consequently placed in a position whereby they must choose between two approaches to confidentiality, the 'law of the land' approach and the 'ethics first' approach.<sup>37</sup>

*"The mistake that we made...was to surrender control of the product, to let a second party take possession of the tapes and transcripts. Once we did that we put ourselves at the mercy of people who did not share our concern for the wellbeing of the interviewees."*

The approach taken by Boston College, to prescribe to the law of the land, is described as a form of *caveat emptor* (principle of 'let the buyer beware') whereby it is ethically acceptable to disclose

<sup>31</sup> *Ibid.*

<sup>32</sup> Steffen, K.L., "[Learning from Our Mistakes: The Belfast Project Litigation and the Need for the Supreme Court to Recognize an Academic Privilege in the United States](#)" 2014 3(1) *Penn State Journal of Law and International Affairs*.

<sup>33</sup> Steffen, *supra* note 49, p.360.

<sup>34</sup> *Ibid.*

<sup>35</sup> Palys, T. & Lowman, J., "[Defending Research Confidentiality "To the extent the law allows"; Lessons from the Boston College Subpoenas](#)" 2012 (10) *J Acad Ethics*.

<sup>36</sup> *Ibid.*

<sup>37</sup> *Ibid.*

information to legal or other authorities as long as the participants are warned about the possibility. However, the issue in the present case is that the participants were not given such warning. At a symposium in 2012, Moloney (research lead) spoke of his regrets about the Boston Project protocol.<sup>38</sup>

*“If academic institutions are to honor their responsibilities to maintain confidentiality at least to the full extent permitted by law it is incumbent upon them to be aware of the relevant law and to be prepared to exhaust all legal avenues to defend research confidentiality. If these lawful attempts to defend research confidentiality fail, and the researcher is ordered to disclose confidential research information, then they would either have to comply (the Law of the Land position) or defy the order in order to maintain their ethical commitment to research-participant confidentiality (the ethics-first approach).”*

Information given to the Confidential Committee was done so under the guarantee of strict confidence. People who gave their stories and spoke of the abuse they suffered were never warned that the information could be disclosed in the future. This has the potential to undermine trust in future Commission of Investigation.

### Academic research and ethical considerations

The European Commission's Information Society Technologies (IST) Programme established and funded the RESPECT project which set up professional and ethical guidelines for the conduct of socio-economic research.<sup>39 40</sup> The project recognises that socio-economic research deals with human beings and therefore raises a range of ethical issues about the researcher's responsibility to:

- Society;
- Funders and employer;
- Colleagues; and,
- The human subjects of the research.

The project drew on existing professional and ethical codes together with current legal requirements in the EU to compile a voluntary [code of practice](#) for conducting socio-economic research in Europe. The code is based on three main principles:

1. Upholding scientific standards;
2. Compliance with the law, and;
3. Avoidance of social and personal harm.

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<sup>38</sup> Moloney, E., “[Problematic stories: Documenting conflict during a peace process](#)”. Paper presented at the International Culture Arts Network (ICAN) Symposium: Nine Tenths Under: Performing the Peace. Held in Belfast 22-24 March 2012.

<sup>39</sup> The IST is one of seven sectors of the European Union's Fifth Framework Program for Research and Technological Development for 1998-2002. It also continued under the Sixth Framework program. The IST program features four key actions, each focused on technologies, issues and objectives of strategic importance to Europe. The objective is to ensure that all European citizens and companies benefit from the opportunities of the emerging Information Society.

<sup>40</sup> See [RESPECT website](#) for further details.

The RESPECT code recommends that:<sup>41</sup>

*“In general, socio-economic researchers should comply with the laws of the country in which they are based or in which they are carrying out research...Researchers have a duty to ensure that their work complies with any relevant legislation. Two areas of law (data protection law and intellectual property law) are particularly relevant for the conduct of research, especially research involving human subjects, and researchers should acquaint themselves with the relevant national and international perspectives.”*

The purpose of the code is to protect researchers from unprofessional or unethical demands.<sup>42</sup> One of the overriding aims of research should be that its results benefit society by improving human knowledge and understanding. As a result, researchers should aim to minimise social harm to groups and individuals and should consider the consequences of participation in the research for all subjects and stakeholders.<sup>43</sup> No participants should be worse off as a result of their involvement in the research. One of the considerations outlined in the code is to ensure that research participants are protected from undue intrusions, distress, indignity, physical discomfort, personal embarrassment or psychological harm.<sup>44</sup>

The Digital Repository of Ireland (DRI)<sup>45</sup> subscribes to the RESPECT code of practice and recognises that under exceptional circumstances, professional research ethics can come into conflict with the law, especially where the law may compel disclosure.<sup>46</sup> The DRI therefore promotes compliance with the law of the land position but advocates for an ethics first approach for how research is conducted. In the case of demands or requests for disclosure of restricted data the DRI will seek to negotiate with the requesting body to agree an acceptable course of action, with particular consideration for protecting confidentiality of participants. If negotiation is not possible the DRI will consider applying to the appropriate court to protect the confidentiality of the data and the participants. If confidential, non-anonymised information must be released, the DRI will endeavour, as far as possible, to inform any person to whom a commitment of confidentiality has been made, prior to the data being released. Unless precluded from doing so by the court, the DRI will make the legal threat to confidentiality public.<sup>47</sup> The DRI will also provide advocacy to archival staff who adopt an ‘ethics first approach’ to consent, that is, they will support archivists who refuse to enable access to data which would be in contravention of a depositor’s wishes.<sup>48</sup> According to the DRI depositors must ensure that data generated through research with human subjects has been processed with due consideration for core ethical principles. The DRI will only ingest data

<sup>41</sup> RESPECT [Professional code for socio-economic research in the information society](#) (2004).

<sup>42</sup> *Ibid.*

<sup>43</sup> *Ibid.*

<sup>44</sup> *Ibid.*

<sup>45</sup> The [Digital Repository of Ireland](#) is a national digital repository for Ireland’s humanities, social sciences, and cultural heritage data.

<sup>46</sup> Digital Repository of Ireland, “[Restricted Data Policy](#)” (May 2015).

<sup>47</sup> *Ibid.*

<sup>48</sup> *Ibid.*

generated through research with human subjects where the participants have provided informed consent for sharing and re-use.<sup>49</sup> The DRI's data policy requires that the Organisational Manager and Depositors must not deposit un-anonymised data collected under consents which promise to protect confidentiality without recognising legal limitations on such promises of confidentiality.<sup>50</sup> Therefore, depositors should be aware, from the outset, that there is a risk of legally mandated disclosure attached to depositing data, even where that data was deposited as a restricted data set. Depositors should therefore ensure that the data is anonymised and any personal or organisational identifiers are removed or disguised before depositing the data.

### Journalistic privilege and the EU Courts

European case-law has shown that the European Court of Human Rights (ECtHR) interprets Article 10 of the [European Convention on Human Rights](#) (ECHR) (which protects the individual's right to express themselves), as protecting journalists from being compelled to disclose the identities of its sources.<sup>51</sup> In addition, the Committee of Ministers of the Council of Europe specifically declared Article 10 as protecting a journalist's right to maintain the confidentiality of its sources.<sup>52</sup> In [Goodwin v United Kingdom](#) the applicant, a trainee journalist with The Engineer magazine, received information regarding the financial status of a company. The information was given by telephone from a source that wished to remain anonymous and appeared to come from a confidential corporate plan. The company obtained orders preventing the applicant from disclosing the confidential information under [section 10](#) of the [Contempt of Court Act 1981](#); an order compelling the applicant to divulge the identity of his source. The applicant appealed unsuccessfully to the Court of Appeal and House of Lords. He refused to disclose his source and was fined £5,000 for contempt. The applicant appealed to the ECtHR, complaining of a violation under Article 10 of the ECHR. The ECtHR noted that compelling journalists to disclose the identity of their journalistic sources could have a 'chilling effect' on the free flow of communication between the media and the public.<sup>53</sup> It added that the important watchdog function served by the press could be undermined if journalists were unable to obtain accurate and reliable information from sources who wish to remain unnamed.<sup>54</sup> In order to assess the alleged violation the court considered three issues:<sup>55</sup>

<sup>49</sup> *Ibid.*

<sup>50</sup> *Ibid.*

<sup>51</sup> Article 10 provides:

"1. Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This Article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises.

2. The exercise of these freedoms, since it carries with it duties and responsibilities, may be subject to such formalities, conditions, restrictions or penalties as are prescribed by law and are necessary in a democratic society, in the interests of national security, territorial integrity or public safety, for the prevention of disorder or crime, for the protection of health or morals, for the protection of the reputation or rights of others, for preventing the disclosure of information received in confidence, or for maintaining the authority and impartiality of the judiciary."

<sup>52</sup> Council of Europe, "[The media in a democratic society. Political Declaration, Resolutions and Statement, 4th Ministerial Conference: Mass Media Policy](#)" Prague, 7-8 December 1994, MCM (94)20.

<sup>53</sup> (1996) 22 EHRR 123.

<sup>54</sup> *Ibid.*

1. Whether or not the government had a **lawful basis** in domestic law which prescribed for the interference. The court found that the publication of the confidential information was already prohibited by injunction, the order for disclosure of the source was not necessary, and thus in breach of Article 10;
2. If the court determines that there was adequate basis in domestic law, they must then consider if the interference pursued a **legitimate aim**. In response the court found that the company's legitimate reasons for wishing disclosure, namely to prevent further dissemination of the confidential information (other than by publication) and to take action against the source who was presumed to be an employee, were outweighed by the interest of a free press in a democratic society;
3. Finally, the court must consider if the **interference is necessary** in a democratic society. The court considered that if journalists are forced to reveal their sources the role of the press as public watchdog could be seriously undermined because of the 'chilling effect' that such disclosure would have on the free flow of information.

Applying these standards to *Retention of Records Bill 2019*, it is questionable if the interference with confidentiality, of sensitive information, could be justified as legitimate and necessary. This is because, firstly, the interference could be lessened by anonymising the material and secondly, the potential chilling effect for future Commissions could outweigh the benefits of releasing the information.

## Conclusion

The treatment of sensitive information in the context of the *Retention of Records Bill 2019* requires detailed consideration given the guarantees that were associated with its collection. The implications arising from the disclosure of uncontested material containing distressing narratives of neglect, emotional, sexual and physical abuse should also be given contemplation. The potential for a chilling effect on future Commissions of Investigation and the potential difficulties arising for the surviving family members of both victims of institutional abuse and those accused of carrying out the abuse (but who never had recourse to fair judicial procedure) are also important factors that should enter into the debate. There is also merit in the argument that this Bill denies citizens access to their own records under the Freedom of Information Acts. By doing so, those that relayed their stories of abuse are prevented from accessing information pertaining to themselves.

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<sup>55</sup> *Ibid.*





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