

Central Lancashire Online Knowledge (CLoK)

Title	Posthumous Medical Confidentiality; The Public Interest Conundrum
Type	Article
URL	https://clock.uclan.ac.uk/11263/
DOI	https://doi.org/10.1163/22134514-00102002
Date	2014
Citation	Choong, Kartina Aisha and Mifsud Bonnici, Jeanne Pia (2014) Posthumous Medical Confidentiality; The Public Interest Conundrum. <i>European Journal of Comparative Law and Governance</i> , 1 (2). pp. 106-119. ISSN 2213-4506
Creators	Choong, Kartina Aisha and Mifsud Bonnici, Jeanne Pia

It is advisable to refer to the publisher's version if you intend to cite from the work.
<https://doi.org/10.1163/22134514-00102002>

For information about Research at UCLan please go to <http://www.uclan.ac.uk/research/>

All outputs in CLoK are protected by Intellectual Property Rights law, including Copyright law. Copyright, IPR and Moral Rights for the works on this site are retained by the individual authors and/or other copyright owners. Terms and conditions for use of this material are defined in the <http://clock.uclan.ac.uk/policies/>

Posthumous Medical Confidentiality

The Public Interest Conundrum

Kartina Aisha Choong

Senior Lecturer in Medical Law & Ethics, University of Central Lancashire,
United Kingdom

k.a.choong@uclan.ac.uk

Jeanne Pia Mifsud Bonnici

Rosalind Franklin Fellow & Chair in European Technology Law and Human
Rights, University of Groningen, The Netherlands

g.p.mifsud.bonnici@rug.nl

Abstract

This paper reflects on the balancing of public interests that needs to be undertaken under English law when dealing with posthumous medical confidentiality. Until 2007, doctors were bound only by professional codes of ethics to maintain confidentiality after their patients' death. In 2008, the High Court stated that it is arguable that confidentiality applies in the post-mortem context. This, it claimed, is in the public interest. The court then followed the ECtHR in using the same basis – public interest – to accept that there may be exceptions to this duty. This paper considers different situations where multiple interests come together for and against the posthumous disclosure of medical information. This examination suggests that there is considerable uncertainty caused by using one notion of public interest to justify confidentiality, and another to make the case for disclosure. It calls for the legislator to intervene to help resolve the conundrum.

Keywords

medical confidentiality – deceased patients – privacy – public interests

1 Introduction

Medical confidentiality¹ is a timeless concept. From the Hippocratic Oath² in ancient times to the present day, the need for doctors to protect patient confidentiality has always been unequivocally expressed. The primary rationale for this obligation is health promotion.³ Without the assurance of confidentiality, it is believed that patients would be reluctant to seek medical treatment and/or be less frank when divulging personal and sensitive information relating to their health concerns.⁴ This would prevent a correct diagnosis from being made and from patients getting the appropriate treatment for their conditions.⁵ This could endanger not only the health of the patients themselves, but also that of the community in the case of transmissible diseases.⁶ Having disclosed candidly and fully, patients should be entitled to expect that the privacy of the divulged information is respected by the confidentiality afforded to it.⁷ The duty thereby helps establish the trust that is crucial for a successful doctor-patient relationship.⁸ It could also enhance autonomy by giving patients control over the use of their personal information.⁹ In view of all these, the obligation of medical confidentiality during the lifetime of the

-
- 1 That is, “the respecting of other people’s secrets (in the sense of information they do not wish to have further disclosed without their permission)” – see R. Gillon, *Philosophical Medical Ethics* (Chichester: John Wiley & Sons, 1994) 107.
 - 2 “Whatever I see or hear in the lives of my patients, whether in connection with my professional practice or not, which ought not to be spoken of outside, I will keep secret, as considering all such things to be private” – ‘Hippocratic Oath’ available at <http://www.nlm.nih.gov/hmd/greek/greek_oath.html> (retrieved 1 October 2013). It is nevertheless interesting to observe that the obligations of secrecy therein was motivated as much by the protection of trade secrets and the desire to control initiatives as it was with the patient’s interests – see I.E. Thompson, ‘The nature of confidentiality’, *Journal of Medical Ethics* 5 (1979) 57.
 - 3 C. Jones, ‘The utilitarian argument for medical confidentiality: a pilot study of patients’ views’, *Journal of Medical Ethics* 29 (2003) 348.
 - 4 P. Sankar, *et al.*, ‘Patient perspectives on medical confidentiality’, *Journal of General Internal Medicine* 18 (2003) 659.
 - 5 J. Carlisle, *et al.*, ‘Concerns over confidentiality may deter adolescents from consulting their doctors: a qualitative exploration’, *Journal of Medical Ethics* 32 (2006) 133.
 - 6 *Z v. Finland*, no. 220009/93 (1997) 25 EHRR 371, para. 95.
 - 7 H.E. Emson, ‘Confidentiality: a modified value’, *Journal of Medical Ethics* 14 (1988) 87.
 - 8 G. Niveau, *et al.*, ‘Medical confidentiality and the competent patient’, *Journal of Medical Ethics* 39 (11) (2013); G. Jenkins, *et al.*, ‘A qualitative study of women’s views on medical confidentiality’, *Journal of Medical Ethics* 31 (2005) 499.
 - 9 C. Jones, (n.3) 348.

patient has long enjoyed legal recognition in the UK.¹⁰ Statute¹¹ and case law have also affirmed that medical information is “obviously private”¹² and that there is a public interest in its protection.¹³ Failure on the part of a doctor to maintain patient confidentiality could amount to an interference with privacy as well as a breach of confidence.¹⁴

In contrast, the existence of and the basis for posthumous medical confidentiality have always been mired in uncertainty. Although professional codes of ethics have consistently expressed that the duty to protect confidentiality extends beyond death,¹⁵ these proclamations are not accompanied by explanations as to why it is important to maintain posthumous medical confidentiality. They therefore do not provide adequate instructions on the basis for, or the interests served by, the ethical duty.¹⁶ Further, the professional codes’ acceptance that the demise of a patient does not obliterate the obligation of medical secrecy¹⁷ was never augmented by concrete legal recognition and protection. In fact, it was only in 2008 that the High Court eventually pronounced in *Lewis v. Secretary of State for Health*¹⁸ that “it is arguable that the duty [of medical confidentiality] does survive the patient’s death.”¹⁹ However, whilst this decision acknowledges that the duty subsists primarily for the same public interest reason as during the patient’s lifetime, the Court did so only when considering whether to allow the disclosure of the medical

10 See e.g. *Coco v. A.N. Clark (Engineers) Ltd* [1969] RPC 41 at 4; *Stephens v. Avery* [1988] Ch 449 at 455.

11 See Directive 95/46/EC as implemented in the UK Data Protection Act 1998 (in particular section 2).

12 *Campbell v. MGN Ltd* [2004] UKHL 22; Article 8 European Convention on Human Rights.

13 *A-G v. Guardian Newspapers Ltd (No 2)* [1990] AC 109.

14 J. Herring, *Medical Law and Ethics* (Oxford: Oxford University Press, 2012) 224.

15 For example, the General Medical Council (GMC) reminds doctors that their “duty of confidence continues *after a patient has died*”. This was echoed by the British Medical Association (BMA) who advised their members that “the ethical obligation to respect a patient’s confidentiality *extends beyond death*”. The Royal College of Psychiatrists too declared that “[a]n individual’s *death does not terminate the duty of confidentiality* owed to the individual” – see GMC, ‘Confidentiality’ (2009) paragraph 70; BMA, ‘Confidentiality and disclosure of health information tool kit’ 49; Royal College of Psychiatrists, ‘Good psychiatric practice: confidentiality and information sharing’ (2010) 11.

16 J. Berg, ‘Grave secrets: legal and ethical analysis of postmortem confidentiality’, *Connecticut Law Review* (2001) 81 at 87.

17 C. Ploem, ‘Medical confidentiality after a patient’s death, with particular reference to The Netherlands’ *Medicine and Law* 20 (2001) 215.

18 [2008] EWHC 2196 (QB).

19 *Per* Foskett J. at para. 18.

records of deceased persons. Indeed, the court framed disclosure as a balancing of public interests, discussed with reference to the exceptional circumstances of the case. We find this juxtaposition of the “public interest” to both acknowledge the existence of a duty of confidentiality and to justify a need for disclosure, intriguing.

In this paper, we seek to consider the different situations where multiple interests come together for and against the disclosure of information provided by deceased patients during their lifetime under the safeguard of medical confidentiality. This is with the aim of ascertaining the implications of *Lewis* on posthumous confidentiality. To do this, Section Two of the work will briefly review the facts of and the decision in the case, noting in particular the exceptional circumstances involved. In the Third Section, the paper reflects on the nature of postmortem disclosure: should access be considered the rule or an exception? Here we compare the position of the European Court of Human Rights (ECtHR) and English law. The paper then discusses whether situations of antemortem disclosure of medical information based on public interest considerations can be extended to a postmortem scenario. This overview leads to the conclusion that the ruling in *Lewis* alone is not enough. It is time for the legislator to intervene. Even if multiple interests are involved when considering disclosure of medical information after death, the complexity of the situation should not discourage the legislator from identifying areas where disclosure of the medical information of a deceased person is desirable. Identifying which disclosures are in the public interest (even if “public interest” is narrowly defined to refer to persons sharing part of the genetic pool of the deceased) *a priori* allows for better legal certainty and is less dependent on a case-by-case weighing of interests.

2 Lewis v. Secretary of State for Health

Although *Lewis v. Secretary of State for Health* was only heard before the High Court, its significance should not be underestimated. The case represents the first ever judicial pronouncement on the need to maintain posthumous medical confidentiality in the UK. Up till then, the closest available authority on the matter was the Information Commissioner’s Office (ICO)’s Information Tribunal’s decision in *Bluck v. Information Commissioner and Epsom and St Helier University NHS Trust*,²⁰ which ruled that the duty of confidence owed by doctors to their patients continues even after the patient has died.

²⁰ EA/2006/0090.

Importantly, the court also agreed with the Tribunal's ruling that posthumous medical confidentiality was a matter in the public interest.

However, it is important to highlight that the pronouncement came about in circumstances where it was actually access to the medical information of deceased patients that was sought. The court therefore had to work backwards and decide beforehand whether such information was subject to a duty of confidentiality. More importantly is the fact that the request for disclosure was made by a public Inquiry co-sponsored by The Secretary of State for Business, Enterprise and Regulatory Reform and The Secretary of State for Health. It therefore had State backing, rather than a request for disclosure made by private individuals. The Inquiry in question was known as *The Redfern Inquiry into Human Tissue Analysis in UK Nuclear Facilities*.²¹ It was set up in 2007 to investigate complaints made by the family members of a number of individuals whose organs/tissues had been removed at NHS (National Health Service) or other facilities without their surviving relatives' knowledge nor consent, and sent to nuclear laboratory facilities for analysis. Those individuals, who died between 1962–1991, had worked in the nuclear industry and the analysis had aimed to determine the radionuclide content of the organs/tissues. In order to investigate the complaints made by their relatives, and make the necessary recommendations to the government, the Inquiry had sought access to the medical records and other relevant documents relating to those individuals.

The custodian of those records and documents, Dr Nicholas Lewis, was willing to comply with the Inquiry's request for information. However, he had been concerned that this might render him and his colleagues in breach of their duty of confidentiality to those individuals. He therefore sought, by bringing this case, the authority of the court to disclose the requested information. It was in determining the lawfulness of this proposed action that the court made the pronouncement that the duty of confidentiality and non-disclosure arguably prevails after death. It then engaged in a weighing exercise to establish whether "the public interest in disclosure of the material sought outweighs the other public interest, namely, that of maintaining the confidentiality of medical records and information".²² In reaching its conclusion to allow for disclosure, the court identified three distinct sets of "public interest". One, that those families are entitled to know "the truth". Next, that it is important to maintain public confidence in the NHS and the nuclear industry either through the findings or the recommendations that would be made if past practices are found to be deficient. Thirdly, the fact that the Inquiry was co-sponsored by

21 Hereinafter referred to as 'The Inquiry'.

22 Para. 58.

two Secretaries of State, which are answerable to Parliament is, according to the High Court, “compelling evidence of the public interest in enabling The Inquiry to have the fullest facilities to carry out its functions”,²³

By framing disclosure as a balancing of public interests, it would appear that access was allowed in *Lewis* in view of the exceptional circumstances of the case. However, would and should disclosure be possible in less exceptional circumstances? If so, how should the balancing exercise be undertaken? These will be looked at next.

3 Balancing the Public Interests

3.1 *Disclosure: Rule or Exception?*

Living in an era where access to information is made easy by the internet, we are used to accessing all forms of information, including (at times very) personal details about ourselves, our loved ones and/or our enemies. It is often said that the internet, and access to information in particular, are important blocks in the building of or the strengthening of democratic societies.²⁴ It is, following the reasoning of the ECtHR, imperative in the public interest for citizens to have access to information (and the right's corollary, the right to freedom of expression). Against this background, any exception to openness and accessibility should be treated as an exception rather than a rule even if the content of that personal information relates to the medical condition of a deceased person.

Indeed in *Plon (Société) v. France*,²⁵ the case concerning the prohibition of the distribution of "Le Grand Secret", the book written by Dr Claude Gubler about President Mitterrand and his cancer diagnosis and treatment, the ECtHR ultimately found that the ban imposed by the French courts nine months after the publication of the book (even if it related to medical information obtained in confidence by the personal physician of the former President) was a violation of Article 10 of the European Convention on Human Rights (ECHR). The reasoning of the Court revolved around whether the request from Mitterrand's widow and children to ban publication of the medical information of the deceased met a pressing social need. The exception to openness and accessibility of information therefore needs to be based on a “pressing

²³ Para. 59.

²⁴ J.M. Balkin, 'Digital Speech and Democratic Culture: A Theory of Freedom of Expression for the Information Society', *New York University Law Review* 79(1) (2004).

²⁵ Application no. 56148/00 of 18 May 2004.

social need". What tipped the balance in favour of openness in this case, were primarily two key points: the information related to a prominent public figure of national importance; and the practical reality that the book, in spite of the interim injunction, had gone viral on the internet and had by then also led to more than 40,000 print copies to be sold at a time when the ban was still in place.²⁶ These two considerations, which represent the public interest in the debate concerning his tenure as the President of France, was said to have outweighed any argument of "pressing social need" by the family to keep the information confidential and out of the public domain. It seems clear from this judgement that the legal protection afforded to medical confidentiality after death is primarily a matter of a balancing of public interests.

This juxtaposition and weighing of two competing public interests was the same approach that was adopted in *Lewis*. This strongly suggests that the High Court had been influenced and inspired by the ECtHR. However, even long before *Lewis* declared that the duty of medical confidentiality survives the patient's death, English Law has not been known to share the ECtHR's ethos of openness and accessibility to medical information relating to deceased patients. In fact, it has taken a predominantly contrary stance: openness (or disclosure) is an exception and not the rule. This is borne out by the fact that despite the existence of two statutes through which access to the health records of deceased patients could be sought, both have determined very limited possibilities of access.²⁷ The Access to Health Records Act 1988, for instance, only allows access to a personal representative or those who may have a claim arising out of the deceased person's death.²⁸ Meanwhile, the Freedom of Information Act 2000, which recognises the right to access any information held by the government or public authorities, provides for exemptions to information that is obtained by those bodies in confidence, which includes most information held in health records. Given this background, it was not surprising that *Lewis* ruled that the duty of confidentiality continues beyond death. It was making explicit what English law has, hitherto, alluded to.

But all this also indicates that the weighing of public interests in the paradigm espoused by the ECtHR takes place in a climate of openness and

26 D. Voorhoof, 'European Court of Human Rights Case of Plon v. France', Case note IRIS 2004–10:3/3, available at <<http://merlin.obs.coe.int/iris/2004/10/article3.en.html>> (retrieved on 15 October 2013).

27 For further discussion, see J.P. Mifsud Bonnici and K.A. Choong, 'Access to the Health Records of Deceased Patients: Why the Law is in Need of Review', *Computer and Security Law Review* 25 (2009) 155.

28 Section 3(1)(f).

accessibility. Whereas, the one adopted in English law might have erred on the side of caution and restraint. Early indications of this can be gleaned from the two judgments themselves. The ECtHR, allowing disclosure a mere nine months after President Mitterrand's death, opined that "the more remote the date of the President's death, the more [the pressing social need for confidentiality] decline in importance and the more the public interest in the debate concerning his two seven-year terms of office outweighed the imperative of protecting ... medical secrecy".²⁹ Foskett J., in the High Court, stated in contrasting terms that "I would not regard...the passage of time generally in a matter of this nature, as eradicating or diminishing significantly the strength of the obligation of confidentiality."³⁰ Admittedly, neither the information to be disclosed nor the stature of the patients in the two cases are similar. However, the conflicting tones may signal that the balancing of public interests under English law may not always easily result in disclosure.

3.2 *The Public Interest in Postmortem Disclosure*

In addition, compared to the existence of numerous well-established cases, and legislative provisions and professional guidelines offering guidance to doctors on the public interests that could outweigh the need to protect antemortem confidentiality, there is relatively little guidance in the case of postmortem confidentiality. But are there similarly persuasive reasons for recognising exceptions in the case of deceased patients? If so, how can these be facilitated without having to wait for a body of case law, legislative provisions and professional guidelines to build up over the years?

For living patients, disclosure of confidential medical information is now accepted and allowed under English law in various circumstances. Apart from when the patients themselves have explicitly³¹ or implicitly³² consented to the divulgence, it is also accepted as justifiable in situations where identifiable individuals or the public can be protected from crime,³³

29 Para. H14.

30 Para. 30.

31 *Hunter v. Mann* [1974] QB 767, per Boreham J. at 772.

32 E.g. those taken care of in modern NHS hospitals are considered to have impliedly consented to the disclosure of their medical information to all health care professionals who need to be involved in their care – see H.E. Emson, 'Confidentiality: a modified value' *Journal of Medical Ethics* 14 (1988) 87.

33 These include risks of murder, manslaughter, rape, kidnapping, domestic violence, child abuse, terrorism, road traffic offences, gun crime and knife crime – see *W v. Egdell* [1990] 1 All ER 835; section 19 of the Terrorism Act 2000; section 172 of the Road Traffic Act 1988;

and communicable³⁴ or hereditary diseases,³⁵ and where the information could facilitate statistical³⁶ and research purposes.³⁷ In those cases, it is assumed that the public interest served by keeping medical information confidential is outweighed by the public interest served by the release of the information.

Returning to deceased patients, the issue that inevitably surfaces following *Lewis'* confirmation of the duty of posthumous confidentiality is whether there should be similar exceptions in the postmortem context i.e. those beyond the exceptional circumstances identified in the case. The literature indicates that there may be a number of circumstances when this may take place. One would be when the patients themselves have consented to the posthumous use of their medical information during their lifetime.³⁸ In such cases, it has been argued that there is a need to attach moral weight to their wishes and preferences

GMC Confidentiality 2009; and GMC, 'Confidentiality: Reporting Gunshot and Knife Wounds (Supplementary Guidance)' (2009) paras. 3a and 5.

- 34 See the Health Protection (Notification) Regulations 2010 (SI 2010/659, Regulation 2) which enumerate several medical conditions (e.g. acute meningitis, anthrax, cholera, diphtheria, food poisoning, measles, typhus and whooping cough) as notifiable diseases. A doctor who treats any patient whom he reasonably suspects is suffering from any of those conditions would be under an obligation to notify the appropriate government authority. This is to enable measures to be taken to prevent those diseases from spreading. Also, although HIV/AIDS is not included within the list of notifiable diseases, doctors are informed that they may disclose to a known sexual contact of a patient who suffers from HIV/AIDS if they have reason to believe that those individuals are at risk of infection and that the patient has not apprised them and cannot be persuaded to do so – see GMC, 'Confidentiality: Disclosing Information About Serious Communicable Diseases (Supplementary Guidance)' (2009), paragraph 10.
- 35 As regards genetic information, doctors have been advised that where consent to reveal the information has been refused by the patient, they are nevertheless justified in releasing the information where the benefit to the recipient is so substantial as to outweigh any distress caused to the patient. Not only that, they are also requested to provide the necessary information on how those relatives can seek a genetics referral for themselves – see e.g. Royal College of Physicians, 'Consent and confidentiality in genetic practice' (2006), paragraph 2.5.3; NHS National Genetics Education and Development Centre, 'Genetic information: consent and confidentiality issues' (2012), paragraph 4.
- 36 For instance, the Abortion Regulations 1991 (SI 1991/499, Regulation 4) requires that the NHS number, date of birth and full postcode of women who underwent termination of pregnancies under the Abortion Act 1967 to be supplied to the Chief Medical Officer.
- 37 E.g. section 251(1) of the National Health Service Act 2006.
- 38 P. van der Hart-Zwart, 'Does the regulation of medical research in the Netherlands adequately protect privacy rights after death?' (2012) 22(4) *TGE Jaargang* 114.

as this demonstrates respect to living persons.³⁹ To do otherwise is to believe and act as if the patient's aspirations, plans and preferences left no moral traces after their death. This, in other words, would merely be an extension of an already accepted practice in relation to matters like the honouring of wills or known wishes relating to the donation of organs or one's body for research.

However, it is a known fact that the vast majority of people do not make explicit decisions about the postmortem use of their medical information for research or other purposes.⁴⁰ At the same time, there could be compelling reasons for favouring access to the information held in their health records. One of the strongest claims relates to genetic information. As highlighted above, disclosure relating to hereditary diseases has been deemed justifiable during a patient's lifetime. If an individual dies of a genetic condition and his relatives thereafter sought access to his medical records, commentators have argued that the relevant information should similarly be disclosed after death where the relatives stood a substantially high risk of developing a serious and otherwise undetected genetic disorder which is preventable or treatable, and where the harm of non-disclosure outweighs the harm from disclosure.⁴¹ Even the NHS has recognised the significance of such disclosure when it specified that the "medical record departments of healthcare facilities should help in accessing medical information about a deceased person if it would help in determining the risk of an individual seeking genetic advice".⁴² In addition to medical conditions that are transmitted vertically through succeeding generations, are contagious diseases that are communicated horizontally to others through some form of contact.⁴³ Since the duty of posthumous confidentiality conflicts with the interests of others either to be protected from harm or to ensure that they are aware of the need to seek medical care, it has been similarly argued that this justifies breaching confidentiality.⁴⁴

39 M.R. Wicclair, 'Ethics and research with deceased patients', *Cambridge Quarterly of Healthcare Ethics* 17 (2008) 87 at 89–90.

40 *Ibid.*, at 89.

41 A.M. Lucassen, *et. al.*, 'Role of next of kin in accessing health records of deceased relatives', *British Medical Journal* 328 (2004) 952 at 953; B.M. Knoppers, 'Professional disclosure of familial genetic information', *American Journal of Human Genetics* 62 (1998) 474 at 474–475; J.L. Gold, 'To warn or not to warn? Genetic information, families, and physician liability' *McGill Journal of Medicine* 8 (2004) 72.

42 NHS National Genetics Education and Development Centre, 'Genetic information: consent and confidentiality issues' (2012), para. 7.

43 B.M. Knoppers, (n.41) 474.

44 K. van Bogaert and G.A. Ogunbanjo, 'Human immunodeficiency virus: confidentiality and disclosure of information to third parties', *South Africa Family Practice* 53(6) (2011) 615 at 616.

Disclosure could also benefit the public in general. To start with, the legislature has already, through the Health Protection (Notification) Regulations 2010, made it compulsory for doctors to notify the relevant government authority where there is reasonable suspicion that the patients they treated died whilst infected: with a notifiable disease or a disease which in their view could have posed significant harm to human health.⁴⁵ The release of this information is to enable the relevant authority to prevent the spread of the disease.

Further, as demonstrated in *Lewis* itself, release of confidential medical information is important to facilitate the smooth running of a public investigation. It is in the interests of a democratic society, for investigations such as the one in this case, to be able to bring into the open (questionable) practices of public bodies, even if in doing so the medical information of individuals may need to be disclosed to the authority or Inquiry team entrusted by statute or sponsored by Secretaries of State which are answerable to Parliament.

In addition to such investigations and research into recent or ongoing events, researchers may also need access to information when investigating incidents that happened in the distant past. In such circumstances, it has been argued that access should be allowed when individual identifiers are removed.⁴⁶ This is in order to uphold society's interest in knowing historical data.⁴⁷

The above considerations would nevertheless have to be balanced against the public interest served by postmortem confidentiality. These include the inherent value of privacy whereupon posthumous confidentiality is expected to function as a means by which the former interests of the deceased in controlling his personal health information are respected.⁴⁸ The protection offered by the duty is particularly valuable at this stage since the patient is no longer available to consent to the disclosure or to defend his or her reputation.⁴⁹ Further, since it would also assure current and future patients that the information which they divulge to their doctors will not be disclosed after death, this would serve to strengthen the institution of confidentiality as well as public trust in doctors.⁵⁰ This is because, knowledge on the part of the living that their health records could be accessed after their death, could affect their behaviour and candour in the doctor-patient relationship. This could in turn

45 Regulation 3.

46 R.D. Strous, 'To protect or to publish: confidentiality and the fate of the mentally ill victims of Nazi euthanasia', *Journal of Medical Ethics* 35 (2009) 361 at 363–364.

47 *Ibid.*

48 A.H. Maixner and K. Morin, 'Confidentiality of health information postmortem', *Archives of Pathology and Laboratory Medicine* 125 (2001) 1189 at 1190.

49 J. Berg, (n.16) 93.

50 A.H. Maixner and K. Morin, (n.48) 1190.

result in suboptimal care being received⁵¹ and at worst, they might not even seek medical treatment.⁵²

Even where a decedent had given consent during his lifetime, the disclosure could potentially harm the decedent's image and reputation in public,⁵³ with the further possibility of distorting the memory of the person as held by his family members. The disclosure could also give rise to potential privacy concerns on the part of all survivors within the radius of interest of the deceased.⁵⁴ After all, information about oneself is often intertwined with those close to them. The release of genetic information to the few who requested for them could potentially reveal the propensity of others within the same family to develop a particular inheritable condition. This could lead to psychological, social and/or financial harm as well as stigmatization, embarrassment and/or discrimination which could affect their employability and ability to take out health or life insurance.⁵⁵ Divulgence could also reveal a host of family secrets like sexual, physical and emotional abuses and neglect that may have taken place. This could compromise the protection of family members and others who have in the past volunteered the information to the decedent's doctor.⁵⁶

All this signifies that the balancing of public interests in the case of deceased patients is far more complex than that for living patients. Yet in spite of the complexity, there is little or no guidance from the legislator on either situations that automatically warrant disclosure or on criteria that can be used when considering whether the information (other than in "automatic" situations) may be disclosed. The exercise of weighing public interests is often a task reserved to Courts and Tribunals. Public authorities or medical practitioners asked to disclose the medical information of deceased persons have little guidance by which to act. As in the *Lewis* case, the decision to disclose or conceal is referred to the Court to decide and guide. At other times, a negative response to disclosure is taken and the person(s) requesting information appeals this decision to the relevant Tribunal or Court (as in *Bluck*). The result of this state of affairs is that there is little legal certainty in this field.

51 D.J. Robinson and D. O'Neill, 'Access to health care records after death: balancing confidentiality with appropriate disclosure', *Journal of the American Medical Association* 297(6) (2007) 634.

52 K. van Bogaert and G.A. Ogunbanjo, (n.44) 616.

53 M.R. Wicclair, (n.39) 94–95.

54 Ibid.; M.H. Kottow, 'Medical confidentiality: an intransigent absolute obligation', *Journal of Medical Ethics* 12 (1986) 117 at 119.

55 D.S. James and S. Leadbetter, 'Confidentiality, death and the doctor', *Journal of Clinical Pathology* 49 (1996) 1 at 2.

56 D.J. Robinson and D. O'Neill, (n.51) 634.

Thus while the confirmation in *Lewis* that medical confidentiality continues even after death has provided some clarity, it is time for more legal precision, ideally from the legislator.⁵⁷ We are conscious that neither all the doubts surrounding disclosure nor all the conditions that need to be taken into consideration while weighing interests can be fully eliminated by law. However, by taking clear legislative steps in some areas, the legislator can remove the tensions that surround requests for disclosure. For example, they may decide that requests for disclosure of medical information (e.g. those connected to genetically inherited medical conditions) can be made where the requesting person satisfies a certain set of conditions (e.g. that he/she is genetically related to the deceased etc). Legislation should clearly outline the circumstances in which disclosure of confidential medical information is acceptable. It should also clarify who can gain access or to whom should the disclosure be made; how much information they are able to access; and whether there should be a time lapse after the patient's death and if so, how long should it be after the death of the patient before access is allowed. It should also be able to balance the need for disclosure with the well-being of surviving relatives.

4 Conclusion

This paper is inspired by the *Lewis* case, where the Court in the UK recognised, for the first time, that medical confidentiality survives death and in the same breath recognised an exception to the duty. This suggests that medical confidentiality after death is primarily a matter of balancing public interests. Aware that the situation in *Lewis* is exceptional, the paper considers other situations where multiple interests come together for and against the disclosure of information previously released under the protection of medical confidentiality by a now deceased person.

Analysis of the different situations and conflicting interests involved show that there is an evident need for clarification, ideally through the statutory route. This would help bypass the need to wait for a body of case law to build up over time before clarity and certainty of when disclosure would be successful is eventually attained. In essence, what is being argued in this paper is that the practice of Courts (including the ECtHR) using the notion of public interest – to accept that there may be exceptions to the duty of confidentiality

57 M. Donnelly and M. McDonagh, 'Keeping the secrets of the dead? An evaluation of the statutory framework for access to information about deceased persons' *Legal Studies* 31(1) (2010) 42 at 68.

after death – cannot remain solely the responsibility of Courts. It is time for the legislator to inject clarity: identifying and spelling out situations where disclosure can be either a *sine qua non* or conditional to the requirements they identified. The argument here is that the legislator is (at least theoretically) better placed, and democratically entrusted, to identify the public interest or interest(s) that the State would like to protect.

The complexity of this task – of spelling out the public interest(s) – should not discourage the legislator. It is, one can argue, their responsibility not to shun from hard questions.⁵⁸ Of course, they do not need to act alone in this process of identifying areas where disclosure of the medical information of a deceased person is desirable. They can, and indeed should, involve stakeholders, lawyers, ethicists and academia to examine the issues and identify which disclosures are in the public interest (even if “public interest” is narrowly defined to refer to persons sharing part of the deceased’s genetic pool). Ultimately, having better legal certainty and being less dependent on a case-by-case weighing of interests, should outweigh the difficulties in addressing the complex ethical, social and legal realities surrounding the disclosure of medical information after death.

58 R. Dworkin, ‘Hard Cases’ *Harvard Law Review* 88(6) (1975) 1057.