JOURNAL OF TRAFFICKING AND HUMAN EXPLOITATION; VOL. 1, NR. 2, 143-160, PARIS LEGAL PUBLISHERS

Mine, Yours, Ours? Autonomy and the Removal and Use of Organs and Tissues before the European Court in *Petrova* v. *Latvia* and *Elberte* v. *Latvia*

Sara Fovargue

Lindsey Claire Hogg*

1. Introduction

Concern over the removal of organs and tissues for transplantation or other purposes, is nothing new, and in the United Kingdom this issue was brought dramatically into the spotlight towards the end of the 1990s and at the start of the 2000s when it was revealed that, following surgery, children's hearts were being retained at Bristol Royal Infirmary without the knowledge and/or consent of their parents. In the subsequent inquiry, it was discovered that similar practices were occurring at Alder Hey Children's Hospital in Liverpool, and in other hospitals throughout the country.[1] At that time, it was not generally known that organs and tissues were retained after a post-mortem for research, teaching, diagnostic or other purposes (and in some cases nothing at all was done with or to them). Many families were outraged and distraught to learn that their consent to post-mortem had been deemed to also be consent to the long-term retention of organs and tissues, and that they had unknowingly buried or cremated 'incomplete' bodies. Understandably, the organ retention scandal received much press and academic attention,[2] and it, ultimately, resulted in new legislation,[3] designed (in part) to ensure that the same could never

* DOI 10.7590/245227717X15090911046539 2452-2775 2017 Journal of Trafficking and Human Exploitation
Sara Fovargue is Reader in Law, Law School, Lancaster University, UK.
Lindsey Claire Hogg is a Ph.D. candidate, Law School, Lancaster University, UK.

1 Bristol Royal Infirmary Inquiry, The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol (Cm 5207(I), 2001).

2 BBC News, 'Organ Scandal Background', news.bbc.co.uk/1/hi/1136723.stm, 29 January 2001; S. Boseley, '50,000 Organs Secretly Stored in Hospitals', www.theguardian.com/society/2001/jan/11/hospitals.health, 11 January 2001; C Hall, N Bunyan & S O'Neill, 'Scandal of the Organ Hoards', www.telegraph.co.uk/news/uknews/1320389/Scandal-of-the-organ-hoards.html, 31 January 2001. Note that it was recently reported that organs retained since the 1990s had been discovered in a North East hospital: ITV News, 'Investigation after families not told about stored organs at North East hospital', www.itv.com/news/tyne-tees/2017-04-10/investigation-after-families-not-told-about-stored-organs-at-north-east-hospital/, 10 April 2017.

3 Human Tissue Act 2004.

happen again via the introduction of an 'appropriate consent' regime to organ and tissue removal and use.[4]

With this background in mind we consider the decisions of the European Court of Human Rights (ECtHR) in two cases heard within six months of each other, both regarding provisions of Latvian legislation concerning when organs and tissues can be removed from a deceased person for transplantation purposes: *Petrova* v. *Latvia* and *Elberte* v. *Latvia*.[5] In the light of Judge Wojtyczek's concurring comment in *Petrova* that while the rights of the potential donor and their closest relatives are 'closely related', 'this entire question deserve[s] deeper consideration, but (...) [that], the different rights at stake and their nature were not properly identified in the judgment',[6] we consider what these cases tell us about how the ECtHR views autonomy in the context of organ and tissue removal and use. We are particularly interested in whether domestic and European law has, should, or is adopting relational autonomy in organ and tissue removal and donation, or whether, as Dove and colleagues contend, the decisions in these cases suggest that the ECtHR has moved towards 'an "autonomy of relations"' approach instead.[7]

We first explain our understanding of relational autonomy and autonomy of relations, before outlining the facts and arguments in the cases and summarising the ECtHR's decisions. We then consider the relevant Latvian law at the time of the cases and the law on organ and tissue removal and use in England as a comparator, and examine which approach(es) to autonomy can be identified in those provisions. We do this because the decisions in *Petrova* and *Elberte* have made us think more broadly about how and where families should fit into the organ and tissue removal and donation decision-making process, if at all.

2. Relational Autonomy

Autonomy is traditionally defined as self-determination and the right to govern bodily integrity, and involves an individual taking control of and deciding what happens to her own body and when. As Tom Beauchamp and James Childress suggest, '[t]o respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their

4 For discussion of this Act see, for example, M. Brazier & S. Fovargue, 'A Brief Guide to the Human Tissue Act 2004', *Clinical Ethics* 1 (2006): 26; D. Price, 'The Human Tissue Act 2004', *Modern Law Review* 68 (2005): 798.

5 Application no. 4605/05, 24 June 2014; Application no. 61243/08, 13 January 2015.

6 *Petrova*, para. 3, Concurring Opinion of Judge Wojtyczek.

7 E.S. Dove et al., '*Elberte* v. *Latvia*: Whose Tissue Is It Anyway – Relational Autonomy or the Autonomy of Relations?', *Medical Law International* 15 (2015): 79.

values and beliefs'.[8] For some, autonomy is the pre-eminent ethical principle in the doctor-patient relationship,[9] for others it is only part of the story.[10] Autonomy is traditionally interpreted as focusing on and concerning the individual, an interpretation which some proponents of feminist ethics and care ethics have sought to challenge because, as Susan Wolf argues, '[b]y depicting the moral community as a set of atomistic and self-serving individuals, [liberal individualism] strips away relationships that are morally central'.[11] Indeed, Jennifer Nedelsky proposes that autonomy is understood as a concept made possible *by relationships*, rather than as individuals being independent from others.[12] For her, relationships are key to an individual's life, and we are all 'constituted by networks of relationships of which [we] are a part', be they intimate relationships with partners, distant relationships with employers, or social structural relationships such as with the government.[13] The individual is determined by 'the relationships through which each person interacts with others',[14] subsequently the 'self' is relational.[15] Although these relationships are significant, they do not result in a self wholly determined by them,[16] because if the relationship determined who a person is or what he or she does or becomes then there would be no true autonomy.[17] Thus, we define ourselves *in* relationship to others and *through* relationships with others,[18] and in relational autonomy 'the focus should be on the responsibilities that flow from our relationships with others' rather than on treating us as individuals with rights and interests which conflict with others.[19]

We see relational autonomy as involving recognition and acceptance of the fact that most people do not make decisions as 'freestanding',[20] isolated beings, but are 'socially, culturally and embedded individual[s]' who 'exercise self-deter-

8 T. Beauchamp & J. Childress, *Principles of Biomedical Ethics*, 7th ed. (Oxford: OUP, 2013), 106.
9 R. Gillon, 'Ethics Needs Principles – Four Can Encompass the Rest – and Respect for Autonomy Should Be "First among Equals"', *Journal of Medical Ethics* 29 (2003): 307.
10 A. Dawson & E. Gerrard, 'In Defence of Moral Imperialism: Four Equal and Universal Prima Facie Principles', *Journal of Medical Ethics* 32 (2010): 200.
11 S.M. Wolf, 'Introduction: Gender and Feminism in Bioethics', in *Feminism and Bioethics*, ed. S. Wolf (Oxford: OUP, 1996), 16.
12 J. Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford: OUP, 2011), 5.
13 Ibid., 19.
14 Ibid., 3.
15 Ibid., 4.
16 J. Downie & J. Llewellyn, *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver: UBC Press, 2012), 5.
17 Nedelsky, *supra* note 12, 31.
18 C. Whitbeck, 'A Different Reality: Feminist Ontology' in *Women, Knowledge, and Reality: Explorations in Feminist Philosophy*, ed. A. Garry, & M. Pearsall (Boston: Unwin Hyman, 1989), 68.
19 J. Herring, *Medical Law and Ethics*, 6th ed. (Oxford: OUP, 2016), 36.
20 Nedelsky, *supra* note 12, 19.

mination in and through networks of relations with others'.[21] Indeed, 'in any decision, there is more than the decision maker's autonomy at stake'.[22] With relational autonomy, X is understood to be situated within a network of relationships, which may (knowingly or not) influence or affect her decisions, but they remain decisions for X to make. This is different to an 'autonomy of relations' approach where it is the autonomy of those *related to* X which is directly engaged, rather than that of X herself. These relatives will thus make decisions because it is *their* autonomy and not X's which is involved in the relevant context. Relational autonomy does not require a specific mode of consent and so, depending on the provisions, can be accommodated within informed consent or presumed consent organ donation systems.

Of particular interest to us, is Nedelsky's desire for 'a relational habit of thought (...) in policy making, and in legal interpretation', and her suggestion that '[a] relational analysis provides a better framework for identifying what is really at stake in difficult cases and for making judgments about the competing interpretations of rights involved'.[23] We seek to explore this here.[24]

3. *Petrova* and *Elberte*

3.1. The Facts

In both cases under consideration, the deceased were involved in accidents, subsequently died, and their organs and/or tissues were removed for transplantation purposes. We consider *Petrova* first as it was heard by the ECtHR before *Elberte*.

In *Petrova*, Mr Petrovs (the applicant's son) sustained serious injuries in a car accident on 26 May 2002, and had surgery at Riga's First Hospital. His condition remained 'very serious' following the operation and he did not regain consciousness.[25] Three days after the accident, at 1.20am, he was pronounced dead. Prior to this, at 11.50pm on 28 May, the transplantation centre at another hospital was contacted and informed that Riga's First Hospital had 'a potential

---

21 Dove et al., *supra* note 7, 80.

22 A. Wardrope, 'Liberal Individualism, Relational Autonomy, and the Social Dimension of Respect' *International Journal of Feminist Approaches to Bioethics* 8 (2015): 45.

23 Nedelsky, *supra* note 12, 4.

24 There are alternative conceptions of relational autonomy: see, for example, S. Sherwin, 'Relational Autonomy and Global Threats' in ed. J. Downie & J. Llewellyn, 13. There are criticisms of the approach too: see, for example, J. Christman, 'Relational Autonomy Liberal Individualism and the Social Constitution of Selves', *Philosophical Studies* 117 (2004): 143; C. MacKinnon, *Feminism Unmodified* (Harvard: HUP, 1987).

25 *Petrova*, *supra* note 5, para. 6.

donor who was undergoing resuscitation'.[26] After Mr Petrovs was pronounced dead, a laparotomy was performed and his kidneys and spleen were removed for transplantation.[27] On 30 May a post-mortem was held as part of the criminal investigation into the accident, and the laparotomy and organ removal were noted in the report. Mrs Petrova (Mr Petrovs' mother) received a copy of the report on 11 February 2003, and it was only then that she realised that organs had been removed from his body.

Mrs Petrova claimed that she was in contact with the doctors while Mr Petrovs was in hospital but that she was not told on 29 May that his condition was deteriorating, nor was she asked whether he was an organ donor. Also, she was not asked whether, in the absence of any express wishes from her son, she would consent to his organs being donated for transplantation. In contrast, the Government claimed that the hospital did not have any contact details of relatives and only the police were informed that Mr Petrovs was in hospital. Mrs Petrova argued that *her* rights under Articles 3 and 8 of the European Convention on Human Rights (the Convention) had been breached because Mr Petrovs' organs had been removed without either his prior consent *or* her consent. She claimed that as she was one of his closest relatives she should have been informed of the removal of his organs and that because this did not occur, she could not exercise *her* right to express consent or refusal to the removal of her son's organs under Latvian law.[28] As such, *she* had been subject to inhuman and degrading treatment and *her* right to private and family life had been interfered with.

There are some similarities between the facts of *Elberte* and those of *Petrova*, but an important difference is that in *Elberte* there was a criminal inquiry into the removal of tissue from Mrs Elberte's husband and others, but no complaints were successful. It is thus necessary to set out the relevant facts of *Elberte* and to, briefly, summarise the elements of the inquiry and its results.

Mr Elberts (the applicant's husband) was involved in a car accident on 19 May 2001 and died in an ambulance on the way to the hospital. The following day his body was taken to a forensic centre for a post-mortem to establish the cause of death. Mrs Elberte, who was pregnant with their second child, first saw Mr Elberts' body when it was transported from the forensic centre for the funeral and she saw that his legs were tied together. He was buried this way on 26 May. About two years later, the Security Police contacted Mrs Elberte and informed her that there was a criminal inquiry into the illegal removal of organs and tissues, between 1994 and 2003, for supply to a pharmaceutical company based in Germany, and that tissue had been removed from Mr Elberts. This

26 Ibid., para. 7.
27 Ibid., para. 9.
28 Ibid., paras 78 and 87.

was the first time that Mrs Elberte was aware that tissue had been removed from her husband.

The tissue removal had occurred under an agreement between the forensic centre where Mr Elberts' post-mortem was conducted and a pharmaceutical company in Germany. Tissue was removed, sent to the company in Germany and transformed into bio-implants, before being sent back to Latvia for transplantation purposes. This agreement had been in place since January 1994 and had been approved by the Ministry of Welfare, which reviewed the agreement on 'several occasions' to ensure that it complied with the law. Two opinions on the compatibility of the agreement with Latvian law, including the Law on Protection of the Body of a Deceased Person, and Use of Human Organs and Tissues (the Law), were also issued by the Prosecutor's Office.[29] Under the agreement, tissue was removed within 24 hours of death, and any qualified member of staff (the expert) could remove tissue on her own initiative.[30] Each expert had to verify that the potential donor had not objected to the removal of organs or tissues by checking for the relevant stamp in their passport, and, notably, '[i]f relatives objected to the removal, their wishes were respected, but the experts themselves did not attempt to contact relatives or to establish their wishes'.[31]

Under the law in force in May 2001, a living person with legal capacity could, in writing, consent or refuse to their body being used after death, and this was binding.[32] The consent or refusal had to be signed by the person concerned, and recorded in their medical record or via a special stamp in their passport.[33] If the deceased had not expressed their wishes regarding the use of their body after death and their closest relatives (defined as children, parents, siblings or spouse) did not object, then organs and tissues could be removed.[34] Despite these provisions, during the criminal inquiry it transpired that there was disagreement over which of the two different legal systems for regulating the removal of organs and tissues applied – presumed consent or informed consent. The head and experts from the forensic centre where the tissue from Mr Elberts were removed, believed that at the relevant time there was a system of presumed consent in Latvia, meaning that 'everything which is not forbidden is allowed'.[35] In contrast, the investigators leading the criminal inquiry believed that the Latvian legal system relied on informed consent, so that 'removal was permis-

29 *Elberte*, *supra* note 5, para. 14.
30 Ibid., para. 15.
31 Ibid., para. 16.
32 Section 2, Law on Protection of the Body of a Deceased Person and Use of Human Organs and Tissues 1992 (the Law).
33 Ibid., section 3.
34 Ibid., section 4.
35 *Elberte*, *supra* note 5, para. 18.

sible only when it was (expressly) allowed ... when consent had been given either by the donor during his or her lifetime or by the relatives'.[36] No successful complaints followed the criminal inquiry, but in one of the court's decisions regarding a complaint it was 'reiterated (...) that the experts did not have any legal obligation to inform anyone about their right to consent to or refuse organ or tissue removal'.[37] Furthermore, Section 4 of the Law 'did not impose any obligation on the expert to explain these rights [of relatives to object to the removal of their relative's organs and tissue] to the relatives', and 'a person could not be punished for a failure to comply with an obligation which was not clearly laid down in a legal provision: the experts had therefore not breached the Law'.[38]

Returning to the facts of *Elberte*, as with Mrs Petrova, Mrs Elberte claimed that *her* rights under Articles 3 and 8 of the Convention had been interfered with because, first, Mr Elberts' tissue had been removed without his prior consent or her consent and, secondly, that in the absence of such consent, his 'dignity, identity and integrity had been breached and his body had been treated disrespectfully'.[39] There were two other matters at issue (the amount of tissue removed and whether Mr Elberts' passport could have been checked for a stamp),[40] but these are not relevant to our discussion here.

3.2. The Decisions

Having reviewed the complaints at domestic level and set out the relevant international documents and domestic law,[41] in *Petrova* the ECtHR noted that, 'the concepts of private and family life are broad terms not susceptible to exhaustive definition'.[42] Article 8 was designed to protect the individual from arbitrary interference by public authorities,[43] and relevant domestic law 'must indicate with sufficient clarity the scope of discretion conferred on the

36 Ibid.
37 Ibid., para. 30.
38 Ibid.
39 Ibid., para. 60.
40 Ibid., para. 8.
41 See *Petrova*, *supra* note 5, paras 27-46 and *Elberte*, *supra* note 5, paras 34-59. Note that in *Elberte*, Directive 2010/53/EU is not listed but, instead, Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells. WHO Guiding Principles on Human Cell, Tissue and Organ transplantation (endorsed by the sixty-third World Health Assembly on 21 May 2010, Resolution WHA63.22), the legal regulations governing the Inspectorate of Quality Control for Medical Care and Working Capability (MADEKKI), and Article 92 of the Constitution, the Administrative Procedure Law and the Law on Compensation for Damage caused by Public Authorities are also listed in *Elberte*.
42 *Petrova*, para. 77, citing *Hadri-Vionnet v. Switzerland*, Application no. 55525/00, 14 February 2008, para. 51.
43 *Petrova*, *supra* note 5, para. 85.

competent authorities and the manner of its exercise'.[44] With regards to the facts of this case, the ECtHR held that 'the rights of the deceased, Mr Petrovs, and his mother, the applicant in the present case, are closely related', and noted that the relevant Latvian law at the time explicitly provided that consent could come from the person concerned *or* their closest relatives, including parents.[45] As Mrs Petrova was not informed of the removal of her son's kidney and spleen, she could not exercise her right to consent or refuse the removal, as provided under domestic law.[46] This was 'sufficient' for the ECtHR to conclude that there had been a breach of *her* Article 8 rights.[47] With regard to the provisions of Article 8(2), the Latvian law allowed closest relatives to express their wishes about the removal of organs for transplant, but 'it did not define with sufficient clarity the scope of the corresponding obligation or the discretion conferred on medical practitioners or other authorities in this respect'.[48] Indeed, when Mr Petrovs died there was no legal procedure for state institutions to follow to determine a person's *own* view on organ donation,[49] *and*:

'it remains unclear how the "presumed consent system", as established under the Latvian law, operates in practice in circumstances in which the applicant found herself, whereby she had certain rights as the closest relative but was not informed – let alone provided with any explanation – as to how and when these rights might have to be exercised'.[50]

The uncertainty and lack of clarity surrounding the law was evidenced not only by the disagreement between the Security Police and Prosecutor's Office and the Minister for Health as to whether the failure to inform Mrs Petrova of the possible removal of her son's organs broke Latvian law, but also by the fact that the legislation was subsequently changed.[51] Furthermore, the Government did not contest Mrs Petrova's contention that there was time for her to express her views about removal and donation because several medical examinations were performed prior to the removal to determine if Mr Petrovs' organs were compatible with the intended recipient.[52] Even though Mr Petrovs' condition was critical and it was considered to be a medical emergency, it could not be said that it had been 'practically impossible to contact his closest relatives or at

44 Ibid., citing *LH v. Latvia*, Application no. 52019/07, 29 April 2014, para. 47.
45 *Petrova*, *supra* note 5, para. 56; sections 4 and 11 of the Law.
46 *Petrova*, *supra* note 5, para. 87.
47 Ibid., para. 89.
48 Ibid., para. 93.
49 Ibid., para. 95.
50 Ibid.
51 Ibid., para. 94. The amendments are discussed at para. 41.
52 Ibid., para. 96.

least to make an attempt to contact them, informing them of his condition and making enquiries about the possible organ transplantation'.[53] Thus, the ECtHR held that there was an interference with Mrs Petrova's right to respect for *her private life* under Article 8(1), which was not in accordance with the law within the meaning of Article 8(2).[54] With regard to Mrs Petrova's claim under Article 3, which was 'linked' to her Article 8 claim and so was admissible, as the ECtHR had already found an interference with her Article 8 rights, it considered that it was 'not necessary to examine whether, in this case, there has been a violation of Article 3'.[55] No further explanation is provided. Mrs Petrova was awarded EUR 10,000 for non-pecuniary damage because of the violation of her Article 8 rights.

Mrs Elberte was also successful in her claim that *her* right to private life had been interfered with under Article 8. The ECtHR held that, with regards to the first part of her complaint, Mrs Elberte had 'adequately demonstrated' that she had been 'directly affected' by Mr Elberts' tissue being removed without her consent, and was a 'direct victim' in that regard.[56] The second part of her complaint concerned her husband's and not her rights, and so was rejected, although part of that complaint overlapped with her complaint under Article 3. Given that Mrs Elberte was not informed that tissue was removed from her husband, sent to a company in Germany and then back to Latvia as bio-implants, and so could not exercise her right to consent to or refuse this, the facts were 'sufficient' to conclude that there had been an interference with *her* right to respect for *private life* under Article 8.[57] The focus, as we return to below, was on Mrs Elberte's *private life* rather than her *family life*.[58] As in *Petrova*, the ECtHR stated that the issue was whether the law was 'sufficiently clear and foreseeable' with regard to allowing closest relatives to exercise their rights to consent or refuse under section 4 of the Law.[59] The disagreements within the Latvian authorities, who were supposed to enforce the law, as to 'the scope of the domestic law' were noted, and this 'inevitably indicates a sufficient lack of clarity' in the law.[60] The legal framework allowing the closest relatives to express consent or refusal in relation to tissue removal was set out, but 'the scope of the corresponding obligation or the margin of discretion conferred on experts or other authorities in this respect' was not.[61] Thus, Article 8 was violated as the interference with

53 Ibid., para. 93.
54 Ibid., para. 98.
55 Ibid., para. 102.
56 *Elberte*, *supra* note 5, para. 65.
57 Ibid., paras 105 and 107.
58 Ibid., para. 89.
59 Ibid., para. 109. The relevant sections are discussed at paras 44-45.
60 Ibid., para. 113.
61 Ibid.

Mrs Elberte's right to respect for *privatelife* was not in accordance with the law, as required in Article 8(2).[62]

With regards to her claim under Article 3, and in contrast to the decision in *Petrova*, the ECtHR held that Mrs Elberte had faced 'a long period of uncertainty, anguish and distress' after learning of the tissue removal two years after her husband's funeral and without knowing what had been removed from her husband's body, how this had occurred, and for what purpose.[63] The opening of a criminal inquiry and the discovery that tissue had been removed 'under a State-approved agreement with a pharmaceutical company abroad', were 'special factors which caused additional suffering for the applicant'.[64] Mrs Elberte's suffering had 'a dimension and character which went beyond the suffering inflicted by grief following the death of a close family member'.[65] The disagreements between the domestic authorities on the scope of the law, the way the complaints were dealt with, their 'disregard' of the deceased and their close relatives, and the impossibility of obtaining any redress, 'contributed to feelings of helplessness on the part of the applicant in the face of a breach of *her* personal rights to a very sensitive aspect of *her* private life, namely giving consent or refusal in relation to tissue removal' (emphasis added).[66] The ECtHR held that Mrs Elberte's suffering was caused by *her* rights as the closest relative being breached, the uncertainty as to what had happened in the forensic centre, and 'the intrusive nature of the acts carried out on her deceased husband's body and the anguish she suffered in that regard as his closest relative'.[67] There was, thus, 'no doubt' that her suffering amounted to degrading treatment under Article 3.[68] Mrs Elberte was awarded EUR 16,000 for non-pecuniary damage for violations under Articles 3 and 8.

4. Relational Autonomy, the Autonomy of Relations, and Organ and Tissue Removal and Use

Nedelsky argues that the law is a powerful means of structuring human relations and maintaining concepts such as self, autonomy and rights,[69] and we are interested in the approaches to autonomy evidenced in these organ and tissue removal and use cases. We first consider the relevant

62 Ibid., para. 112.
63 Ibid., para. 139.
64 Ibid.
65 Ibid., para. 140.
66 Ibid.
67 Ibid., para. 142.
68 Ibid., para. 143.
69 Nedelsky, *supra* note 12, 3-4.

law in Latvia at the time of the factual circumstances of *Petrova* and *Elberte*, before looking at how similar facts (the removal of organs or tissue without the consent or refusal of the deceased, and the knowledge and consent of their relatives) would have been dealt with under current English law, for comparative purposes. Having identified the approach(es) to autonomy, we consider how relational autonomy in the context of consent to organ and tissue removal and use might be accommodated by law, and also consider Dove and colleagues concern that the decision in *Elberte* at least, introduces the possibility of a 'potentially more worrying precedent of an "autonomy of relations"'.[70]

As we have already noted, under the Latvian law at the time of the cases, written consent or refusal of a person with capacity to their body being used after death was binding if it was signed and recorded in their medical record or via a special stamp in their passport,[71] and their organs and tissues could be removed if they had not expressed their wishes but their closest relatives did not object to the removal.[72] Thus, neither Mrs Petrova nor Mrs Elberte was *required by law* to consent to the removal and use of organs and tissues from their husband or adult son. *Prima facie*, the rights of neither Mrs Petrova nor Mrs Elberte had been breached by the removal and use of their relative's organs and tissues post mortem. However, the ECtHR held otherwise on the basis of the relative's inability to express *their* wishes and so exercise *their* rights provided by the Law.[73]

If we compare the Latvian law at the time of these cases with the current law on organ and tissue removal and use in England, which is found in the Human Tissue Act 2004, this statute provides that 'appropriate consent' to organ and tissue removal and use after death for certain purposes[74] can be provided from one of three people: (i) the deceased themselves if they were over 18 and had capacity before they died, or (ii) if they did not consent themselves, they may have nominated a representative to consent after their death, or (iii) if neither of these apply, consent can be provided by someone who is in a qualifying relationship with the deceased.[75] Thus, the English law follows an informed consent model,[76] and explicitly provides a mechanism for an individual's relationship with a relative to continue after their death as it enables relatives to decide on behalf of the deceased whether to donate their organs. In doing

70 Dove et al., *supra* note 7, 79.
71 Section 3 of the Law.
72 Section 4 of the Law.
73 See *supra* notes 46-47 and 60-62.
74 Section 1(1) and Schedule 1 of the Human Tissue Act 2004 (2004 Act).
75 Section 3(6). See section 4 of the 2004 Act for further provisions relating to nominated representatives.
76 Note that in Wales presumed consent is now the model: Human Transplantation (Wales) Act 2013.

so, the law on organ and tissue removal and use challenges the traditional approach to health care decision-making where, as Roy Gilbar suggests, the English law and professional ethical guidelines related to decisions by adults with capacity rely on an individual expressing her autonomy.[77] In contrast, the decision as to whether an individual's organs and tissues are removed and used can be made by the relatives of the deceased, who could be respecting the autonomy of their deceased relative by expressing their wishes, but may, of course, use this as an opportunity to exert their own autonomy and make the decision that they prefer.

Applying English law to a factually similar case to that of *Petrova* or *Elberte*, before the organ or tissue can be removed from an adult appropriate consent must be provided from one of three parties, as set out above. The Act contains no further information on how this consent should be provided or obtained, but guidance can be found in the Human Tissue Authority's (HTA) *Codes of Practice* which accompany the Act. In *Code A* it is noted that discussions with the family may occur before their relative has died because they might know what their wishes are, but that 'it should be made clear to them that *knowing and understanding the dying person's wishes is different from giving consent on their behalf* following their death' (emphasis added).[78] Seeking consent from the now-deceased prior to death or from their relatives or those close to them after death, 'requires sensitivity',[79] and when 'those close to the deceased' object to the activity but the deceased or their nominated representative has explicitly consented to it, 'the healthcare professional should seek to discuss the matter sensitively with them. They should be encouraged to accept the deceased person's wishes and *it should be made clear that they do not have the legal right to revoke valid consent*' (emphasis added).[80] In *Code F*, which deals specifically with solid organ and tissue donation, it is expressly stated that '[w]here valid consent has been given by the donor, but relatives object to organ or tissue donation proceeding, then they should be sensitively supported to respect the prospective donor's consent to ensure his or her wishes are fulfilled. *A relative's objection does not nullify appropriate, valid consent from the prospective donor*' (emphasis added).[81] Having said that, the HTA is also clear in *Code F* that '[t]he existence of appropriate, valid consent permits an activity to proceed, but does not mandate that it must. The final decision about whether to proceed with the activity rests

77 R. Gilbar, 'Family Involvement, Independence, and Patient Autonomy in Practice', *Medical Law Review* 19 (2011): 192.
78 Human Tissue Authority (HTA), *Code A: Guiding Principles and the Fundamental Principle of Consent* (HTA, 2017) para. 98.
79 Ibid., para. 99.
80 Ibid., para. 37.
81 HTA, *Code F: Donation of Solid Organs and Tissues for Transplantation* (HTA, 2017), para. 120.

with the medical practitioner'.[82] Thus, where there is express consent from the now-deceased but their relatives are objecting to the donation, that donation might proceed but this will depend on individual health professionals being happy to proceed in the face of relatives' objections.

In order to determine whether the soon-to-be-deceased or the now-deceased consented or objected to organ donation, the Organ Donor Register should be checked to see if their wishes are known, and in *Code A* it is noted that their consent and wishes 'have primacy when removing, storing and using human tissue' because 'human tissue, or bodies of the deceased, should be used in accordance with the expressed wishes of donors'.[83] If their wishes are not known, it must be explored whether a nominated representative was appointed.[84] If there has been no appointment, '[a]n approach should be made to the deceased person's spouse or partner, relatives or close friends' with the aim of 'establish[ing] *any known decision of the potential donor*' (emphasis added).[85] In this situation, the views of relatives and others are sought with the aim of establishing what they know about what the *deceased* wanted.

With regards to approaches to autonomy, English law on organ and tissue removal and use can be seen to recognise traditional notions of autonomy, relational autonomy, and (in the last instance) the autonomy of relations. It respects the autonomy of the deceased in the traditional sense by giving primacy to their consent or objection to organ and tissue removal and use. At the same time, health professionals are reminded that most people live in and within families and relationships, and so others might have (or want to have) a say in what happens to their relatives' organs and tissues once they have died. This is the case even when the deceased has clearly expressed her wishes. The role of relatives and others in the organ and tissue removal and use decision-making process has been the subject of debate,[86] but in donation systems where communication with relatives and others are required or permitted, the suggestion that 'the autonomy of the deceased person is always "relational"' is difficult to counter.[87] Furthermore, in certain circumstances English law permits relatives to decide whether the deceased's organs should be donated, and while this is supposed to be based on what the deceased would have wanted, there is nothing

82 Ibid., para. 121.
83 HTA, *Code A*, para. 20.
84 HTA, *Code F*, para. 127. See paras. 131-132, and *Code A*, paras. 79-85 for further information on nominated representatives.
85 HTA, *Code F*, para. 130. See paras. 133-134, and *Code A*, paras. 30-39 for further information on qualifying relationships.
86 See, for example, G. den Hartogh, 'The Role of Relatives in Opt-in Systems of Postmortal Organ Proceurement', *Medicine Health Care and Bioethics* 15 (2012): 195; S. McGuinness & M. Brazier, 'Respecting the Living Means Respecting the Dead too', *Oxford Journal of Legal Studies* 28 (2008): 297.
87 Dove et al., *supra* note 7, 87.

to ensure that this is grounded on the views of the deceased. In some ways then, and as a last resort, the autonomy of relations is also recognised.

In contrast, we suggest that the ECtHR's interpretation of the law in Latvia in both *Petrova* and in *Elberte*, was an endorsement of traditional notions of autonomy (in the sense that consent could have been provided by the deceased prior to death) and the autonomy of relations (as it was the relatives' rights which were engaged), but that the ECtHR could (should) also have interpreted the law as recognising relational autonomy (the relatives could have been expressing the deceased's wishes and not their own). The first endorsement is uncontroversial and is clear in section 2 of the Law.[88] However, with regards to the second, the ECtHR was explicit that the rights engaged in those cases were *Mrs Petrova's and Mrs Elberte's own personal rights* and that they were not seeking (could not seek) to engage their deceased relative's rights, because the deceased could not be considered to be persons.[89] This idea that it was the relatives' own personal rights which were engaged was criticised by Judge Wojtyczek in his concurring opinion in both cases. In *Petrova* he commented that:

'*the relatives do not act as autonomous right-holders, but as depositaries of a right which belonged to the deceased person. They should exercise this right according to the wishes of the deceased*. This important aspect of the right under consideration has not been sufficiently stressed in the judgment' (emphasis added).[90]

Furthermore, he suggested that *Mrs Petrova's rights* were infringed under the 'protection of family life' aspect of Article 8, which 'encompasses the right to respect for the dignity of a deceased close relative', especially with regards to the parent-child relationship.[91] *Her* right to dignity was violated 'because she was denied the possibility to express *her son's wishes*' (emphasis added).[92] Similarly, in *Elberte* Judge Wojtyczek said that:

'*the applicant's right* to oppose the transplantation of her deceased husband's organs *is not an autonomous right* (...) [it] is derived from the right of the deceased man to decide freely on the transplantation of his organs. *The surviving relative acts as the depositary of the rights of the deceased*. Holding otherwise would transform the body of a deceased person into an object of arbitrary decisions by relatives' (emphasis added).[93]

---

88 *Supra* note 32.
89 *Petrova*, *supra* note 5, para. 54. Also, *Elberte*, *supra* note 5, paras 65-66.
90 *Petrova*, *supra* note 5, para. 3, Concurring Opinion.
91 Ibid.
92 Ibid., para. 5, Concurring Opinion.
93 *Elberte*, *supra* note 5, para. 2, Concurring Opinion.

Again, in his opinion the right to express the wishes of a deceased relative fell within the scope of family life and not private life and, as such, 'ensues a multidimensional protection, since it protects not only the wishes of the deceased person but also those of the deceased person's relatives themselves, *and relationships within the family*' (emphasis added).[94]

We agree that it was not the relatives' personal rights that were engaged in these cases and suggest that Mr Petrov's and Mr Elbert's relational autonomy would, appropriately, be recognised if these statements of Judge Wojtyczek's in his concurring opinion were adopted by the ECtHR. We also agree with Judge Wojtyczek that the cases properly fell within the family life aspect of Article 8, and not the private life aspect as the ECtHR held. While this may seem to be a minor matter, the inclusion of private life and family life as separate aspects within the Article indicates that the two are not synonymous, although there are clearly significant overlapping areas. The ECtHR has not offered a clear and precise definition of private life, seeing it as a broad concept incapable of exhaustive definition.[95] It is, we suggest, more individual-centred in nature, and includes the right to respect for sexuality, physical and psychological integrity. We see the right to respect for family life as, necessarily, wider, and includes relationships with others, such as parents, children, and siblings. Given this, in *Petrova* and *Elberte* and other such cases, it might be expected that the relatives' claims would be determined to fall within the ambit of family life as opposed to private life. But this was not so.

Furthermore, Katri Lõhmus suggests that:

'the Court has caused a more substantial shift in the understanding of what the protection of 'private life' entails: Article 8 demands not just protection from the state's interference in what was understood as one's private sphere, but to protect an individual's freedom to choose the course of his or her own life'.[96]

This transformation of the meaning of private life into a 'general freedom of action' was criticised by Judge Wojtyczek in his concurring opinion in *Elberte*, where he stated that 'such an extensive interpretation of Article 8' does not have a 'sufficient legal basis in the Convention'.[97] And previously in *Petrova*, also in his concurring opinion, Judge Wojtyczek argued that the case required the notions of private and family life to be sufficiently defined, and that the ECtHR's

94 Ibid., para. 3, Concurring Opinion.
95 *Costello-Roberts v. The United Kingdom*, Application no. 13134/87, 25 March 1993.
96 K. Lõhmus, *Caring Autonomy: European Human Rights Law and the Challenge of Individualism* (Cambridge, CUP, 2015), 49.
97 *Elberte*, *supra* note 5, para. 4, Concurring Opinion.

failure to do so led to 'a high level of uncertainty as to the meaning and scope of Article 8'.[98] In the absence of a definition of these aspects of Article 8 from the ECtHR, *how* complaints under this Article are classified remains unclear. Indeed, in some of their decisions, the ECtHR has not been clear about whether the issues in the case under consideration fell under the private life or family life aspect, they merely stated that there was a breach of Article 8.[99] This occurred in *Petrova* when the ECtHR was considering the admissibility of the complaint,[100] but it later stated that it was Mrs Petrova's right to private life which had been violated.[101] There was, however, no lack of clarity in *Elberte* because the ECtHR explicitly said that as the Latvian Government did not contest that Mrs Elberte's complaint fell within the private life aspect, there was no need to explore or explain why it did not fall within family life.[102] While we appreciate that if the ECtHR classifies a complaint as falling under one aspect of Article 8 it does not need to address whether it falls under any other aspect, it would be useful to know how and why it was determined that this complaint fell within private life rather than family life, and why the ECtHR did not just leave it open rather than classify it under a specific aspect. In so doing, the ECtHR could clarify whether it was approaching consent to organ and tissue removal and use as a manifestation of the autonomy of relations (regardless of the deceased's wishes), or relational autonomy (recognising the deceased as situated within networks of relationships and as giving voice to the deceased's wishes).

5. Some Concluding Thoughts

We concur with Judge Wojtyczek that both *Petrova* and *Elberte* rightly fell within the family life aspect of Article 8, and suggest that the ECtHR's decisions in these cases emphasise the autonomy of the deceased and the autonomy of their relatives, rather than the relational autonomy of the deceased. As such, we disagree with the reasoning presented in these cases. If the ECtHR had adopted the notion of relational autonomy under the family life aspect of Article 8, then the same decisions could have been reached; however, the right to decide would have been appropriately located as belonging to Mr Petrov and Mr Elbert (the deceased), with their relatives' roles limited to voicing the wishes of their relatives and not their own personal views. Given the primacy accorded

98 *Petrova*, *supra* note 5, para. 3, Concurring Opinion.
99 *Girard v. France*, Application no. 22590/04, 30 September 2011; *Elli Poluhas Dodsbo v. Sweden*, Application no. 61564/00, 17 January 2006.
100 *Supra* note 47.
101 *Supra* note 54.
102 *Elberte*, *supra* note 5, para. 89.

to bodily autonomy and integrity, and its recognised inclusion within the ambit of Article 8,[103] we argue that this is the preferred foundation on which to base laws on organ and tissue removal and use. Indeed, as the law in England indicates, it is possible to include all three approaches to autonomy within a donation system, with priority rightly given to the autonomy of the deceased, the relational context of decisions recognised, and the autonomy of relations also appreciated.

We hope that legislators and regulators reflect on the decisions in these cases and consider not only whether their laws and organ and tissue removal and use systems would permit such cases to be brought to court,[104] but also what form of autonomy is recognised within those systems. We also hope that if, in the context of organ and tissue removal and use, the ECtHR continues to recognise the autonomy of relations as opposed to relational autonomy when the relevant provisions permit either approach to be recognised, then its reasons for doing so are clearly set out and the consequences and implications are explicitly addressed. What, for example, might the ECtHR's response be to a case where the relative's own right under Article 8 is engaged but their decision does not match the appropriately and clearly expressed decision of the now deceased individual? If the relative's right stands alone, does this mean that *their* Article 8 right takes precedence?[105] The HTA *Codes* in England recognise this possibility and, as we discussed above, emphasise that the law is clear – health professionals can proceed with the donation with appropriate consent from the now-deceased.[106] In contrast, and following the logic of the ECtHR in *Petrova* and *Elberte*, it appears that the ECtHR *could* only consider the rights of the relative in such a case, and any prior decision of the deceased (if there was one) could be viewed as irrelevant and so not considered. This is because the ECtHR is concerned with *the private life of the relative*, and not the family life of the now-deceased. But we do not know if this interpretation is correct. If it is, then we propose that how it could and should be reflected in the regulation of organ and tissue removal and use in Europe requires careful thought.

These questions follow from the decisions and reasoning in *Petrova* and *Elberte*, which indicate that the ECtHR has, we think, taken a surprising direction with regards to its understanding and application of the concept of autonomy in relationships. At the very least, the decision in *Elberte* provides 'a mysterious, mixed message' about relationality[107] because of the ECtHR's acceptance that the complaint was part of Mrs Elberte's own private life and not under the family life aspect, which has relational connotations. If the ECtHR were to

---

103 See, for example, *Pretty v. United Kingdom*, Application no. 2346/02, 29 July 2002.

104 We note at least one other case with similar facts: *Sablina v. Russia*, Application no. 4460/16, communicated on 21 September 2016.

105 See also Dove et al., *supra* note 7, 91.

106 *Supra* notes 81-82.

107 Dove et al., *supra* note 7, 96.

consider the complaint under the family life aspect of Article 8, we would expect the decision on removal and use to be based on the decision made by the deceased when they were alive *and* that of their closest relative. In that way, relational autonomy is respected. In considering the complaint under the private life aspect, it appears that only the opinion of the relative is important and that if the deceased made any decisions when they were alive, these are now irrelevant. The autonomy of the living relation is thus prioritised, but the impact of this has not yet been explained or the implications thought through. Given the importance of organ and tissue removal and use, especially for donation purposes, it is imperative that the systems which provide for and regulate these decisions are trusted, legally clear and ethically appropriate. We hope that the ECtHR takes the opportunity to consider and clarify the matters raised here sooner rather than later.