The Governance of Foetal Tissue Use in England and Wales

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Abstract

This thesis examines how the use of deceased foetal tissue should be governed in England and Wales. It demonstrates the inadequacies of the current Human Tissue Act 2004 framework in governing this area and argues that reform is required. It identifies the ethical, philosophical, and legal questions that must be examined to determine how this material should be governed. It offers an analysis of the legal and moral status of deceased foetal tissue, how the law should manage competing external interests in the use of foetal tissue, how a consent requirement for tissue donation should be formulated, and whether this material should be governed by property law.

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ECtHR	European Court of Human Rights
HRA	Health Research Authority
HFEA 1990	Human Fertilisation and Embryology Act 1990
HFEA 2008	Human Fertilisation and Embryology Act 2008
HFE Authority	Human Fertilisation and Embryology Authority
HTA 2004	Human Tissue Act 2004
HT Authority	Human Tissue Authority
IVF	In vitro fertilisation
MCA 2005	Mental Capacity Act 2005
NHS	National Health Service
Peel Report and Code of Practice	The Use of Foetuses and Foetal Material for Research
Polkinghorne Report and Code of Practice	Review of the Guidance on the Research Use of Fetuses and Fetal Material
Pregnancy Loss Review	The Independent Pregnancy Loss Review - Care and support when baby loss occurs before 24 weeks gestation
REC	Research Ethics Committee
RCOG	Royal College of Obstetricians and Gynaecologists
Redfern Report	The Royal Liverpool Children's Inquiry Report
SC	Stem cells

Table of cases

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Human Tissue Authority, *Code of Practice 1: Consent* (September 2009).. 31, 36, 37, 38

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Human Tissue Authority, *Code of Practice and Standards E: Research* (June 2023) 12, 146

Human Tissue Authority, *Code of Practice F part two: Deceased organ and tissue donation* (June 2023)..... 116, 117

Human Tissue Authority*, Guidance on the disposal of pregnancy remains following pregnancy loss or termination* (March 2015, updated September 2024).... 4, 17, 64, 73, 106, 111, 132, 149, 161

John Peel, *The Use of Fetuses and Fetal Material for Research* (London HMSO, 1972) 30, 31, 32, 33, 34, 35, 65, 148

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Introduction

This thesis intends to start a conversation about the governance of deceased embryonic and foetal tissue in England and Wales. The use of this material – such as in medical research and the creation of vaccines – is a polarising topic which can provoke strong objections. These include comparisons to the 'experiments conducted by some of Hitler's doctors during the war'.[1] The legal and ethical questions surrounding its use have attracted critical attention in other jurisdictions such as the US. Over the last few decades, the US has gone back and forth on issuing and revoking total or partial bans on the use of foetal tissue in federally funded medical research on the basis of ethical and religious objections.[2] In contrast, these questions have received little attention in the UK.[3] Extensive consideration has been given to the governance and status of the *living* embryo and foetus in English law, under the Human Fertilisation and Embryology Act 1990 (as amended), but this interest has not extended to the use of these materials after the death of the foetus.[4] The discussion of the latter remains limited and does not include a comprehensive analysis of whether the existing legislative controls placed

[1] Peter Paterson, 'Dilemma of spare-part babies' *Daily Mail* (London, 5 January 1988) 19, 19.

[2] Kelly Servick, 'Biden administration scraps human fetal tissue research restrictions' *Science* (16 April 2021) <https://www.science.org/content/article/biden-administration-scraps-human-fetal-tissue-research-restrictions> accessed 14 July 2025; Institute of Medicine (US) Conference Committee on Fetal Research and Applications, *Fetal Research and Applications: A Conference Summary* (National Academic Press, 1994) 4. <https://www.ncbi.nlm.nih.gov/books/NBK231997/> accessed 14 July 2025.

[3] The primary commentary on this topic is found in Simon Woods and Kenneth Taylor, 'Ethical and governance challenges in human fetal tissue research' (2008) 3 Clinical Ethics 14.

[4] See Naomi Pfeffer and Julie Kent, 'Consent to the use of aborted fetuses in stem cell research and therapies' (2006) 1 Clinical Ethics 216.

on embryonic and foetal tissue in England and Wales are fit for purpose.[5] This thesis has two aims. First, to fill the gap in the literature by addressing how deceased embryonic and foetal tissue should be governed. Second, this work intends to facilitate further discussion of this topic by demonstrating why it needs critical attention and providing the groundwork for future analysis.

Due to the fact that there is little direct discourse on this topic, this thesis poses a broad overarching research question: How should deceased embryonic and foetal tissue be governed in England and Wales? The answer provided in this thesis focuses on breadth rather than depth to lay the analytical groundwork for future discourse. In particular, it focuses on the classification, collection, and use of deceased embryonic and foetal tissue and identifies the underlying legal and ethical issues that surround the use of these materials that must be considered when determining how they should be governed.

Because of the intended breadth of this thesis, a few limitations and clarifications must be recognised. The scope of this thesis will broadly cover all uses of embryonic and foetal material. It will not, however, consider at a granular level how the law should control *specific* uses of these materials, such as whether these tissues should be used in art or in certain types of medical research. Further research is needed to examine such questions. Furthermore, the scope of this thesis specifically covers the *ex vivo* deceased embryo and foetus after implantation in the womb. It does not cover embryonic material that dies before implantation into a human womb. It will be argued that the lived experiences of pregnant people and

[5] Previous regulatory controls on embryonic and foetal tissue were criticised by John Keown, but these regulations have since been superseded by the Human Tissue Act 2004 framework: John Keown, 'The Polkinghorne Report on Fetal Research: nice recommendations, shame about the reasoning' (1993) 19 J Med Ethics 114.

other parents of the embryo and foetus before its death must be a primary consideration for the law in this area.[6] Embryonic material which is not implanted into a womb consequently falls outside of the scope of this thesis. Questions about how the law should be formulated outside the jurisdiction of England and Wales will also not be considered within the scope of this study. This limitation is necessary to allow for enough space to adequately consider the issues that arise in this jurisdiction. As D Gareth Jones and Maja Whitaker explain, societal and cultural views about the use of dead bodies vary between societies:

> To dissect human bodies or study human bones is an intrusion into the intimacy and privacy normally reserved for the dead, and where societies tolerate these activities, they do so only within given parameters. These vary between societies, and a society's acceptance of a given activity should not be taken for granted.[7]

These values are relevant considerations in the assessment of how deceased embryonic and foetal tissue should be governed. To answer this question within the jurisdiction of England and Wales, it is necessary to confine the assessment of societal and cultural values to these countries. Further research is needed to compare the approach to governance in this jurisdiction with others. In this thesis, all references to *the law*, and occasionally *English law*, are shorthand for *the law in England and Wales* for the purposes of brevity, unless stated otherwise.

This thesis looks at embryonic and foetal tissue: human material which originates from pregnancy loss (whether from induced abortion or spontaneous miscarriage). A variety of terms are used to refer to this material. Whilst it is desirable for this thesis to align with the pre-existing terminology used, this is

[6] See Chapters 3 and 4.

[7] D Gareth Jones and Maja I Whitaker, *Speaking for the Dead: The Human Body in Biology and Medicine* (2nd edn, Routledge 2009) 19.

challenging because preferred terminology differs between social, legal, and medical settings (as outlined below). There is no widespread consensus on what terminology should be used, possibly because of the limited attention this topic has received. This thesis will discuss the use of this material in all three settings. Therefore, clarification is required regarding what terms will be used to define this material.

A wide range of terms are used in social settings to refer to the deceased embryo and foetus, ranging from 'baby' and 'child' to 'a bunch of cells' or 'a thing'.[8] Legal terminology also uses several different terms. The Human Tissue Act (HTA) 2004 framework alone refers to it in multiple ways, including 'fetal tissue', 'the mother's tissue', 'stillbirths', 'pregnancy remains', and 'products of conception'.[9] There is no single, consistent term used in social or legal settings. It is therefore challenging to identify a single term that aligns with existing legal terminology. The terminology used in medical practice is more consistent. The material is termed *embryonic tissue* if death occurred in the first eight weeks after fertilisation, and *foetal tissue* thereafter.[10] These terms are used uniformly within the medical field and so will be used in this thesis for clarity and consistency. For the purposes of brevity, singular terms may be used to refer to these organisms and materials collectively in this thesis. The term *foetus* may be used to refer to both the living

[8] Naomi Pfeffer, 'What British women say matters to them about donating an aborted fetus to stem cell research: A focus group study' (2008) 66 Soc Sci Med 2544, 2548-2549.

[9] Human Tissue Authority, *Code of Practice A: Guiding principles and the fundamental principle of consent* (June 2023) 28-29 at [141]-[142]; Human Tissue Authority, *Guidance on the disposal of pregnancy remains following pregnancy loss or termination* (March 2015, updated September 2024).

[10] Similarly, during gestation, the term *embryo* is used for the first eight weeks after fertilisation and the term *foetus* is used thereafter: see for example James S Nelson, 'Developmental and Perinatal Neuropathology' in James S Nelson, Hernando Mena, and Joseph E Parisi (eds), *Principles and Practice of Neuropathology* (2nd edn, OUP 2003) 24.

(post-implantation) embryo and foetus and *deceased foetus* or *foetal tissue* may be used to refer to both the deceased embryo and foetus and their separated tissue. Other collective terms, such as *this material* or *it* may be used. These terms are only used to facilitate the flow of discussion and are not intended to devalue or obscure the status of embryonic and foetal tissue. This thesis does not recommend that these terms should be used in practice, whether by researchers collecting foetal tissue or by lawmakers. The terminology that should be used in these contexts is discussed in Chapter 3.

The experiences of pregnant people constitute a significant aspect of the discussion surrounding this material. They have an unique and intimate physical and personal relationship with the foetus in both life and death.[11] They will be referred to as the *pregnant person* or *pregnant people*. These terms are preferred over the traditional legal terms of *mother* or *pregnant woman* because they provide a more accurate description of these individuals. Firstly, not everyone who has experienced pregnancy loss will identify as a *mother*, so it should not be used to refer to this group collectively.[12] There is also insufficient space within this thesis to consider whether the conflation of mothering and gestation can be harmful.[13] Secondly, not everyone who can become pregnant identifies as a woman. Thirdly, the focus of this thesis is on deceased embryonic and foetal tissue, so while questions about whether gendered language should be used to refer to the pregnant

[11] They alone experience gestation and pregnancy loss; see Chapter 3 for a detailed discussion of this unique relationship.

[12] For example, someone who chooses to have an abortion to avoid having a child and becoming a parent would not identify as a mother.

[13] See for example Zaina Mahmoud and Elizabeth Chloe Romanis, 'On Gestation and Motherhood' (2023) 31(1) Med Law Rev 109.

person are important, they are not directly relevant here and should be examined separately. The terms used in this thesis must include all persons who are capable of becoming pregnant (and therefore capable of producing deceased foetal tissue) and exclude all others. The terms *pregnant person* and *pregnant people* satisfy these criteria. As Elizabeth Chloe Romanis and Victoria Adkins point out, other commonly used terms are less suitable because 'the term "woman" is both under-inclusive (trans men and non-binary people can become pregnant) and over-inclusive (many women cannot become pregnant for a variety of reasons).'[14] It should be noted, however, that other terms are used by the law or by other commentators to refer to pregnant people, and these will be used in this thesis as needed.

It is also important to consider the experiences of non-gestational parents within this thesis.[15] The term *parent* will be used to refer to a range of different types of parents – including gestational and non-gestational – who will be specified in Chapter 3.[16] The term *parent* is only used for the purposes of clarity. In practice, only some people will consider themselves to be parents following pregnancy loss. Others will not view themselves in this way, even when they are the progenitors of and are genetically related to the foetus. For example, it may not be appropriate to describe someone as a parent if they are seeking an abortion for the purpose of not having a child. Questions about terminology will be considered further in Chapter 3.

[14] Elizabeth Chloe Romanis and Victoria Adkins, 'Artificial placentas, pregnancy loss and loss-sensitive care' (2023) 50(5) J Med Ethics 299, 299 footnote i.

[15] See Chapter 3 and 4.

[16] See 3.3.1.

This thesis will start by identifying the primary legal and ethical issues that arise from the classification, collection, and use of deceased foetal tissue. In doing so, it will outline why we need to think about the governance of this material differently from that of other human tissue. It will then analyse to what extent the current governing framework under the HTA 2004 adequately responds to these issues. The following chapters will each focus on one of the identified issues in greater depth by analysing the legal, ethical, philosophical, and sociological dimensions of each issue to determine how the law should respond to them. The final chapter will draw these conclusions together to assess what type of framework should govern the use of this material. As many of the legal and ethical issues surrounding the use of foetal tissue have not yet been identified or comprehensively analysed, especially within the law of England and Wales, this thesis provides a significant contribution to existing commentary.

Chapter 1: The History of Foetal Tissue Governance

1.1 Introduction

Most of this thesis is dedicated to assessing *how* foetal tissue should be governed. This chapter will answer the prior question of *why* this topic requires examination. Foetal tissue is a type of human material. It is currently governed alongside other human tissues under the Human Tissue Act (HTA) 2004 framework. Little consideration has been given to the question of whether foetal tissue should be governed differently to other tissues. This chapter will examine whether and why this should be the case. To do so, focus will be given to four questions. Firstly, whether the control of foetal tissue should be within the purview of the law. Secondly, whether foetal tissue should be governed in the same way as other human tissues, and crucially, whether there are any unique issues raised by the use of foetal tissue that require us to distinguish it from other tissues. Thirdly, to what extent the current law has responded to these issues and whether it is fit for purpose. Finally, it will consider how the law should respond to any outstanding issues identified in this chapter.

1.2 Should foetal tissue be subject to legal controls?

The use of foetal and other human tissues in England and Wales is primarily governed by the HTA 2004. This legislative framework applies to deceased human bodies and tissue that has been excised from a body (whether living or deceased)

with few exceptions.[1] The framework regulates the use of these materials for specific purposes including medical research and transplantation treatment.[2] The Human Tissue Authority (HT Authority) oversees the day-to-day use of these materials by operating a licensing system and issuing regulatory guidance.[3] Alternatively, tissue may be used in medical research without a HTA licence if ethical approval is obtained from the Health Research Authority and a Research Ethics Committee (REC).[4] The current governance of human tissue has received its fair share of criticism.[5] Nevertheless, there are good reasons for closely regulating the use of these materials within a legal framework.

The use of human tissue raises complex ethical and legal questions. What constitutes unethical use of tissue? Should specific uses be prohibited or limited? Who should decide how tissue is used? Must consent be sought for its use? Should organs be conscripted for life-saving medical treatment? These and many other questions also apply to the use of foetal tissue. The law is well placed to navigate these by creating rules to limit or prohibit unethical behaviour. For example, it has

[1] Human tissue is a broad term that is used to refer to most human material, such as a single foetal brain cell, a blood sample, or a liver: Human Tissue Act (HTA) 2004 section 53(1). There are some exceptions where the use of some types of human tissue falls outside the remit of the HTA framework, namely 'gametes', 'embryos outside the human body' and 'hair and nail from the body of a living person': HTA 2004 section 53. Gametes and embryos (outside the body) are instead governed by the Human Fertilisation and Embryology (HFEA) framework: HFEA 1990 and HFEA 2008.

[2] HTA 2004 Schedule 1.

[3] A HTA licence is required for most uses of human tissue: HTA 2004 Part 2 and Schedule 3; Human Tissue Authority (HT Authority), 'What is a HTA licence' (updated 5 November 2024) <https://www.hta.gov.uk/guidance-professionals/licences-inspections-and-fees/licensing/what-hta-licence> accessed 14 July 2025.

[4] HTA 2004 sections 1(8)-(9); Health Research Authority, 'Use of human tissue in research' (updated 1 February 2024) <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/use-tissue-research/> accessed 14 July 2025.

[5] See for example David Price, 'The Human Tissue Act 2004' (2005) 68(5) MLR 798.

been used to prohibit the sale of human material for transplantation in response to ethical concerns about its commodification.[6]

Human tissue can be used in a variety of ways. It is sought after for different uses to serve different interests. The dead body represents the former person and is used in social, familial, and cultural rites surrounding death. As Margaret Brazier points out, 'How the mortal remains of that person are laid to rest (or otherwise disposed of) is of overwhelming importance for the health and future of that family.'[7] Bodies may be used for anatomical and surgical training, displayed in museums, or used in artwork, in furtherance of historical, cultural, and educational interests.[8] Tissue is also frequently used in medical treatment, such as organ transplants and blood transfusions. Its use can save lives and treat disease. In medical research, it is used to develop our understanding of disease and create treatments such as vaccines. These uses further our interests in advancing public health.

Foetal bodies and tissues can be used in similar ways. Deceased foetal bodies are used in rites surrounding death, as well as in art and museum displays.[9] In medical research and treatment, they are used to study disease; to create

[6] Introduced by the Human Organ Transplants Act 1989 section 1 and later replaced by HTA 2004 section 32; for a discussion of the ethical and philosophical questions surrounding the sale of body parts, see Dimitris Katsikis, 'A philosophical justification of the individual's proprietary right to sell her body parts' (2009) 15 UCL Juris Rev 72.

[7] Margaret Brazier, 'Organ retention and return: problems of consent' (2003) 29 J Med Ethics 30, 32.

[8] See for example the Body Worlds exhibition of plasticised human bodies: 'Body Worlds' <https://bodyworlds.com/> accessed 14 July 2025; the British Museum holds over 6,000 human remains: British Museum, 'Human Remains' <https://www.britishmuseum.org/our-work/departments/human-remains> accessed 18 July 2025.

[9] Whether the foetus is used in rites around death may depend on whether the foetus was conceptualised as a child before death. For foetal bodies in art, see Rick Gibson, 'Human Earrings' <https://www.rickgibson.net/o018-earrings.html> accessed 14 July 2025; Body Worlds ibid.

products like vaccines and stem cells; and to develop treatments such as foetal surgery.[10] Foetal and other human tissues are sought for these various uses, but they cannot always be used in multiple ways. For example, the religious or personal values of a family may require them to bury or cremate the bodies of their loved ones whole.[11] In such cases, tissue could not also be taken from these bodies for use in medical research without disrupting the family's ability to lay the body to rest in line with their values. Conflicts of interest can arise over the way or ways in which bodies and tissues should be used. In the given example, we would need to consider whether the body of the deceased person should be used in line with the family's wishes or to further public health interests.[12]

The events of the Organ Retention Scandal provided a clear illustration of conflicts of interest over human tissue use and the consequences that can arise when conflicts are not adequately managed. As the name suggests, it involved the collection and retention of organs and human tissue for use in medical research in the UK in the late twentieth century. The largest collection was found at Alder Hey Children's Hospital, where there had been a 'systemic full-scale removal of organs' and foetal bodies.[13] These were notably retained without the knowledge of – and in some cases, against the express wishes of – the families of the deceased.[14] When

[10] Meredith Wadman, 'The Truth About Fetal Tissue Research' (2015) 528(7581) Nature 178; The Lancet Respiratory Medicine, 'Fetal tissue research: focus on the science and not the politics' (2019) 7(8) Lancet Resp Med 639.

[11] Brazier (n 7) 32.

[12] This will be discussed in Chapter 3.

[13] Michael Redfern, *The Royal Liverpool Children's Inquiry Report* (HC 2001, HC12-II, London: The Stationery Office 2001) (hereafter Redfern Report) 4, 28 and 100-110.

[14] Ibid.

these collections were discovered, it sparked widespread public outrage.[15] Many affected parents were 'devastated' and traumatised when they learnt that parts of their children's bodies had not been returned to them.[16]

The government responded to the Organ Retention Scandal by creating the HTA 2004. The framework manages conflicting interests by prioritising and giving legal force to one set of interests over all others in certain scenarios. In most cases, it does this through a legal requirement to obtain informed consent for donation and use. Consent must be obtained from the tissue progenitor, or their loved ones, and tissue cannot be used in ways that fall outside of what has been consented to.[17] This ensures that these interests are prioritised over others. The framework includes a few exceptions where consent is not required. For example, 'surplus' tissue can be used in medical research without consent if it 'will not be identifiable to the researcher and it will be used in a specific project' given ethical approval by a REC.[18] Here, priority is given to public health interests. The law has therefore provided much-needed clarity for all parties involved regarding which interests are prioritised in the event of a conflict over how tissue is used. The Organ Retention Scandal was not a discrete event: it followed a tumultuous history of conflicting

[15] BBC News, 'Organ scandal doctors "presumed too much"' *BBC* (23 September 1999) <http://news.bbc.co.uk/1/hi/health/background_briefings/the_bristol_heart_babies/455738.stm> accessed 26 July 2024.

[16] See the evidence given by parents in the Redfern Report (n 13) 19-20, 391-443.

[17] If a person gives specific consent for their blood sample to only be used in Research Study A, it cannot then be used in Research Study B unless additional consent is sought, because informed consent must be obtained for any 'purpose' under the Act: HTA 2004 sections 1(1)(a)-(g).

[18] HT Authority, *Code of Practice and Standards E: Research* (June 2023) 10 at [32]; HTA 2004 section 44; (n 4).

interests in the use of bodies and tissue in England and Wales.[19] It only added fuel to the fire and eroded public trust in the researchers using these materials.[20] The introduction of legal controls – and sanctions for those who contravened them – helped to restore public confidence and guard against future scandals.[21] Several good reasons for controlling the use of human tissue have been outlined, and these also apply to foetal tissue.[22] It is therefore desirable for foetal tissue to remain subject to legal controls.

1.3 Should foetal tissue be governed in the same way as other human tissues?

Under the HTA 2004 framework, the same legal provisions apply to both deceased foetal tissue and other human tissues. If the foetus dies before twenty-four weeks of gestation, it is classified as 'the mother's tissue' and is governed by provisions applying to other tissue from the living.[23] The HTA Code of Practice on Consent states that this classification does not apply to 'stillbirths (babies born dead after 24 weeks gestation)', and that:

[19] See Ruth Richardson, *Death, Dissection and the Destitute* (Routledge & Kegan Paul 1987); Jenna M Dittmar and Piers D Mitchell, 'From cradle to grave via the dissection room: the role of foetal and infant bodies in anatomical education from the late 1700s to early 1900s' (2016) 229 J Anat 713.

[20] See for example BBC (n 15); see evidence given by parents in the Redfern Report (n 13).

[21] Matthew Limb, 'Organisations voice concerns over plans to disband Human Tissue Authority' (2012) 345 BMJ 7897, 7897.

[22] The purpose of this discussion is not to conduct a comprehensive analysis of the HTA 2004 framework and the justifications in favour of it, but simply to illustrate why human and foetal tissue should be subject to controls.

[23] HT Authority, *Code of Practice A: Guiding principles and the fundamental principle of consent* (June 2023) 28 at [141].

> Seeking consent for the removal, storage or use of the tissue of babies from stillbirths … should be handled in accordance with provisions for seeking consent for use of the tissue of the deceased.[24]

This implies that tissue from foetuses that die at or after twenty-four weeks is recognised as originating from the stillborn foetus and makes clear that the consent provisions applying to tissue from the deceased apply, which are different to those from the consent provisions for the living. If deceased foetal tissue is the same as other human tissues – and the issues raised by the use of them are identical – then applying the same legal controls to all these materials would be unproblematic. However, this is not the case. Foetal tissue is different, and its use raises unique issues.

What is foetal tissue? To answer this question, we must consider how we conceptualise it. We are essentially asking: what do we think it is? What views and values do we ascribe to it? When we determine this, we can then answer other ethical and legal questions surrounding it such as how it should be governed. For example, it would be acceptable to keep a plant in your house for several years. It would not be acceptable to do the same with a deceased human body. We draw a distinction here because of the different views and values we ascribe to plants and bodies. Take another example. It would be acceptable to taxidermy the body of a pet after its death and keep it in your house. Yet it would be unacceptable to do the same to the body of a child after death. We consider these bodies to be different, so we do not use them in the same way. To formalise these distinctions, we assign different statuses to different things. We assign each of them a moral status that reflects the values and views we ascribe to it. A moral status reflects the way we

[24] Ibid 29 at [142].

view something and whether and why particular uses of it are acceptable. We view plants, deceased animal bodies, and deceased human bodies differently and so we do not assign them the same moral status. Ethically speaking, what may be seen as an acceptable use of one may not be for another.

Certain uses of bodies may be deemed acceptable if we consider them as not undermining this moral status. For example, in contrast to the example above about storing a deceased body in your house, it would be acceptable to keep the ashes of a deceased pet, child, or relative in your house or to display plasticised human bodies in museums such as the Body Worlds exhibit.[25] We may also disagree on what is an acceptable use of a thing and what moral status should be assigned to it. Foetal tissue is a good example of this. Some people see it as 'a bunch of cells' whilst others view it as a 'baby'.[26] These views will be explored further in Chapter 3.

We also assign legal statuses to things to place legal limits on how they are used. For example, a living human adult is recognised as a legal person in life and a deceased person after death. This allows the law to protect them from being used in certain ways, such as being bought and sold. Different bodies and objects are governed in distinct ways under the law. We are free to buy and sell plants but cannot do the same with deceased human organs.[27] The prohibition on organ sales is an example of a legal limitation that was introduced due to ethical concerns.[28]

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[25] Body Worlds (n 8).

[26] Naomi Pfeffer, 'What British women say matters to them about donating an aborted fetus to stem cell research: A focus group study' (2008) 66 Soc Sci Med 2544, 2548-2549.

[27] (n 6).

[28] Ibid.

To ascertain what legal controls we would want to place on something, we must start by asking how we view it. Only then can we turn to questions about whether and how these views should shape the legal controls we place on something. The crucial question to start with here is whether we view foetal tissue differently to other human tissues.

After death, the human body represents the former person. The body still looks like and is linked to the memories that a family have of their loved one. It may be honoured in rituals around death. The foetal body is viewed differently. It is conceptualised on a sliding scale between two polarised views: the unborn child and the unwanted pregnancy.[29] It is an unthinkable tragedy for a parent to have to bury their child, especially one that never survived to draw first breath. The excitement and anticipation of expecting a child is cruelly juxtaposed with a sudden and unexpected loss. It is a different kind of loss from the slow, anticipated death of an elderly relative who lived a long, full life. Some foetal bodies are used in rituals around death, but parents and family will not have made memories with the foetus in the same ways as they will have with other living relatives. Before death, the foetus does not have an independent existence from the body of the pregnant person. Unlike other humans, it does not live to experience physical interactions with others, or to express interests. The foetus also lives a short life. We cannot form relationships with the foetus in the same way as we do with other humans. The way families grieve the foetus may therefore be different.[30] At the

[29] The terms 'wanted' and 'unwanted' are used for clarity of discussion and to highlight the range of possible conceptualisations. Yet, as Pfeffer notes, 'women may have mixed feelings' and 'both terms fail to capture the fluidity of women's feelings about the fetus': Pfeffer (n 26) 2547.

[30] See for example Helen Keane, 'Foetal personhood and representations of the absent child in pregnancy loss memorialization' (2009) 10(2) Fem Theor 153.

other end of the scale, the deceased foetus may be an unwelcome reminder of a pregnancy that was unwanted and intentionally terminated. The pregnant person may want nothing to do with the deceased foetus. They may want it to be completely destroyed.[31] Foetal bodies may also be disposed of via incineration instead of being used in rituals around death.[32] Other human bodies are not disposed of using this method.

Furthermore, tissue taken from an adult body clearly originates from that person's body (whether living or deceased). It is *their* tissue. That is not to say that they *own* that tissue in a property sense, but rather that we recognise the tissue as originating *from* them. The question of where foetal tissue originates from is more complex. If the foetus dies at a late stage in pregnancy, it has a clearly identifiable body. We would recognise foetal tissue as originating from this body, such as in the case of tissue taken from a stillborn foetus at thirty-eight weeks of gestation. Yet, if an embryo dies in the first days or weeks of gestation, we might view it as a clump of cells that originates from the pregnant person's body. Moreover, humans are recognised as legal persons after live birth. Most human tissue therefore originates from the body of a person (or a former person after death). The foetus is not born alive before its death, and so never attains this legal status.[33] When we recognise foetal tissue as originating from the foetal body, and not from the pregnant person, it is tissue from a body that never became a legally recognised person.

[31] Pfeffer (n 26) 2551.

[32] HT Authority, *Guidance on the disposal of pregnancy remains following pregnancy loss or termination* (March 2015, updated September 2024) 4.

[33] *Attorney-General's Reference (No 3 of 1994)* [1998] AC 245.

The medical utility of foetal tissue is also different. It is a more valuable resource in medical research and treatment due to its unique applications and scarcity. Foetal tissue can be used in ways that other human tissues cannot:

> Fetal tissue is a flexible, less differentiated tissue. It grows readily and adapts to new environments, allowing researchers to study basic biology or use it as a tool in a way that can't be replicated with adult tissue.[34]

Because of these properties, foetal tissue can be transplanted to treat 'diabetes, certain blood disorders, radiation poisoning, and a variety of neurological disorders' including Parkinson's and Alzheimer's disease.[35] Specific cell types have unique applications: foetal liver cells were used to treat radiation sickness in Chernobyl; foetal spinal cells have been implanted to treat spinal-cord injuries; and the Salk polio vaccine was developed using foetal kidney tissue cultures.[36] Even when other tissues can be used in applications, foetal tissue is often seen as 'the gold standard'.[37] It is also a 'precious' and 'scarce resource'.[38] This scarcity is caused by the challenges faced in collecting foetal tissue, the large quantity of material required for medical treatment, and the need for tissue to be 'fresh'.[39] For

[34] Wadman (n 10) 179; see also Justin Brumbaugh and others, 'Human fetal tissue is critical for biomedical research' (2023) 18 Stem Cell Rep 2300.

[35] Institute of Medicine (US) Conference Committee on Fetal Research and Applications, *Fetal Research and Applications: A Conference Summary* (National Academies Press, 1994) 7.

[36] Richard B Miller, 'On Transplanting Human Fetal Tissue Presumptive Duties and the Task of Casuistry' (1987) 14(6) J Med Philos 617; Wadman (n 10); Steven Maynard-Moody, 'Managing Controversies over Science: The Case of Fetal Research' (1995) 5(1) J-PART 5.

[37] Shari E Gelber, Laurence B McCullough, and Frank A Chervenak, 'Fetal tissue research: an ongoing story of professionally responsible success' (2015) 213(6) Obstetrics 819, 819.

[38] Simon Woods and Kenneth Taylor, 'Ethical and governance challenges in human fetal tissue research' (2008) 3 Clinical Ethics 14, 15.

[39] Naomi Pfeffer, 'How Work Reconfigures an 'Unwanted' Pregnancy into 'The Right Tool for the Job' in Stem Cell Research' (2009) 31(1) Sociol Health Ill 98, 104-106; Ashleigh Furlong, 'UK forges ahead with studies using foetal tissue' *Research Professional News* (1 November 2019) <www.researchprofessionalnews.com/rr-news-uk-politics-2019-9-uk-forges-ahead-with-studies-using-foetal-tissue/> accessed 14 July 2025.

example, when foetal brain tissue is transplanted to treat neurological conditions, 'A single operation involves using hundreds of thousands of brain cells from as many as six eight-week-old foetuses.'[40] For these reasons, foetal tissue may be more sought after by researchers than other tissues.

The views and values placed on the deceased foetus vary depending on how and by whom it is conceptualised. Although these may also vary for human tissue, they remain distinct. For example, views on the latter are not entwinned with the social context and personal experiences of abortion and miscarriage.

1.3.1 Abortion and miscarriage

Over the last few decades, certain social narratives and attitudes about abortion and miscarriage have emerged in England and Wales. These include the controversial and political history of abortion law and the cultural secrecy and shame surrounding miscarriage. This history has little bearing on the use of most human tissue. It is, however, closely connected to foetal tissues because these are derived from abortion and miscarriage. An exploration of this history will demonstrate how it has permeated and influenced social attitudes about foetal tissue, and it will in turn identify further distinctions between foetal and other human tissues.

Foetal tissue is situated in a complex web of conceptualisations and interests. Part of this complexity stems from the context of abortion. There is disagreement over the extent to which abortion has been politicised in England

[40] Sinead L O'Gorman, 'Foetal Brain Cell Transplants: A Utilitarian Perspective' (1996) UCL Jurisprudence Rev 84, 85.

over the last century. Nonetheless, it will be demonstrated that political and social attitudes towards abortion have had a significant influence on how foetal material is viewed and regulated. Strong objections to abortion have been a consistent force throughout recent history. Abortion has long been illegal in England and Wales.[41] Up until 1968, access to legal abortion was far more limited than it is today. Legal abortion could only be obtained under a defence where the act was 'done in good faith for the purpose only of preserving the life of the mother.'[42] In the early twentieth century, there was a substantial rise in the incidence of maternal mortality caused by unsafe illegal abortions.[43] Concerned medical professionals petitioned lawmakers to establish further grounds for legal abortion to permit them to be carried out safely.[44] Even in light of the disturbing rate of maternal mortality, several legislative reform Bills failed to be passed by Parliament.[45] They were defeated by a combination of filibustering – from those opposed to abortion – and a general reluctance from politicians to engage in discourse about abortion.[46] Eventually, further grounds for legal abortion were established under the Abortion Act 1967.

This sparked the beginning of the anti-abortion movement in England and Wales.[47] Prior to the passing of the 1967 Act, there was no organised opposition to

[41] Offences Against the Person Act 1861 sections 58-59; Infant Life (Preservation) Act 1929.

[42] Infant Life (Preservation) Act 1929 section 1(1); *R v Bourne* [1939] 1 KB 687.

[43] Olivia Dee, *The Anti-Abortion Campaign in England, 1966-1989* (Routledge 2019) 7-19.

[44] Ibid.

[45] Ibid.

[46] Ibid.

[47] Ibid 34-35.

abortion and few public or political figures openly opposed it.[48] Even the Catholic Church remained silent on the matter.[49] Following the 1967 Act, anti-abortion views quickly spread and were considered 'widely present' in Parliament.[50] Over the next few decades, the anti-abortion campaign presented several Bills to Parliament which sought to repeal or limit the new defences to abortion.[51]

To promote their cause, the anti-abortion campaign regularly publicised incidents of inadequate abortion care. These included real or perceived abuses against foetal life.[52] In 1970, explosive accusations that aborted '"live" foetuses were being "sold" for the purposes of sinister medical experiments' were widely publicised: 'nearly all national and provincial papers carried banner headlines' of the allegations.[53] This public scrutiny also brought to light the lesser-known practices of how abortion clinics were supplying deceased foetal tissue to research centres. This included the discovery of a Medical Research Council funded foetal tissue bank which had been operating for 12 years.[54] Up until this point, the use of this material in research received little public scrutiny. These practices suddenly received backlash from anti-abortion campaigners and the media as perceived abuses to the foetus. Research practices were also directly constrained, as the Secretary of State for Social Services immediately 'stopped private abortion clinics

[48] Ibid.

[49] Ibid.

[50] Ibid 53.

[51] Ibid.

[52] Ibid 54 - 57; The Lancet, 'The First Year of the Abortion Act,' (1969) 293(7600) Lancet 867.

[53] Madeline Simms, 'The great foetus mystery' *New Scientist* (London, 31 December 1970) 592; British Medical Journal, 'Experiments on the Fetus' (1970) 5707 BMJ 433.

[54] Simms ibid.

supplying foetuses to research'.[55] The Department of Health commissioned an investigation into these allegations but did not reveal their findings.[56]

Anti-abortion rhetoric against the use of foetal tissue continued to grow. In 1974, *Babies for Burning* was published, which made claims about alleged malpractice by abortion providers.[57] It included claims that doctors were selling live and deceased foetuses to researchers and 'to soap factories for profit'.[58] Although these claims were never substantiated, these 'horror stories' were heavily propagated by activists.[59] This continued the public narrative that foetal tissue research was immoral, harmful to foetal life, and motivated by profits. Negative narratives about researchers also continued. In the 1970s, new developments involving the use of human embryos in research emerged including in-vitro fertilisation (IVF) treatment. In response, anti-abortion narratives compared embryo researchers to 'Nazi doctors'.[60]

Another scandal drew public attention in 1988. The British press reported that foetal tissue was being transplanted into adult human patients as a treatment for Parkinson's.[61] This revelation received mixed responses including comparisons to the 'experiments conducted by some of Hitler's doctors during the war' and

[55] NHS clinics were still permitted to continue supplying foetal tissue: Simms ibid.

[56] The allegations were denied in John Roper, 'Foetus denial by surgeon' *The Times* (London, 21 May 1970); Simms ibid. No evidence was provided to support the original allegations.

[57] Michael Litchfield and Susan Kentish, *Babies for Burning* (Serpentine Press, 1974); Dee (n 43) 52-67.

[58] Litchfield and Kentish ibid 145–150; Dee ibid 53.

[59] Dee ibid 52, 66, and 75.

[60] Mary Kenny, 'You can't put a ban on babies' *Daily Mail* (London, 21 July 1984) 6.

[61] Peter Paterson, 'Dilemma of spare-part babies' *Daily Mail* (London, 5 January 1988) 19, 19; Jenny Hope, 'The ultimate transplant!' *Daily Mail* (London, 12 April 1988) 6.

anticipation of the treatment 'offering a life-line' for patients with Parkinson's disease.[62] The media also highlighted concerns that the use of foetal tissue in these operations would lead to 'a trade in potential human life as mothers are paid money – or subjected to emotional bribery – to conceive' in order to provide tissue.[63]

Those who oppose abortion have loudly and repeatedly objected to the medical use of embryonic and foetal tissue. They believe that the use of foetal tissue is intrinsically tied to the prior act of abortion. Its use may 'legitimize' the procedure.[64] There are also concerns that the supposedly immoral act of abortion may morally taint any future application of the resulting foetal tissue.[65] Over the past few decades, the anti-abortion campaign has made several high-profile allegations that have cast foetal tissue use in a controversial light. This history suggests that the past regulation the use of foetal tissue has been unavoidably intertwined with the politicised and contentious history of abortion.

The link between pregnancy loss and foetal tissue extends to the cultural associations of the former to the latter. The social and cultural perceptions and personal experiences of abortion vary. For some, abortion can bring 'relief and happiness' and 'another chance at life.'[66] For others, abortion can carry a social

[62] Paterson ibid 19; Hope ibid 6.

[63] Hope ibid.

[64] John Burn and Tom Strachan, 'Human embryo use in developmental research' (1995) 11 Nat Genet 3, 3.

[65] See for example James Tunstead Burtchaell, 'University Policy on Experimental Use of Aborted Fetal Tissue' (1988) 10(4) IRB: Ethics & Human Research 7.

[66] My Body My Life, 'Real Stories of Abortion' <https://www.mybody-mylife.org/post/real-stories-of-abortion-125> accessed 26 October 2025.

stigma and be 'a negative stigmatised, even guilt-ridden, experience'.[67] For example, Kate Greasley notes that some characterise 'it as a kind of "cosmic shame" and a "grave moral decision"'.[68] As the My Body, My Life project observes, 'those experiencing or providing abortion can still be impacted by abortion stigma'.[69] Miscarriage – the other source of foetal tissue – is also surrounded by social disquiet. It is seen as a failure of the body that disrupts linear expectations of pregnancy.[70] Many experiencing miscarriage are faced with 'uncertainty, ambiguity and silence'.[71] They are 'frequently … not offered comprehensive information' about the physical experience of miscarriage, and may instead be given 'euphemistically-phrased information'.[72] For example, many women have reported being unaware that they needed to give birth to the foetus after its death.[73] Additionally, 'the pain of labour is often downplayed by clinical and medical staff'.[74] Some women who experience miscarriage before twenty-four weeks of gestation feel like their loss is not recognised or validated, because the death of the foetus is also only legally

[67] Pfeffer (n 39) 109.

[68] Kate Greasley, *Arguments About Abortion* (OUP 2017) 16 quoting Ronald Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (Harper Collins 1993) 32; Pfeffer ibid.

[69] My Body My Life <https://www.mybody-mylife.org/> accessed 26 October 2025.

[70] Keane (n 30) 153; Karolina Kuberska and others, 'Death Before Birth: Liminal Bodies and Legal Frameworks' in Chris Dietz, Mitchell Travis, and Michael Thomson (eds) *A Jurisprudence of the Body* (Palgrave Macmillan 2020) 149, 150.

[71] Danielle Fuller and others, 'Death Before Birth: Preliminary project findings for meeting with representatives of the Department of Health and Social Care' (24 August 2018) <https://testprojectwebsiteblog.wordpress.com/wp-content/uploads/2019/03/summary-of-project-findings-report-for-dhsc.pdf> accessed 26 July 2025 3; see also Jenny Littlewood, 'From the invisibility of miscarriage to an attribution of life' (1999) 6(2) Anthropol Med 217.

[72] Fuller ibid 8.

[73] Ibid 8-10.

[74] Ibid 8.

recognised if it occurs after this timepoint.[75] Despite being common experiences, both abortion and miscarriage are surrounded by a cultural silence.[76] The collection and conceptualisation of foetal tissue has inevitably become intertwined with this context.

The unique cultural context that surrounds foetal tissue further distinguishes it from other human tissues. This context warrants legislative consideration. We should question whether and how legal provisions controlling the use of this material should be shaped to address these differences.

1.4 Is the current legal governance of foetal tissue fit for purpose?

Several differences between foetal and other human tissues have been identified. This section will explore to what extent the HTA framework has recognised and responded to them. The HTA framework does not directly acknowledge or answer any of the unique ethical and legal questions that arise from foetal tissue use. For example, consideration has not been given to questions about whether the social or medical utility value placed on foetal tissue, or social and medical interests in its use, should shape its moral or legal status. For the most part, the same legal provisions apply to both foetal and other human tissues, despite their differences.[77] No explanation for this is provided. The framework does, however, make a distinction in the legal statuses assigned to these materials. Human tissue is

[75] Births and Deaths Registration Act 1953 section 41 (as amended by the Stillbirth (Definition) Act 1992 section 1(1)); ibid 14.

[76] Keane (n 30) 153-154; Littlewood (n 71).

[77] See 1.3.

classified separately depending on whether it is taken from a living or a deceased body. Different requirements and protections apply depending on this classification.[78] In either case, it is recognised as originating from a single body. In contrast, deceased foetal tissue can be recognised as tissue from the deceased or as tissue from *another* living body. Foetal tissue of less than twenty-four weeks of gestation is classified as the living tissue of the 'mother', whereas tissue of twenty-four weeks of gestation or greater appears to be recognised as deceased tissue from the stillborn foetus.[79] No explanation is given for these distinctions: for why *two* classifications were created; why they are distinguished based on gestational age; why twenty-four weeks was chosen as the dividing line; and why it can be recognised as the tissue of another person. Whilst the HTA framework has clearly established two legal statuses for foetal tissue, it has not sufficiently answered questions about why they should be formulated in this way.

The classification of younger deceased foetuses as the pregnant person's tissue is inconsistent with the legal status given to the living foetus. During pregnancy, the law recognises a distinction between the latter and the pregnant person. Asim Sheikh and Denis Cusack observe that 'the courts have expressed that mother and foetus are two separate organisms.'[80] Lord Mustill in *Attorney-General's Reference (No. 3 of 1994)* gives the following account:

> The mother and the foetus were two distinct organisms living symbiotically, not a single organism with two aspects. The mother's leg was part of the mother; the foetus was not … I would, therefore, reject the reasoning which assumes that since

[78] HT Authority, *Code of Practice A* (2023) (n 23) 5 and 17-28; HT Authority, *Code of Practice E* (2023) (n 18) 9-11.

[79] HT Authority, *Code of Practice A* (2023) ibid 28-29 [141]-[142]; see 1.3.

[80] Asim A Sheikh and Denis A Cusack, 'Maternal Brain Death, Pregnancy and the Foetus: The Medico-Legal Implications for Ireland' (2004) 23 Med L 237, 249.

> (in the eyes of English law) the foetus does not have the attributes which make it a "person" it must be an adjunct of the mother. Eschewing all religious and political debate I would say that the foetus is neither. It is a unique organism. To apply to such an organism the principles of a law evolved in relation to autonomous beings is bound to mislead. [81]

If they are legally separate in life, it is inconsistent to recognise them as legally indistinguishable after death. Other bodies that are legally separate in life continue to remain so after death.

This classification also affects who is permitted to give consent for foetal tissue donation. For tissue of less than twenty-four weeks of gestation, the pregnant person's consent must be sought because it is *their* tissue.[82] In rare cases, consent may be given by another person, but only if the pregnant person is unable to do so.[83] For foetal tissue of twenty-four weeks of gestation or greater, the HTA Code of Practice on Consent states that:

> Seeking consent for the removal, storage or use of the tissue of babies from stillbirths … should be handled in accordance with provisions for seeking consent for use of the tissue of the deceased … It is recommended that, whenever possible, the consent process for the examination of stillbirths and neonatal deaths involves the mother, and that, where appropriate, both parents are involved.[84]

Consent for the donation of tissue from the deceased may be given by a person in a 'qualifying relationship' under the HTA 2004, which are 'ranked in the following order' in section 27(4):

> (a) spouse, civil partner or partner;

[81] *AG's Reference* (n 33) 255-256 per Lord Mustill, taken from Sheikh and Cusack ibid.

[82] HT Authority, *Code of Practice A* (2023) (n 23) 28 at [141].

[83] Anyone else in a qualifying relationship with the foetus may give consent for tissue donation, for example if the pregnant person is deceased: HTA 2004 section 27(4)(a)-(h).

[84] HT Authority, *Code of Practice A* (2023) (n 23) 29 at [142].

(b) parent or child;

(c) brother or sister;

(d) grandparent or grandchild;

(e) child of a person falling within paragraph (c);

(f) stepfather or stepmother;

(g) half-brother or half-sister;

(h) friend of longstanding.

Of these, the parents of the deceased foetus are in the closest qualifying relationship. This is supported by the statement in the HTA Code of Practice on Consent, which recommends that 'the consent process for the examination of stillbirths and neonatal deaths involves the mother, and that, where appropriate, both parents are involved.'[85] It also states that 'consent is needed from only one person in the hierarchy of qualifying relationships.'[86] Therefore, it appears that consent is needed from one just parent for the donation of tissue from a stillborn foetus.

HTA 2004 permits any parent to give consent, and the HT Authority recommends 'where appropriate, both parents are involved'.[87] Others may also give consent if the parents cannot.[88] The framework does not explain why other parents should not be asked for consent, and why it is not recommended that they should be involved in the decision, simply because the foetus died before twenty-four weeks. Regardless of gestational age, consent is only required from one person

[85] Ibid.

[86] Ibid 10 at [33].

[87] HTA 2004 section 27(4)(b); HT Authority, *Code of Practice A* (2023) (n 23) 29 at [142].

[88] For example, if the parents are deceased (n 83).

for donation. The HTA does not explain why consent should not be required from more people, such as both parents. What if the parents disagree? Little guidance is provided for such situations. The HTA's Code of Practice on Consent suggests that:

> Where there is a conflict between those accorded equal ranking, this should be discussed sensitively with all parties, whilst explaining clearly that so far as the HT Act is concerned, the consent of one of those ranked equally in the hierarchy is sufficient for the procedure to go ahead. This does not mean that the consent of one person must be acted on, and a decision not to proceed may be made on the basis of the emotional impact that this would have on family and friends.[89]

Detailed guidance is not provided about when consent should and should not be acted upon in the event of a disagreement between family members about donation. Nevertheless, this guidance makes it clear that the interests of a parent who is willing to give consent *could* be legally prioritised over those who object to donation, regardless of the distress that this may cause. The rationales behind these rules are not explained. Careful consideration must be given to questions about whose interests should be taken into account in decisions about the use of foetal tissue and from whom consent should be sought.[90]

More generally, the HTA framework makes no distinction between tissues when managing conflicts of interest over tissue use. The legal provisions which prioritise certain interests over others apply equally to both human and foetal tissues.[91] However, because interests in deceased foetal bodies are distinct, any conflicts over their use may need to be approached differently when compared to conflicts over human tissue. This raises the question of whether the law needs to

[89] HT Authority, *Code of Practice A* (2023) (n 23) 10 at [36].

[90] These questions will be discussed in Chapters 3 and 4.

[91] See 1.2.

manage conflicts over foetal tissue use in a different way. It is unclear whether this has been considered.[92]

The governance of foetal tissue has not received direct and comprehensive attention when compared to the governance of other human materials. This is well-illustrated by the historical implementation of legislative controls on tissue. These were first placed on foetal tissue decades after they were applied to other human material. Foetal tissue has only been controlled by legislative provisions since the enactment of the HTA 2004. Prior to this, it was subject to limited common law and regulatory provisions.[93] Human tissue has been governed by the law for far longer under the Anatomy Acts 1832 and 1871 and the Human Tissue Act 1961. Foetal tissue did not fall within the scope of these Acts.[94] It also did not fall under the Human Fertilisation and Embryology Act (HFEA) 1990: the legislative framework created to govern gametes and pre-implantation embryos.

The issues posed by this legislative oversight are illustrated by how questions of governance have been approached. The HTA 2004 created a comprehensive framework to govern human tissue. It addressed many specific issues arising out of the Organ Retention Scandal. For example, it added a legal requirement for consent to be obtained for tissue use and sanctions to back this up, to allow certain interests to be prioritised and enforced.[95] A similarly extensive

[92] This question is not directly answered within the HTA framework.

[93] John Peel, *The Use of Fetuses and Fetal Material for Research* (London HMSO, 1972) (hereafter Peel Report and Code of Practice); John Polkinghorne, *Review of the Guidance on the Research Use of Fetuses and Fetal Material* (Cm 762, 1989) (hereafter Polkinghorne Report and Code of Practice); for a discussion of the common law applying to foetal tissue, see later in this section.

[94] Peel Report ibid 8 at [37]; *AB v Leeds Teaching Hospitals NHS Trust* [2004] EWHC 644 (QB), [2005] QB 506 at [122].

[95] See for example HTA 2004 sections 1(1) and 5(7).

framework for gametes and pre-implantation embryos was created by the HFEA 1990. The very first examination of how these materials should be governed by the Warnock Committee quickly led to the creation of this robust legislative framework.[96] The UK is even considered a world leader in the governance of embryos.[97] In contrast, the governance of foetal tissue has not received comprehensive examination. The first attempt to regulate the use of foetal tissue was the creation of the Peel Code of Practice in 1972.[98] It presented *non-legal* and *non-binding* recommendations for the use of the live and deceased foetal subject in medical research alone. This was replaced by the Polkinghorne Code of Practice in 1989.[99] The scope of the new Code was expanded to include guidance on the use of foetal tissue for medical treatment. Other uses or ethical issues were not considered. The Polkinghorne Code was eventually replaced by the HTA 2004 framework, which also does not adequately address the unique ethical questions raised by its use.[100] Only the third attempt to regulate foetal tissue use led to the creation of legislative measures, and this can largely be attributed to the law's reluctance to differentiate it from other human tissues. Out of all these materials, only the governance of foetal tissue has not been approached in a comprehensive way.

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[96] Mary Warnock, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (Cmnd 9314, London HMSO 1984).

[97] Human Fertilisation and Embryology Authority, 'Modernising fertility law' (November 2023) <https://www.hfea.gov.uk/about-us/modernising-the-regulation-of-fertility-treatment-and-research-involving-human-embryos/modernising-fertility-law/> accessed 14 July 2025.

[98] Peel Report (n 93).

[99] Polkinghorne Report (n 93).

[100] HT Authority, *Code of Practice 1: Consent* (September 2009) at [157]-[161].

This disparity is highlighted in the process of collecting materials for stem cell research. Both pre-implantation embryos and post-implantation embryonic and foetal tissues are used in this research because they are valuable sources of stem cells.[101] Julie Kent and Sarah Franklin point out that whilst the supply of pre-implantation embryos is standardised and strictly controlled, the supply of embryonic and foetal tissue is comparably far less regulated or uniformly managed.[102]

Furthermore, questions about how foetal tissue should be governed have only been examined as a reaction to public scandals. The Peel Committee was established in 1970; the same year that the Department of Health was investigating allegations of foetal research misconduct.[103] Although the Committee was kept separate from the investigation, it is unlikely to be a coincidence that the first widespread allegations about foetal research misconduct sparked the first regulatory examination of the use of this material.[104] The Polkinghorne Committee was also set up in response to reports in 1988 of foetal tissue transplants being used for the treatment of Parkinson's.[105] Continuing this trend, the HTA 2004 was drafted following the Organ Retention Scandal.[106]

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[101] Ariff Bongso and Mark Richards, 'History and perspective of stem cell research' (2004) 18(6) Best Pract Res Clin Ob 827; Brumbaugh (n 34) 2300.

[102] Julie Kent, 'The fetal tissue economy: From the abortion clinic to the stem cell laboratory' (2008) 67 Soc Sci Med 1747, 1748; Sarah Franklin, 'Embryonic Economies: The Double Reproductive Value of Stem Cells' (2006) 1 BioSocieties 71 taken from Kent ibid 1748.

[103] See 1.3.1; Kenny (n 60).

[104] The Peel Committee was not established as an inquiry within the scope of the Tribunals of Inquiry (Evidence) Act 1921 (now repealed by the Inquiries Act 2005) and did not directly or openly overlap with the Department of Health's investigation.

[105] (n 103).

[106] See 1.2.

Even when foetal tissue has been subject to controls, they have been inadequate. Neither the Peel Code nor the Polkinghorne Code were legally binding, and they did not contain sanctions for those who contravened their recommendations. No remedy or sanction could therefore apply following the high-profile breaches of the Polkinghorne Code during the events of the Organ Retention Scandal.[107] Both Codes were also limited in scope – likely because they were intended to directly respond to the events of the public scandals that preceded them, rather than to comprehensively consider controls for all uses of foetal tissue. The scope of the Peel Code only covered the use of the foetus in research, and the Polkinghorne Code only extended this to uses in medical treatment. Other uses – such as the use of foetal bodies in art displays – fell outside the scope of both.[108] John Keown identifies several additional shortcomings in the Polkinghorne Code, arguing that 'the recommendations are too often couched in vague terms' and pointing out several unresolved inconsistencies between them.[109] Whilst the HTA 2004 resolved some of these issues – by including foetal tissue in a legislative framework which covered a wider scope of potential uses – it has failed to address many others.[110]

The HTA 2004 also created new problems. For example, different legal provisions apply to foetal tissue depending on its gestational age. Tissue of twenty-four weeks of gestation or greater appears to be legally classified as *deceased* foetal

[107] Redfern Report (n 13) 102-103.

[108] See for example Gibson (n 9).

[109] John Keown, 'The Polkinghorne Report on Fetal Research: nice recommendations, shame about the reasoning' (1993) 19 J Med Ethics 114, 115.

[110] See 1.3 and 1.4.

tissue, whereas tissue of less than twenty-four weeks of gestation is the *living* tissue of the pregnant person.[111] The rules governing the use of living and deceased tissue are different.[112] No explanation is given for why foetal tissue should be governed by different sets of rules purely based on gestational age. Ironically, the Polkinghorne Code was praised for removing the gestational age-based categories that were included in the preceding Peel Code.[113] The HTA Codes have also not addressed the potential implications of obtaining consent when foetal tissue is classified as the pregnant person's tissue. There is a conceptual difference between asking the pregnant person to consent to donate the tissue of another – the foetus – and asking them to consent to donate *their own* tissue. It does not appear that the HTA framework has considered whether this distinction is important or not.

It is evident, then, that many of the unique issues surrounding foetal tissue have not been adequately acknowledged or addressed by the current or previous regulations. This oversight extends to the practical collection of tissue. Unlike other human tissues, foetal tissue is collected following abortion and miscarriage. Obtaining informed consent for tissue donation within these contexts may present unique issues and challenges that do not arise in other tissue collection contexts. As observed by a bereavement midwife 'when you lose a baby initially you are in a state of shock, grief, sadness and denial. You cannot be 100% sure that they absorb all the information'.[114]

[111] HT Authority, *Code of Practice A* (2023) (n 23) 28-29 at [141]-[142]; see 1.3.

[112] (n 78).

[113] Keown (n 109) 115.

[114] Louise Austin and others, 'Effective Communication Following Pregnancy Loss: A Study in England' (2021) 30 Camb Q Healthc Ethic 175, 183-184.

Yet all current and previous regulations have failed to consider and provide practical guidance about any potential issues regarding tissue collection in this context. The original Peel Report contained only a passing reference to abortion and avoided any direct discussion or acknowledgment of foetal tissue collection.[115] The Polkinghorne Report discussed this more directly, but only in response to one specific anti-abortion objection.[116] The Committee made it clear that they did not agree with the view that foetal tissue obtained from abortion was morally tainted and concluded that this tissue could still be used in research.[117] In spite of this position, the Polkinghorne Code recommended 'that great care should be taken to separate the decisions relating to abortion and to the subsequent use of foetal tissue' to ensure a 'separation of these moral issues'.[118] The separation principle had two purposes: firstly, to ensure that the decision to terminate a pregnancy was made before the pregnant person could be approached about donating foetal tissue; and secondly, to separate the source and user of the foetal tissue. Keown argues that the Polkinghorne Committee's justification for this first part of the separation principle was inconsistent:

> [I]t is difficult to see why the report takes such pains to separate the decision to abort from that to use the material when it does not regard abortion as immoral in the first place. Although the report is unclear about the circumstances in which abortion is unethical, it rejects the view that abortion is always immoral.[119]

[115] Peel Report (n 93).

[116] Polkinghorne Report (n 93) 4-5 at [2.5]-[2.8].

[117] Ibid.

[118] Ibid 4 at [2.6], 9 at [4.2], and 10 at [4.6].

[119] Keown (n 109) 118.

The separation principle therefore contradicts the Committee's position that abortion is not immoral and does not morally taint foetal tissue, because surely on this view the separation between donor and user would not be necessary.[120] This separation principle was eventually overridden by the HTA 2004 framework.[121] The Polkinghorne Code does not otherwise provide practical guidance for tissue collection. Such guidance is also absent from the HTA framework. The avoidance of this topic does little to help researchers navigate these contexts when collecting foetal tissue.

Furthermore, the presence of the foetus within the HTA framework is obscured. When it was first passed into law, the HTA 2004 did not make any direct reference to foetal tissue. The language it used – the body of or material from 'a deceased person' – did not appear to include the deceased foetus because the latter is not a legal person.[122] The absence of any mention of the foetus was surprising. Over a thousand foetal bodies were retained as part of the Organ Retention Scandal, which the HTA 2004 was a direct response to.[123] The legal control of the bodies and tissue of 'stillborn children and foetuses' were considered within the scope of the 2002 public consultation and green paper Human Bodies, Human Choices that led up to the creation of the new framework.[124] The consultation specifically acknowledged that it provided 'the opportunity to re-examine some of the Polkinghorne guidelines in the light of more recent developments and attitudes'

[120] Ibid.

[121] HT Authority, *Code of Practice 1* (2009) (n 100) at [157]-[161].

[122] HTA 2004 section 1(1)(a)-(g); see *AG's Reference* (n 33).

[123] Redfern Report (n 13) 100-110; see 1.2.

[124] Department of Health, *Human Bodies, Human Choices: The Law on Human Organs and Tissue in England and Wales: A Consultation Report* (Department of Health, 2002) 5 at [1.15] and 134-147.

and proposed that a higher standard of consent should be required for foetal tissue.[125] This oversight is questioned by Simon Woods and Kenneth Taylor: 'at some point between the consultation of 2002 and the drafting of the code of practice on consent, the issue of foetal tissue was either forgotten or for some reason removed.'[126] Foetal tissue was not the only issue to have been left out of the Human Tissue Bill. Kathleen Liddell and Alison Hall point out that 'rules to address the use of tissue and DNA from incapacitated adults' were also omitted.[127] These rules were later added to the Bill via an amendment.[128] No amendments were introduced to include foetal tissue. Seemingly left out of the HTA 2004, foetal tissue appeared to be one of the very few types of human material not governed by legislative controls or a regulatory authority. At this time, most human tissues were governed by the HTA framework and gametes and embryos were governed by the HFEA framework.

This confusion was finally clarified in 2009 when the HT Authority issued Codes of Practice stating that foetal tissue did fall under the HTA 2004.[129] They specifically stated that the recommendations of the Polkinghorne Code were superseded by the informed consent requirements under the Act.[130] Even so, the mention of foetal tissue within the HTA framework remains scarce. To this date, it is not directly mentioned in the text of the HTA 2004, only in the Codes of

[125] Ibid 135.

[126] Woods and Taylor (n 38) 16.

[127] Kathleen Liddell and Alison Hall, 'Beyond Bristol and Alder Hey: The Future Regulation of Human Tissue' (2005) 13 Med L Rev 170, 193.

[128] Ibid 193-194.

[129] HT Authority, *Code of Practice 1* (2009) (n 100) at [157]-[161].

[130] Ibid.

Practice. Even references in the latter are few and far between. Furthermore, references to the foetus within these Codes have been reduced since their first publication. All statements about the Polkinghorne Code being overridden in the HTA's 2009 Code of Practice on Consent were removed in subsequent revisions.[131] The legal classifications of foetal tissue serve to further obscure their subject. Foetal tissue of less than twenty-four weeks of gestation is renamed as the 'mother's tissue'.[132] Its name is erased from the narrative. In contrast, the HTA framework does not shy away from mentioning human tissue. It is openly declared in the names of the Act and the governing authority.

Even outside of the HTA framework, the law governs foetal and other human tissues in the same way. Deceased human bodies cannot be the subject of property rights under English law.[133] This also extends to the bodies of stillborn foetuses, as recognised in the case of *AB v Leeds Teaching Hospitals NHS Trust*.[134] It involved claims from three sets of parents for wrongful interference with the organs of their children when they were removed after postmortems. One claim concerned the body of a stillborn foetus. The parents argued that they had a right to the lawful possession of the bodies of their children for burial and that the retention of their organs constituted unlawful interference with this right. The court rejected the claims for wrongful interference on the basis that 'the claimants have no right of

[131] The references were first removed in the 2017 update of the Code and remain absent in the following 2023 revision: HT Authority, *Code of Practice A: Guiding principles and the fundamental principle of consent* (April 2017); HT Authority, *Code of Practice A* (2023) (n 23).

[132] HT Authority, *Code of Practice A* (2023) ibid 28-29 [141]-[142].

[133] The court in *R v Kelly* noted that this principle has 'questionable … historical origins' but it is now considered to be entrenched in law: *R v Kelly* [1999] QB 621, 630.

[134] *AB* (n 94).

burial and possession of organs lawfully removed at post mortem and retained'.[135] It ruled that the parents could not have property rights in the bodies because of the long-standing rule in English law that there could be no property in a corpse, which also applied to stillborn foetuses.

There is a notable exception to this rule. Human bodies and tissue can be subject to property rights following an application of work and skill. This exception was laid down in the Australian case of *Doodeward v Spence*.[136] It concerned whether a two-headed 'dead-born' foetus which had been preserved in a jar could be the subject of property rights.[137] The court ruled that it could because the preservation was an application of work and skill. The principle from this case was adopted in English law in *R v Kelly*.[138] The exception has now been codified in the HTA 2004, which applies equally to foetal and other human tissues.[139]

In conclusion, the governance of foetal tissue in England and Wales has been an afterthought. The controls placed on it have been inadequate. In particular, the current HTA framework does not sufficiently acknowledge or address the unique ethical questions that arise in the use of foetal tissue. Instead, the law simply governs foetal and other tissues under the same legal provisions. A pattern has developed where questions about the governance of foetal tissue are avoided or obscured unless a public scandal arises which requires a direct response. In contrast, the governance of other human tissues and embryos have received direct and

[135] Ibid at [161].

[136] *Doodeward v Spence* (1908) 6 CLR 406.

[137] Ibid 416.

[138] *R v Kelly* (n 133).

[139] HTA 2004 section 32(9)(c).

comprehensive legal attention. Because of these oversights, the law is not fit for purpose.

1.5 How can this be resolved?

The outstanding issues that have been avoided must be addressed. Direct consideration must be given to how these issues should shape and inform legal provisions governing foetal tissue. However, it is unlikely that this will be instigated by lawmakers. The cultural context surrounding foetal tissue is one of stigma and silence.[140] It remains a controversial topic within both social and regulatory spheres. The stigma and silence surrounding pregnancy loss makes it easier for problems associated with these experiences to be neglected. Recent government inquiries have highlighted inadequacies in miscarriage and pregnancy care that have long been overlooked.[141] Cases of obstetric violence have also been the subject of recent academic attention.[142] The reluctance of politicians to discuss abortion law reform is also not confined to history. In recent years they have been hesitant to extend legal abortion to include the provision of remote treatment, even though this has long been considered safe.[143] This history of social stigma and silence has set the tone for the governance of foetal tissue use. It engenders a strong deterrent against

[140] See 1.3.1.

[141] Department of Health and Social Care, *The Independent Pregnancy Loss Review - Care and support when baby loss occurs before 24 weeks gestation* (July 2023); Lord Darzi, *Independent Investigation of the National Health Service in England* (September 2024).

[142] See for example Camilla Pickles and Jonathan Herring (eds), *Childbirth, Vulnerability and Law: Exploring Issues of Violence and Control* (Routledge 2019).

[143] Philippa Kemp, 'At-Home Early Medical Abortions Made Permanent in England and Wales' *Oxford Law Blogs: Family & Medical Law Blog* (5 July 2023) <https://blogs.law.ox.ac.uk/family-and-medical-law/blog-post/2023/07/home-early-medical-abortions-made-permanent-england-and> accessed 14 July 2025.

any direct consideration of its governance and the unique issues it raises. It is therefore unsurprising that this topic has been avoided or approached as an afterthought by lawmakers.

This trend also extends to the academic sphere. There is an abundance of discourse on the ethical and legal questions surrounding the control of human tissue and pre-implantation embryos. Examples include whether human tissue should be governed by property law and whether the law should be extended to permit research on pre-implantation embryos after 14 days.[144] By comparison, questions about the use and governance of deceased foetal tissue have received little attention, especially from lawyers.[145]

Whilst these cultural associations remain, it is unlikely that the status quo will suddenly change in the near future. Yet the problems remain – the governance of foetal tissue is inadequate. Rather than shy away from this topic, the law must purposively respond to these outstanding problems. To do so, the groundwork for this must be laid. Yet, because this topic has been largely overlooked by scholarship, there is little existing commentary to draw from. This thesis will lay the foundations by initiating preliminary discussions about the outstanding issues in this area. Several of these have been identified within this chapter and will be expanded upon later in this thesis. Doing so will also highlight this area as one that requires further analysis and attention from both scholars and lawmakers.

[144] Simon Douglas and Imogen Goold, 'Property in Human Biomaterials: A New Methodology' (2016) 75(3) CLJ 478; Sarah Franklin and Emily Jackson, *The 14 Day Rule and Human Embryo Research: A Sociology of Biological Translation* (Routledge 2024).

[145] The primary commentary on the legal position of foetal tissue in England and Wales comes from Woods and Taylor (n 38).

1.6 Conclusion

Like other human tissues, the use of foetal tissue raises several issues which require careful management. Otherwise, conflicts and scandals can occur. The law is well placed to navigate these issues. Yet foetal tissue use raises unique ethical and legal issues. The HTA framework does not appear to recognise these, nor does it adequately respond to them. These unique issues have been overlooked due to the social stigma and silence surrounding foetal tissue, which notably does not apply to other human tissues. Whilst this persists, it is likely that these issues will continue to be overlooked by lawmakers and scholars. This thesis will provide a foundation for directly examining these overlooked issues which pertain to the governance of foetal tissue.

Chapter 2: The Legal and Moral Status of the Deceased Foetus

2.1 Introduction

This chapter will examine what legal status should be given to the deceased foetus. It is through a legal status that we can assign legal protections to a subject and place limits on its use. The law must manage the ethical and legal questions raised by foetal tissue use by placing protections and limits on it, much in the way that the Human Tissue Act (HTA) 2004 has done so for human tissue.[1] These should be different from those placed on other human tissues, because foetal tissue is distinct from other materials and raises unique issues.[2] Therefore, the question of what legal status should be assigned to it requires discrete examination.

The use of foetal tissue only raises issues because we place moral value on it. If it had little to no moral importance, we would not be concerned with questions such as whether foetal remains should be treated with respect or whether it is ethical to use its tissue for transplantation treatment.[3] The law, in seeking to manage these issues, must consider the moral value we place on the deceased foetus and which uses of it are perceived as ethically acceptable. But what moral status should we ascribe to the deceased foetus? This question has not received sufficient attention. Much of the literature focuses only on whether the foetus is a

[1] See 1.2.

[2] See Chapter 1.

[3] See for example Richard B Miller, 'On Transplanting Human Fetal Tissue: Presumptive Duties and the Task of Casuistry' (1989) 14 J Med Philos 617, 623.

person. Theories that suggest that at least some foetuses are not persons do not go further to examine what moral status the foetus should have. This chapter will consider what moral status should be given to the deceased foetus, and how and to what extent the law should be shaped by it. The discussion will cover the following questions: whether it should have the same moral status as a deceased person; how we assign a moral status to the deceased foetus; whether its status should vary depending on gestational age; and whether separate statuses should be assigned to whole bodies and separated tissue.

2.2 Is the deceased foetus a deceased person?

If the deceased foetus is morally indistinguishable from a deceased person, then we have a straightforward answer to the question about what its moral status is. When we refer to a deceased person, we are referring to the body of someone who attained moral personhood before death. Therefore, a deceased foetus should only be recognised as such if we would have viewed the foetus as a person in life.

Should we recognise the living foetus as a person? A foetus – whether living or deceased – is a human by virtue of having human DNA. It is also a unique human being – it has a distinct genotype. But genetic material alone does not make a person.[4] Other qualities must be attained before we recognise a being as a person.[5] The irrelevancy of human genetics is highlighted by the possibility of there being non-human persons. For example, Bonnie Steinbock gives the example of the

[4] See Margaret Little, 'Abortion and the margins of personhood' in John P Lizza (ed), *Potentiality: Metaphysical and Bioethical Dimensions* (Johns Hopkins University Press 2014) 174, 176.

[5] For example, Mary Warren suggests five central traits of personhood: Mary Anne Warren, 'On the moral and legal status of abortion' (1973) 57(1) The Monist 43, 55.

fictional character ET as a non-human who may satisfy the criteria for personhood.[6]

Foetuses undergo rapid growth throughout gestation. During this time, they develop several capabilities such as cognitive function and the capacity to feel pain.[7] In ability-based personhood theories, a person is a being who has attained certain capabilities. The qualities that a person must possess vary between theories. Examples include sentience, the capacity to feel pain, and the development of cognitive abilities such as reasoning.[8] Thresholds for when personhood is automatically attained are also offered, such as at conception, viability, and birth.[9] Within these theories, the foetus can be recognised as becoming a person once it has reached a certain threshold.

However, we should not recognise the foetus as attaining personhood at a fixed-point during gestation. Scientific understandings of the foetus do not support the notion of it being transformed and rapidly gaining cognitive abilities at a single point. Foetal development is gradual – its physical body and cognitive abilities develop gradually over time. While there may be a notable difference in cognitive abilities between a foetus at nine weeks and at thirty-nine weeks, there is little difference between the same foetus at twenty-three weeks and six days and at

[6] Bonnie Steinbock, *Life Before Birth: The Moral and Legal Status of Embryos and Fetuses* (2nd edn, OUP 2011) 52-53.

[7] See for example Royal College of Obstetricians and Gynaecologists (RCOG), *Fetal Awareness Evidence Review* (December 2022) <https://www.rcog.org.uk/media/gdtnncdk/rcog-fetal-awareness-evidence-review-dec-2022.pdf> accessed 12 July 2025.

[8] See Warren (n 5) 55; Steinbock (n 6).

[9] For further discussion see Kate Greasley, *Arguments About Abortion* (OUP 2017) 106; see also Hugo Tristram Engelhardt, 'Viability, abortion, and the difference between a fetus and an infant' (1973) 116(3) Am J Obstet Gynecol 429.

twenty-four weeks. This criticism is echoed by Christopher Kaczor, who argues that these theories equate personhood with thresholds that cannot be morally distinguished from the being that existed immediately before it.[10]

There is scientific uncertainty about when the foetus develops certain capacities, such as conscious experience.[11] Picking a fixed threshold for personhood that rests on an uncertain basis will likely result in overinclusion – the inclusion of early foetuses that have not yet developed this ability – or the exclusion of foetuses that have developed this before the fixed threshold. This threshold may move over time as the scientific understanding of foetal development advances. Furthermore, Kate Greasley argues that the foetus' capacity to survive outside of the womb is not wholly dependent on gestational age, but also on the immediate environment:

> A twenty-four-week fetus inside a pregnant woman on a plane is not viable for the few hours it is in the air, but could become so again when the plane lands and neonatal care units are in close proximity.[12]

Margaret Little concurs, suggesting that the term viability masks underlying variables and issues which can dictate survival outside the womb:

> [H]ow good the chances of survival, how brutal the interventions, how sober the risks of catastrophic impairment, how enormous the resources to assist to relative independence.[13]

[10] Christopher Kaczor, *The Ethics of Abortion: Women's Rights, Human Life, and the Question of Justice* (3rd edn, Routledge 2023) 49.

[11] RCOG (n 7).

[12] Greasley (n 9) 111.

[13] Little (n 4) 183.

These thresholds are arbitrary.[14] Arbitrary limits can serve a justified purpose when used in the law, because its purpose is not to wholly reflect moral status or the nature of a being. It has many other purposes, and arbitrary limits may be necessary to serve them, such as to find a compromise between competing interests or for the practical function of a law.[15]

However, we should consider any moral thresholds that fall partway through gestation as being *unjustifiably* arbitrary, because they do not sufficiently reflect the nature of the foetus. Whilst legal thresholds can be justifiably arbitrary in certain circumstances, as described above and explained in Chapter 3, moral thresholds serve different purposes.[16] Fixed moral thresholds for foetal status are unsuitable because the foetus is a liminal being.[17] It exists in the space between several pre-defined categories. It is not yet a baby but not quite a nothing. It has developed beyond merely being the reproductive material of the genetic parents. It lives within and is dependent upon the body of another person. It cannot create memories in the same way as other humans but does intimately exist within and interact with the body of the pregnant person and can create some physical memories. It is developing new capabilities but has not reached the full extent of these. Although the foetus grows day by day, it does so in small, unquantifiable steps. It does not make great leaps in development as is suggested by threshold theories. Liminal beings do not fit into neat, pre-defined categories. As Karolina

[14] See Greasley (n 9) 195 and 112-115.

[15] For a discussion of when and why the law can be arbitrary, see Timothy Endicott, 'The Impossibility of the Rule of Law' (1999) 19 OJLS 1.

[16] Ibid; see 3.2.2.

[17] Karolina Kuberska and others, 'Death Before Birth: Liminal Bodies and Legal Frameworks' in Chris Dietz, Mitchell Travis, and Michael Thomson (eds), *A Jurisprudence of the Body* (Palgrave Macmillan 2020) 149.

Kuberska and others argue, liminality is not something that needs 'resolving into a more permanent condition in order to be understood and accepted.'[18] Yet this is what these theories seek to do, by recognising foetuses as non-persons before a threshold is reached and as persons after. To do so is to deny the liminal nature of the foetus.

Proponents of the conception theory argue that it avoids this arbitrariness issue because it captures the entirety of foetal life.[19] They suggest that conception marks the start of both foetal life and personhood, ensuring that the foetus does not attain this status at an arbitrary threshold partway through foetal development. However, Greasley cogently argues that the moment of conception is made up of several biological events – she identifies at least ten – and so it remains unclear which event constitutes the morally relevant threshold of conception.[20] She suggests that if we look at foetal development through a microscopic lens, we can break down the process of conception even further, and if a single point is chosen within this process, then it constitutes a threshold.[21] Furthermore, Sinead O'Gorman argues that the idea of recognising foetal life (and so personhood) as starting at conception is a fiction which does not align with biological development:

> 'Life' does not begin at conception - both the egg and the sperm are alive in all sense of the word. Sperm in particular display great activity. At fertilisation, it is merely a genetically novel kind of cell that comes into existence, and if it is successfully attached to the lining of the womb, this cell has the potential to become a human 'individual'. However, even this is not completely true because

[18] Ibid 154.

[19] See for example Kaczor (n 10) chapter 4.

[20] Greasley (n 9) 115.

[21] Ibid 115-116.

> as late as two weeks after fertilisation, the egg may divide and form twins - thus being 'individuals' and not just an individual. Equally, it is possible that the fertilised egg will not form a 'potential human being' but a rather dangerous tumour known as a 'hydatidiform mole'.[22]

Therefore, the issues with fixed threshold theories also apply to the conception theory. They do not reflect the growing capabilities and liminal nature of the foetus. This is also true of any theory which seeks to recognise the foetus as having the moral status of a person at the earliest stage of development, including the potentiality theory.

Under the potentiality theory, embryos and foetuses are assigned an equal moral status to persons on the basis that they have the potential to become persons.[23] This theory lacks specificity. What does potential mean? If given a broad meaning – the potential to become a person – then it would compel us to treat all beings equally on the basis of them holding this potential. An embryo created outside the body would have this potential, but a skin cell would not, because only the former could become a person (if implanted into a womb). Assigning an equal status to the embryo and foetus at every stage of development – such as personhood – would not reflect its liminal nature. The foetus does not remain fixed in time. It is continuously developing capabilities throughout gestation, and we do not view a seven-week embryo in the same way as we view a foetus at thirty-seven weeks. Furthermore, the application of this theory produces absurd results. This is well illustrated by the much-discussed Embryo Rescue Case.[24] A person is given the

[22] Sinead L O'Gorman, 'Foetal Brain Cell Transplants: A Utilitarian Perspective' (1996) UCL Jurisprudence Rev 84, 89.

[23] See for example Michael Tooley, 'Abortion and Infanticide' (1972) 2(1) Philos Public Aff 37; see also a discussion of potential in Greasley (n 9) 154.

[24] For discussion of the Embryo Rescue Case, see Greasley ibid 108; S Matthew Liao, 'The embryo rescue case' (2006) 27 Theor Med Bioeth 141.

choice to rescue a baby or several embryos from a burning hospital.[25] Intuitively, we would choose to save the baby. But if we were to accept that embryos have the same moral status as any person, because they have the potential to become persons, then, as Greasley puts it, we must reach the 'absurd' conclusion that it would be more reasonable to save the embryos in order to save a greater amount of people.[26]

If potential is given a more limited definition – perhaps based on the realistic prospect of becoming a person in the near future – we might limit it to foetuses within the womb and exclude *ex vivo* embryos. The question of how potential should be defined remains outstanding. Should potential depend on the foetus' health and survival potential? If so, a dying foetus would cease to enjoy the moral status of a person because it has lost its potential to become one. As John Keown asks, 'what is the moral status of a fetus which does not enjoy this potential because, for example, it suffers from a condition which will result in neonatal death?'[27] Potentiality is not easily quantified. Regardless of how we define potential, this theory would recognise embryos and foetuses as holding this potential – and therefore all having the same moral status, equal to that of a person – regardless of their gestational age. This theory also fails to reflect the liminal nature of the foetus.

The distinct liminal nature and environment of the foetus should prevent us from recognising it as a person before birth. A person is a pre-defined concept that was not created to capture the unique nature of the foetus. As Little argues:

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[25] Note that these are *ex vivo* embryos.

[26] Greasley (n 9) 108.

[27] John Keown, 'The Polkinghorne Report on Fetal Research: nice recommendations, shame about the reasoning' (1993) 19 J Med Ethics 114, 115.

> Kinds are not just names; they are summary concepts that bring with them wholesale patterns of reasoning, precedent, and the like. The matured fetus is the same as a newborn in intrinsic status, but regulating the body is different from regulating the custody of a child. The category of "person," like the category of "child," was made with physically individuated and separated persons in mind; these are sortals animated by the enterprise of regulating human social interactions. They are, in a phrase, not designed with fetuses in mind. This doesn't mean that fetal status does not matter; it means that it needs to be developed in a theory that is adequate to the, shall we say, unique conditions under which it lives. Fetuses are not natural persons, not because they have no moral status, but because the fetus deserves a theory of its own. Not because the fetus has a lesser intrinsic moral status than the newborn, as though its location inside and attachment to the pregnant woman dilutes its import, but because legal personhood is a concept that has a pragmatic life of its own, and one which, developed to deal with other scenarios, may not extend well to those who reside in another's body.[28]

As Little suggests, we can simultaneously recognise that the late term foetus has a moral status and can become developmentally equal to the just born neonate but at the same time not recognise the foetus as a person. Furthermore, it appears that the status of personhood was not made with the foetus in mind. Unlike other persons, the foetus is hidden within the body of another and is still growing inside their womb. It is a liminal being which defies, and should not be forced into, pre-defined fixed statuses such as person. The environment of the foetus – inside a womb, inside another person – is distinct from the environment of any other person. Pregnancy is unique and unlike any other life stage or relationship. The bodies of the pregnant person and the foetus are entwined during gestation due to a 'constant exchange of gases, glucose and antibodies'.[29] After birth, the pregnant person and the baby have physically separate, independent bodies. Growth in the womb is also unique – it is more rapid and fundamental than growth outside of the womb. The nature of the living foetus is more in flux when compared to the slow growth of

[28] Little (n 4) 187.

[29] Donna Dickenson, *Property in the Body: Feminist Perspectives* (1st edn, CUP 2009) 98.

humans outside of the womb. Physical and mental capabilities are gained in days and weeks for the former, and across months, years, and decades for the latter. As Stuart Derbyshire and Ellie Lee argue, 'seeking an equivalence between foetus and baby … is bound to produce disappointment and exaggeration.'[30]

The differences between foetus and baby are morally significant and allow us to recognise the latter as a person after birth but not the former when hidden in the womb. Whilst birth is a threshold, it is not one that falls partway through gestation, so it does not raise the aforementioned issues associated with other thresholds. Furthermore, these differences make it morally defensible. As Greasley argues:

> Against the conventional view that birth is completely morally arbitrary, I suggested that the transition from the womb to the extrauterine environment is a meaningful event in the life of a new human being. The many physical transformations occasioned by birth are not 'merely' extrinsic. Moreover, reflection upon the importance of separate embodiment in the world for distinctively personal life reveals the ways in which **birth, far from being meaningless, places a new human being in the context within which the capacities of personhood are made possible**.[31]

The foetus should not be recognised as a person, even though it can develop to a stage before birth that compels us to recognise a moral status that is close to or perhaps equal to that of a person. Therefore, the deceased foetus is not a deceased person.

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[30] Stuart Derbyshire, 'Why I see no place for science in the abortion debate' *Times Higher Educational Supplement* (21 January 2005) <https://www.timeshighereducation.com/news/why-i-see-no-place-for-science-in-the-abortion-debate/193606.article> accessed 29 July 2025 taken from Ellie Lee, 'The abortion debate today' in Kirsty Horsey and Hazel Biggs (eds), *Human Fertilisation and Embryology: Reproducing Regulation* (Routledge-Cavendish, 2007) 231, 239.

[31] My emphasis added: Greasley (n 9) 198, see also 195.

Questions about foetal personhood have primarily been explored in the debate about abortion.[32] The focus has been on whether the foetus has a right to life and how this bears on the morality of elective abortion. As a result, other issues raised in the foetal context have not been sufficiently considered. Crucially, there has been little examination of what status the foetus should have – whether living or deceased – if it is not a person.

2.3 How should we assign a moral status to the deceased foetus?

For some, death is seen as a loss. It is the permanent and complete loss of the conscious and living part of a person, and with it the loss of full personhood status. Yet the moral status of personhood is so important during life that some of this importance carries over to the dead body. As James Burtchaell argues, 'If we honor a person while she is living we have no choice but to honour her body after death.'[33] The body is not honoured *as* a person – we do not consider the dead to be identical in status to the living, and so the status of personhood does not remain intact after death. But there is something that remains, that reminds us of the significance of the former status and compels us to treat the body with respect.

This notion of moral status being carried over after death is rejected in the theory of dualism, which instead proposes that there is a moral separation between the two substances that make up a person: the mind and the body. The two are entwined during life but permanently separated after death as the soul departs and

[32] See for example Little (n 4).

[33] James Tunstead Burtchaell, 'University Policy on Experimental Use of Aborted Fetal Tissue' (1988) 10(4) IRB: Ethics & Human Research 7, 8.

the body is left behind.[34] Harry Emson argues that 'without the soul, the body is not and can never again be a part of the person. The cadaver is not, what the body has been.'[35] It is true that the deceased body is no longer identical to the former living person in terms of moral status. A dead body is clearly distinguishable from a living person. Yet Emson's argument that the deceased body becomes an 'object without intrinsic value' and cannot be recognised as a part of the former person are unpersuasive for two reasons, both of which also apply to the foetus.[36]

Firstly, the biography of the person persists after death. The body still resembles the former person shortly after death and matches the images of the person who lives on in the memories of their loved ones. The body does not immediately become a stranger, detached from the former person. As Margaret Brazier argues:

> The dead infant, the wife succumbing to breast cancer at 35, the elderly father dying suddenly of a heart attack do not change their nature for their mother, husband or daughter. They remain Susannah, Lucy and Dad.[37]

Neonates and foetuses, who either have not attained personhood or have only just attained it, may not have established selves that can be as easily preserved in memory after their death. They have not spent years interacting and creating memories with their family and loved ones. Sheelagh McGuinness and Brazier argue that these bodies may therefore be *more* important that older deceased

[34] See for example Harry E Emson, 'It is immoral to require consent for cadaver organ donation' (2003) 29(3) J Med Ethics 125.

[35] Ibid 125.

[36] Ibid 126.

[37] Margaret Brazier, 'Retained Organs: Ethics and Humanity' (2002) 22 Legal Stud 550, 560-561.

persons, because in lieu of memories the body comprises a more significant representation of the former individual:

> The death of a child before her parents is a reversal of the natural order … When an adult or an older child dies, the family share a set of memories of what that person did and said. The physical memory remains, but is supplemented by other kinds of recollection. With the baby or small child, that physical memory may be all that there is. **The body is the baby**.[38]

The biography of the individual – who they were, their memories, the time they spent with others or residing within a person's body – is retained in the body. For young babies and foetuses, the body is a more significant representation of this biography after death.

Secondly, human beings are special by virtue of being human, and the specialness of this human nature is not lost after death. Here, human beings are defined as human organisms with a unique genotype and the potential to develop into persons while living. As Steven Wheatley argues, 'the human species enjoys a uniqueness and specialness that is itself deserving of protection.'[39] The specialness of human bodies can be demonstrated by considering what happens to this specialness when bodies are commodified. A useful illustration of this argument can be seen in Margaret Radin's commentary on the commodification of bodies within a market regime.[40] Radin argues that when people or things are treated in a certain way, this has wider connotations for how they are subsequently viewed. Giving the example of baby selling, she explains that if we allow babies to be

[38] My emphasis added: Sheelagh McGuinness and Margaret Brazier, 'Respecting the Living Means Respecting the Dead too' (2008) 28(2) OJLS 297, 304.

[39] Steven Wheatley, 'Human rights and human dignity in the resolution of certain ethical questions in biomedicine' (2001) 3 EHRLR 312, 322.

[40] Margaret Jane Radin, 'Market-Inalienability' (1987) 100 Harv L Rev 1849, 1925-1928.

bought and sold then we would turn them into commodities. This would not only place market value on the babies, but it would also cause market value to be placed on factors that may influence the overall value of babies, such as their attributes or the reproductive labour of the parents.[41] As such, the commodification of one thing thus creates a domino effect because it has knock-on consequences for the potential commodification of other factors or actors.

Furthermore, Radin claims that when beings have market value placed on them, it can alter social perceptions about them including creating a commodified self-conception.[42] Commodification is not necessarily a bad thing. A whole host of goods and services are commodified and are ascribed market value without raising ethical issues such as food and clothing. Commodification is unproblematic when it applies to things which have no moral status. However, it becomes problematic when it applies to things that have a moral value which is negatively affected by the commodification domino effect described by Radin, namely the special status of human beings. Radin suggests that it is easy to see the 'commodification of babies as an inevitable and grave injury to personhood'.[43] It should also be seen as an inevitable and grave injury to the specialness of human beings, including non-persons and foetuses, because this special nature would also be negatively affected if any human beings were commodified. This is exemplified by the public outcry over the 'horrible' idea of the foetus being, or perceived as being, commodified.[44]

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[41] Ibid 1925.

[42] Ibid 1926.

[43] Ibid.

[44] See 1.3.1; Madeline Simms, 'The great foetus mystery' *New Scientist* (London, 31 December 1970) 592; British Medical Journal, 'Experiments on the Fetus' (1970) 5707 BMJ 433.

Not only does this special status extend to the foetus in life, but it also extends to foetal bodies after death. Michelle Bourianoff Bray argues that Radin's argument should apply to human bodies and tissue.[45] The deceased foetal body is still human – and so it still holds a special moral status. To hold otherwise – that the special status of the foetus does not extend after death – undermines the notion of humans being special. As Joanna Kinney and Richard Miller argue, 'combining our respect for fetal life with our respect of the non-fetal dead creates a presumption of respect for the fetal dead.'[46] Deceased human bodies are still human. Deceased bodies are made up of human cells and represent a stage of the process of human development. If we fail to recognise foetal bodies as special, and treat them accordingly, this will undermine the specialness of other human bodies. A similar argument is made by Burtchaell, albeit in the context of human dignity. Burtchaell argues that we must honour the bodies of human beings – including foetuses – both in life and after death, because to do otherwise 'discredits all ostensible dignity we accorded that person *in vivo* and orients us to treat still other persons with contempt.'[47]

Recently deceased or well-preserved bodies still look identifiably human, even if they are strangers. Imogen Goold argues that, as humans ourselves, the body has significance for our self-identity and personal 'beliefs about the relationship of the physical body to the notion of "self"', which extends to how we

[45] Michelle Bourianoff Bray, 'Personalizing Personalty: Toward a Property Right in Human Bodies' (1990) 69 Tex L Rev 209.

[46] Joanna Kinney summarising and concurring with Miller: Joanna H Kinney, 'Restricting Donative Choice: Fetal Tissue Transplantation and Respect for Human Life' (1995) 10 JL & Health 259, 283, footnote 119; Miller (n 3).

[47] Burtchaell (n 33) 8.

respond to the bodies of strangers.[48] There is a special reaction that occurs when we recognise another human. We recognise them as being part of the same human race, as something different and special, which is not recognised when we compare ourselves to non-human objects or beings.

Researchers and medical professionals who regularly work with deceased bodies and tissue may be more desensitised to emotional responses, especially when the material is not visually recognisable as human. Emson, a pathologist, argues that working with bodies fundamentally changes one's perspective and leads to the belief that they are not special.[49] But research demonstrates that researchers and medical professionals do have unique responses to human bodies and tissues.[50] Such reactions have also been observed in those working with foetal tissue.[51] It appears that reactions to bodies are not consistently altered by desensitisation. Therefore, we should not accept Emson's argument that bodies cannot be considered special on this basis.

Unsurprisingly, the specialness argument invites criticism for constituting speciesism.[52] Jukka Varelius suggests that this view is unfair to other species and is 'morally on a par with such isms as sexism and racism.'[53] But recognising the

[48] Imogen Goold, 'Why does it matter how we regulate the use of human body parts?' (2014) 40(1) J Med Ethics 3, 5.

[49] Emson (n 34) 125.

[50] Goold (n 48); Joseph W Lella and Dorothy Pawluch, 'Medical students and the cadaver in social and cultural context' in Margaret Lock and Deborah Gordon (eds) *Biomedicine examined* (Kluwer Academic Publishers 1988) 125.

[51] Naomi Pfeffer, 'How work reconfigures an 'unwanted' pregnancy into 'the right tool for the job' in stem cell research' (2009) 31(1) Sociol Health Ill 98, 107-108.

[52] See for example Peter Singer, *Animal Liberation* (New edn, Vintage Digital 2015) 22.

[53] Jukka Varelius, 'Minimally Conscious State and Human Dignity' (2009) 2(1) Neuroethics 35, 38.

specialness of humans does not automatically come at the cost of denying the specialness or moral status of other non-human beings. As Kaczor argues, this position does not give a direct answer to questions about animal rights, and it 'leaves open the possibility that there are many other beings of moral worth who are not human.'[54] In the absence of determining a status for non-humans, this argument is not automatically speciesist, nor does it aim to be.

Thus far, this chapter has argued that the foetus has a special, liminal moral status. This status cannot be accurately captured by threshold-based theories that classify foetuses differently at particular points during gestation. It is important to recognise that the living foetus does develop throughout gestation, which involves gradual changes in its physical and mental capabilities. A theory which reflects these changes is the gradualist theory. Greasley points out that there is no clear or fixed moral status conferred by gradualism but notes that the theory is captured by the basic proposition that the moral status of the foetus gradually increases in line with its development during gestation.[55] Gradualism avoids the issues associated with threshold-based theories by avoiding fixed thresholds altogether. Rather, it acknowledges that foetal moral status is constantly in flux. It is therefore able to capture the nature of the foetus as a being that changes day by day; as one that does not remain fixed in time or development; and recognises that foetuses may develop in different ways.

[54] Christopher Kaczor, *A Defense of Dignity: Creating Life, Destroying Life, and Protecting the Rights of Conscience* (University of Notre Dame Press, 2013) 18.

[55] Greasley (n 9) 117, footnote 21. For examples of gradualist arguments see Little (n 4); Warren Quinn, *Morality and Action* (CUP 1994) 20.

For humans outside the womb, we do not view their moral status as increasing (or otherwise significantly changing) as they get older. However, the distinction here is that humans attain moral (and legal) personhood upon live birth.[56] There is no greater moral status that can be attained after this point. The foetus, however, has not yet attained personhood, but will eventually do so if it is birthed as a living person. Throughout gestation, they become developmentally closer to just-born neonates and to a point when they could attain (moral and legal) personhood. A foetus at thirty-seven weeks of gestation will have become more developed than it was at nine weeks, even if it suffers from a developmental disability. The gradualist theory therefore provides a compelling account of foetal moral status (whilst living) because it reflects its liminal, developing nature.

This liminal nature carries over from the living foetus to the deceased foetal body, as is the case for other elements of the moral status of the foetus. The liminality of the deceased foetus is different to the living foetus. The living foetus is in a state of transition during gestation but has the potential to be born as a human baby, whereas a foetus that dies during this transition remains in this liminal state and cannot develop further. Depending on a variety of factors, such as gestational age, a particular foetus may appear closer to one end of the scale than the other. A thirty-nine-week-old stillborn foetus will have attained a greater moral status than a nine-week-old foetus before death. Nevertheless, it remains impossible to quantify differences between deceased foetuses that are closer in time, such as a day or two apart in gestation. Once the foetus dies, it may appear that its moral status becomes fixed in time, because it is not continuing to develop. Yet the

[56] *Attorney-General's Reference (No 3 of 1994)* [1998] AC 245.

liminal nature of the foetus persists because differences between deceased foetuses of different ages remain unclear.

The living foetus has a special moral status by virtue of being human, and this carries over to the body of the deceased foetus. Because of the deceased foetus' special status, its body must be treated with respect. This increases in line with its development throughout gestation. Nevertheless, it should not be treated as a nothing, even when its status is at its lowest, because it still has a special status at every stage.

2.4 To what extent should the law reflect this moral status?

The liminality of the foetus poses a challenge for the law. As Kuberska and others recognise, it 'has the power to destabilize or disrupt legal categories, and such disruption often demands a regulatory response'.[57] Their argument is made in the context of the law applying to miscarriage, but it can be extended to the governance of foetal tissue. The deceased foetus does not fit within the HTA framework's binary categorisations of tissue from the 'mother' or from the stillborn foetus.[58] It forces the foetus into pre-existing legal statuses which deny its liminal nature.

Conceptualising the foetus as the living tissue of the 'mother' also does not reflect its liminality, nor the fact that it is a separate human being.[59] This

[57] Kuberska (n 17) 154.

[58] Foetuses of less than twenty-four weeks of gestation are considered as the 'mother's tissue' alongside 'non-foetal products of conception', and foetuses of twenty-four weeks of gestation or more appear to be recognised as stillborn foetuses: Human Tissue Authority (HT Authority), *Code of Practice A: Guiding principles and the fundamental principle of consent* (June 2023) 28-29 at [141]-[142].

[59] Ibid 28 at [141].

classification places it in the same category as the pregnant person's personal tissue, organs, and 'non-fetal products of conception (i.e. placenta, membranes, umbilical cord, amniotic fluid)' without explaining whether any distinction should be made between these materials.[60] This categorisation fails to recognise that it is the body of a separate human being that, during life, had the potential to grow into a separate human person. As Burtchaell argues, 'the tissue is from within her body but it is the body of another, with distinct genotype, blood, gender'.[61] None of the other tissues in the same category – such as the pregnant person's organs and the placenta – can be described in this way, yet under the HTA 2004 they are unceremoniously grouped together.

There may, nevertheless, be some benefits to treating foetal tissue as the pregnant person's tissue. As will be explored in Chapter 3, some difficult cases may arise if foetal tissue is not categorised as the pregnant person's tissue and thus only controlled by them.[62] Additionally, Donna Dickenson argues that 'we would risk tumbling down some increasingly slippery slopes without a firm notion that women and women alone own their labour in producing reproductive tissue'.[63] In the context of surrogacy arrangements, she argues that 'To say that gamete donation [from a genetic father] and surrogate motherhood should be treated alike is to miss the special nature of women's property rights in labour and childbirth.'[64] The core of her argument is that the reproductive labour of the pregnant person in

[60] Ibid.

[61] Burtchaell (n 33) 8.

[62] See 3.3.

[63] Dickenson (n 29) 69.

[64] Donna Dickenson, *Property, women, and politics: subjects or objects?* (Rutgers University Press 1997) 165.

gestating the foetus should not be discounted or made invisible and indeed may demand greater recognition when compared to the gamete donation from the genetic father. This thesis does not suggest that this reproductive labour should generally be overlooked or discounted. However, it is not the only relevant consideration when determining how we should conceptualise foetal tissue and who should control its use.

The foetus is a distinct and new human being – it is something *more* than just the gametes of the genetic parents and the reproductive labour of the pregnant person. When a child is born alive, we do not assume that this labour alone grants the pregnant person a right to have control over or parent the child. Instead, we recognise that the child is a distinct person who does not inherently belong to the parents, and there are other factors that must be considered in determining who has parental responsibility for them. Similarly, the deceased foetus is a physically distinct being who does not inherently belong to the parents and there are many factors to consider when determining who should decide how this tissue is used. As Dickenson recognises, 'there is the difficulty of knowing how much weight to allow to the genetic contribution of the father; the fetus's genetic endowment is not the potential mother's alone.'[65] In addition to this, I will argue in Chapter 3 that the interests of many parents (not just genetic parents) are engaged in the use of foetal remains and thus must be taken into consideration.[66] Furthermore, if foetal tissue is classified as the tissue of the pregnant person, then they alone would be able to control how it is used. The approach of giving such control to one person

[65] Ibid 169.

[66] See 3.3.1.

has been criticised for giving individuals too much control over the use of tissue.[67] Therefore, this chapter argues that the law must reflect that foetuses are not created by just one person.

The foetus is created from the reproductive material from both genetic parents, not just tissue from the pregnant person. Although the foetus is created from one person's egg, it ceases to be tissue from only that person when the egg is inseminated by the sperm of the second genetic parent. If an egg donor is used, then none of the reproductive material that develops into the foetus will originate from the pregnant person, yet it will still be legally classified as their tissue. The Human Tissue Authority (HT Authority) stipulates that the HTA 2004 'makes no distinction between the disposal of pregnancy remains and the disposal of other tissue from a living person; pregnancy remains are regarded as the tissue of the woman.'[68] Despite this, the HT Authority created specific guidance about how foetal tissue of less than twenty-four weeks of gestation should be disposed of following pregnancy loss.[69] By doing so, the HTA framework has clearly recognised that unique ethical issues arise that distinguish foetal tissue from any other tissue from the pregnant person. As Naomi Pfeffer and Julie Kent rightly argue, 'Policy makers … acknowledge that the public regard pregnancy-related

[67] See for example Jonathan Herring and P-L Chau, 'My Body, Your Body, Our Bodies' (2007) 15 Med L Rev 34, 54-55.

[68] HT Authority, *Guidance on the disposal of pregnancy remains following pregnancy loss or termination* (March 2015, updated September 2024) 2; HT Authority, *Code of Practice A* (n 58).

[69] HT Authority, *Guidance on the disposal of pregnancy remains* ibid.

tissue differently to other residual tissue.'[70] Yet the legal statuses assigned to foetal tissue under the HTA 2004 fail to fully reflect these differences.

The HTA framework uses gestational age as an arbitrary threshold to assign different legal statuses to the deceased foetus. Earlier in this chapter it was acknowledged that the law sometimes needs to use arbitrary limits or thresholds.[71] Yet such thresholds are not necessary to govern foetal tissue. This was demonstrated by the Polkinghorne Code of Practice, which did exactly this and also removed the age-based threshold introduced by the previous Peel Code.[72] The Polkinghorne Committee recognised that the living foetus has a 'special status … at every stage of its development' which carries over to the deceased body.[73] The law must therefore reflect that the deceased foetus is a separate being worthy of its own categorisation. It is not the tissue of another. The law should recognise deceased foetuses has having a special status at every stage of its development. It should always be recognised as deceased tissue from the deceased foetus and separate from the pregnant person.

[70] Naomi Pfeffer and Julie Kent, 'Consent to the use of aborted fetuses in stem cell research and therapies' (2006) 1 Clinical Ethics 216, 216.

[71] See 2.2.

[72] John Polkinghorne, *Review of the Guidance on the Research Use of Fetuses and Fetal Material* (Cm 762, 1989) (hereafter Polkinghorne Report and Code of Practice); John Peel, *The Use of Fetuses and Fetal Material for Research* (London HMSO, 1972).

[73] Polkinghorne Report ibid 4 at [2.4].

2.5 Should separated foetal tissue have the same status as whole foetal bodies?

We should not assume that the moral status of the deceased foetal body should carry over to every separated body part, such as separated foetal brain cells, because this is not the case for other bodies. When material or body parts are removed from a person, the separated material does not retain the identical moral status of the person's body, whether living or deceased. We may recognise that it is from that person, but it is not *that person*. Once removed from their body, these separated materials have a lesser status. As John Harris points out, some human tissue is treated with no reverence and is thrown away as a waste product, such as material attached to 'toilet-paper, soiled bandages, [and] plasters'.[74] This attitude does not apply equally to all body parts. McGuinness and Brazier suggest that although we may be content to discard these materials, we would not want them to be used in certain ways. We might throw away our loose hairs, but we would not be content for our hairdresser to sell our hair to a biotechnology company seeking the commercial use of our DNA.[75] Brazier has also argued that certain organs, such as hearts, can have more significant moral value than other organs or tissue.[76] Therefore, because separated body parts have a lesser status than the person they are taken from, we should not assume that the status of the deceased foetal body should apply equally to separated parts. There also appears to be variation in the status assigned to different materials, such as the difference between a heart and

[74] John Harris, 'Law and Regulation of Retained Organs: The Ethical Issues' (2002) 22 Legal Stud 527, 546.

[75] McGuinness and Brazier (n 38) 300.

[76] See Brazier (n 37); Margaret Brazier, 'Organ retention and return: problems of consent' (2003) 29 J Med Ethics 30.

skin cells left on soiled bandages. As such, it should be considered whether all separated foetal tissues should have the same status.

The foetus is not a person. Because of its distinct nature, we should view the relationship between foetal bodies and separated foetal tissue differently to how we view the relationship between other bodies and their separated parts. The deceased foetus may not have a clearly identifiable body. At times, it may visually appear as a collection of tissue. This can depend on gestational age and how it is removed from the womb, such as the method of extraction used for abortion. For example, dilation and evacuation (D&E) extracts 'fragmented' foetal and placental tissue.[77] Other methods, such as low-pressure aspiration abortion, can minimise disruption to the resulting tissue when it is extracted, but the foetal body may still be broken up.[78] This collection of tissue will constitute the entire deceased foetus (and sometimes other parts, such as placental tissue) but it will not resemble an intact whole body.

It does not make sense to assign a different moral status to a body simply because it is not easily identifiable as a whole body. If a person was crushed in a car crash, so much so that their body was comprised of a mass of crushed tissue, this would constitute the primary components of their body. In such a case, we would still consider it the remains of the person rather than body parts that have been separated from the main body. The collection of crushed tissue would have the status of a deceased person. The absence of an identifiable whole body is not a

[77] Linda M Ernst, Lori Gawron, and Michael K Fritsch, 'Pathologic Examination of Fetal and Placental Tissue Obtained by Dilation and Evacuation' (2013) 137 Arch Pathol Lab Med 326, 327.

[78] G Michael Nauert and Thomas B Freeman, 'Low-Pressure Aspiration Abortion for Obtaining Embryonic and Early Gestational Fetal Tissue for Research Purposes' (1994) 3(2) Cell Transplant 147, 148.

good enough reason to classify material as separated tissue. In the same way, if a foetus is comprised of fragmented tissue, then it should be recognised as the body of the whole foetus and assigned the same moral status. In most cases, the foetus will have a whole body while inside the womb and will only become fragmented during procedures such as abortion. The method of termination or extraction from the womb should have no bearing on the moral status of the foetus because these are actions by external actors which do not fundamentally change the moral nature of the foetus.

Even if some foetal tissue becomes separated – such as if it is removed from the foetal body or from the collection of tissue comprising the foetus – it should retain the same special moral status. This is because separated tissue constitutes a more substantial part of what the foetus is when compared to separated tissue from a deceased person. The deceased person represents the former person who exercised autonomy over their body and possibly had interests regarding the disposition of their body and parts after death. By comparison, a deceased foetus has not experienced memories or interests in the same (or in any) way. Individuals are made up of a combination of memories, feelings, interests, physical bodies, and other qualities. When we remove several of these things – as the foetus may not have identifiable memories, feelings, or interests – then the remaining elements such as their physical body become a more significant part of who they are, or were, as an individual. This makes the physical tissue a more substantial aspect of what the deceased foetus *is* when compared to a deceased person..[79]

[79] See McGuinness and Brazier (n 38) 304.

Furthermore, when a body part is removed from a whole adult body, it is just a small part of the entire body. We can still confidently identify the main body of a person even after both their legs are amputated. The deceased embryo or foetus is very small – especially at an early gestational age – and so the removal of any part may constitute a significant portion of its body. We might also struggle to visually identify a collection of tissue as comprising the body of a foetus when it is fragmented, even before sections of tissue are taken and used elsewhere. The recognition of an intact foetal body is not a necessary condition for assigning a special moral status to it, and so the same applies to separated tissue.

There is also a clear limit to the moral status we are willing to assign to the separated body parts from a person. It would be ridiculous to assign personhood to a human arm. Therefore, we would not accept that an amputated arm would retain the full moral status of personhood when it is removed from the body of a living person. This issue is avoided in the case of the foetus because it should not be considered a person. Therefore, the argument that its separated body parts should retain the same moral status does not fall foul of the ridiculous idea of assigning personhood to an arm.

In conclusion, the deceased foetus is distinct enough from the relationship between whole human bodies and separated body parts that we cannot make the same assumptions about whether a different status should be assigned to foetal bodies and foetal tissue. In lieu of this assumption, separated foetal tissue should be assigned an equal special moral status to whole foetal bodies because it comprises a substantial part of the foetus.

2.6 What if foetal tissue cannot be separated from non-foetal products of conception?

In practice, it can be difficult to distinguish foetal tissue from other types of material. Foetal tissue is ejected or extracted from the womb alongside other conception tissue including the placenta, membranes, and amniotic fluid. If the tissue is disrupted, which is often the case with abortion methods, then it may be difficult to distinguish between foetal tissue and other conception tissue.[80] If we cannot either distinguish or separate foetal tissue from other tissue, what status should we assign to this collection of material? To answer this, we must first consider how we should classify conception tissue.

In medical and wider literature, non-foetal conception tissue is conceptualised in different ways: as tissue from the foetus, tissue from the gestational person, or a mixture of both. For example, Kent, Maria Fannin, and Sally Dowling point out that medical literature often presents the placenta as 'genotypically foetal tissue'.[81] There is also a debate over whether umbilical cord blood belongs to the baby or the pregnant person after live birth.[82] Biologically speaking, conception tissue is a mixture of material from both the foetus and the pregnant person.[83] Donna Dickenson argues that we cannot make clear distinctions between foetal and maternal tissue within conception tissue because

[80] Ernst, Gawron, and Fritsch (n 77); Nauert and Freeman (n 78).

[81] Julie Kent, Maria Fannin, and Sally Dowling, 'Gender dynamics in the donation field: human tissue donation for research, therapy and feeding' (2019) 41(3) Sociol Health Ill 567, 574.

[82] Dickenson (n 29) 97-98; see for example Stephen R Munzer, 'The Special Case of Property Rights in Umbilical Cord Blood for Transplantation' (1999) 51(3) Rutgers Law Rev 493.

[83] Kent, Fannin, and Dowling (n 81) 574; Dickenson ibid 97-98.

their bodies are so entwined during development due to a 'constant exchange of gases, glucose and antibodies'.[84]

If we can say that conception tissue is at least in part foetal tissue, then this material should be assigned the same status as other foetal tissue. This argument can be understood by exploring the consequences of not assigning a status in this way. This chapter has argued that a collection of foetal tissue should be assigned the same status as a foetal body. This should also apply to separated foetal tissue. However, if foetal tissue is mixed up with conception tissue, and we assign a lesser status to conception tissue, then we cannot say that the collection of tissue as a whole should be assigned the same moral status as a deceased foetus. If this collection of tissue comprises all the tissue from a single foetus, and the conception tissue cannot be separated from it, then none of the foetal tissue can ever hold the special moral status assigned to other foetal bodies. The only way for that foetus to be assigned the moral status accorded to other deceased foetuses is if we assign the same moral status to the collection of tissue that includes conception tissue.

Furthermore, if conception tissue can be separated from foetal tissue, this material should still be given the same moral status as foetal tissue but should be classified separately. This chapter has argued that all separated foetal tissue should be assigned the same status as a foetal body. Conception tissue is still biologically foetal tissue, even if only in part, and so should be assigned moral status in the same way as other foetal tissues. However, conception tissue should not be conceptualised as wholly foetal tissue, because it is also partly derived from the pregnant person. Assigning a moral status to conception tissue that is equal to the

[84] Dickenson ibid 98.

moral status of foetal tissues does not prevent us from conceptually recognising that it derives from both the foetus and the pregnant person.

It is also inappropriate for any of these tissues to be classified as waste. The HTA 2004 allows any human tissue to be disposed of as 'waste' after it has been used for a scheduled purpose – such as medical research or treatment – or is taken from a body after:

> (a) receiving medical treatment,
>
> (b) undergoing diagnostic testing, or
>
> (c) participating in research.[85]

The category of clinical waste also includes

> [A]ny waste which consists wholly or partly of: human or animal tissue; blood or other body fluids; excretions; drugs or other pharmaceutical products; swabs or dressings; or syringes, needles or other sharp instruments.[86]

In short, it includes many materials that either have no moral value or do not hold the same special moral status as foetal bodies and tissues. As Harris reminds us, many of these materials will be unceremoniously disposed of without much objection.[87] However, other human materials with significant moral status – such as the whole bodies of deceased persons – are never classified as waste.[88] Instead, there is a legal requirement for them to be buried or cremated.[89] Foetuses that die

[85] Human Tissue Act (HTA) 2004 section 44(2), section 44 generally, and Schedule 1.

[86] HT Authority, *Code of Practice A* (2023) (n 58) 40; The Controlled Waste Regulations 1992 section 1(2).

[87] Harris (n 74) 546.

[88] Whole bodies are not included in HTA 2004 section 44.

[89] See for example Public Health (Control of Disease) Act 1984 section 46.

after twenty-four weeks of gestation must also be legally buried or cremated.[90] However, this requirement does not apply to foetuses of less than twenty-four weeks of gestation, or other separated foetal tissue, and they can still fall within the definition of waste. In 2015, the HT Authority issued specific guidance about the disposal of 'pregnancy remains', including the recommendation that they should be stored in a separate container 'to other clinical waste' when incinerated.[91] However, they can still be disposed of alongside clinical waste. Foetal bodies and tissue should instead be disposed of in a manner that reflects their special moral status. This does not necessarily need to involve burial or cremation.[92] There should, however, be more separation between these tissues and other clinical waste. This may involve disposing of it separately – not just in a separate container – especially when it is for a whole deceased foetal body. Furthermore, the language of waste itself indicates that the foetus has no relevant moral value, thus undermining its special status. It does not compel us to treat the foetal body with respect.

2.7 Conclusion

We should not recognise the foetus as a person during life or as a deceased person after death because the foetus is a distinct liminal being that cannot fit into the pre-defined status of personhood. Instead, the deceased foetus should attract a special

[90] Births and Deaths Registration Act 1953; affirmed in *AB v Leeds Teaching Hospitals NHS Trust* [2004] EWHC 644 (QB), [2005] QB 506 at [272].

[91] 'Pregnancy remains' refers to foetal tissue of less than twenty-four weeks of gestation under the HTA: HT Authority, *Guidance on the disposal of pregnancy remains* (n 68) 6 at [38]-[39].

[92] To require burial or cremation for *all* foetal tissues may produce absurd consequences.

moral status because of its nature as a unique human individual. Because of this status it must have a corresponding legal status which requires it to be treated with respect and not classified as waste material or as tissue from the pregnant person. This moral status increases in line with foetal development, meaning that the moral status of a deceased foetus of thirty-nine weeks of gestation is greater than a deceased foetus of nine weeks of gestation. It is enough for the law to recognise that all foetuses have a special moral status which increases as gestation progresses. Because of its unique nature, the way we view the relationship between the whole foetal body and separated tissue should be viewed differently to how we would traditionally view the relationship between the bodies of deceased persons and their separated tissue. As a result, a special moral status should apply equally to whole bodies and separated tissue from the deceased foetus, including conception tissue.

Chapter 3: Managing Conflicting Interests in Foetal Tissue Use

3.1 Introduction

Several groups have interests in how the deceased foetus is used. Public health interests are engaged when foetal tissue is used in medical treatment and research. Parents may see the foetus as their child and want to memorialise them by having a funeral and burying the body. Many religious communities believe that the foetal body should be treated with respect and used in specific rites or ceremonies. These are only a few examples. At times, these interests may conflict. Group A may want to use foetal tissue for purpose A, which would prevent Group B from using foetal tissue for purpose B. When these conflicts arise, who should decide how foetal tissue is used?

Take the following examples. The performance of rituals around death for the foetal body are important to many families after pregnancy loss. This may include holding a funeral and having the body buried or cremated.[1] As Margaret Brazier suggests, funerals are an important way for families to honour the body of their loved one because they represent 'the last service those who loved him or her can render to them.'[2] In some communities, it may be important for the body to be buried in accordance with religious or other traditions, such as burying the body

[1] Aimee Middlemiss, 'Pregnancy remains, infant remains, or the corpse of a child? The incoherent governance of the dead foetal body in England' (2021) 26(3) Mortality 299, 307-308.

[2] Margaret Brazier, 'Retained Organs: Ethics and Humanity' (2002) 22 Legal Stud 550, 560.

whole or as soon as possible after death.[3] These traditions may prevent the foetus from being used in other ways to benefit other interests. If the foetus is buried whole, none of its tissue will be donated for use in medical research or treatment for the furtherance of public health interests. Similarly, if the body is buried as soon as possible after death, it may take place before questions about tissue donation can be raised.[4] Parents may also object to the donation of foetal tissue for a number of reasons such as religious beliefs, fears that the foetus will be mistreated, or feeling 'ethical responsibility' for the foetus and wanting to retain control over how its body is used.[5] If their wishes are followed, it would prevent foetal tissue from being used to further other interests. These examples highlight the conflicts of interest that can arise over how the foetal body should be used. Further conflicts may arise if parents disagree amongst themselves about donation. In some cases, it will not be possible for all these interests to be realised. A single foetus cannot be used in conflicting ways: it cannot have its tissue donated to medical research *and* be buried whole.

Every scenario will be different. In many cases, the interests held by these groups may align, and no conflict will arise. For example, parents may happily agree to donate foetal tissue. In others, conflicts will persist. This chapter will consider how persisting conflicts over foetal tissue use should be resolved. It will

[3] See for example beliefs in the Romany community about burying bodies whole: Sheelagh McGuinness and Margaret Brazier, 'Respecting the Living Means Respecting the Dead too' (2008) 28(2) OJLS 297, 309.

[4] See for example Islamic beliefs about burying the body as soon as possible after death: Kiarash Aramesh, 'The Ownership of Human Body: An Islamic Perspective' (2009) 2 J Med Ethics Hist Med 4.

[5] Naomi Pfeffer, 'What British women say matters to them about donating an aborted fetus to stem cell research: A focus group study' (2008) 66 Soc Sci Med 2544, 2552; McGuinness and Brazier (n 3).

discuss how interests should be managed, including whether a compromise should be reached or whether one set of interests should override others. This will be considered both for conflicts between interest groups, such as between parental and public health interests, and intergroup conflicts, such as disagreements between parents. The remainder of the chapter will examine how interests should be protected and enforced.

3.2 How should conflicts of interest be managed?

Conflicts of interest also arise over decisions about the use of human organs. A common conflict that arises is as follows: should organs be used for life-saving transplantation treatment if families object to the donation of their deceased loved one's organs? Whose interests should be followed – those of the family or public health interests and those of the dying patient? These questions – which came to the fore following the events of the Organ Retention Scandal – sparked a debate over how such conflicts should be managed.[6] Both Brazier and John Harris argue that conflicts should be resolved by identifying which set of interests should be prioritised over others, at least as a starting point.[7] They both recognise that the paramount interests are those of the deceased, their loved ones, and those who would benefit from the use of the organs. However, they disagree on which interests should be prioritised and why. Harris tells us that in order to balance interests we must determine which 'carry most moral weight', and ultimately

[6] For a discussion of the Organ Retention Scandal, see Chapter 1.

[7] Brazier (n 2); Margaret Brazier, 'Organ retention and return: problems of consent' (2003) 29 J Med Ethics 30; John Harris, 'Law and Regulation of Retained Organs: The Ethical Issues' (2002) 22 Legal Stud 527.

argues that the interests of the living who would benefit from the receipt of organs should take priority.[8] Against this, Sheelagh McGuinness and Brazier argue that pitting interests against each other is too simplistic an approach.[9] This is because interests are variable and cannot easily be quantified, so we cannot justifiably assign blanket value to particular interests. Due to this variability, it is not possible to perform a fair balancing exercise in every scenario. Furthermore, this exercise is highly subjective and would produce a different result depending on who is performing it. For example, Harris affords little moral weight to the grief experienced by families and loved ones because they are 'illusions' that only entitle them 'to sympathetic consideration, not a greater obligation or right to dispose of the body.'[10]

Brazier counters that Harris does not give sufficient consideration to personal and family interests.[11] Brazier argues that these interests should be prioritised because they represent the views of either the former person or those in the closest relationship to the former person. In her view, the interests of the former person and their loved ones will suffer the greatest harm (as compared to other interests) if organs or tissue are used against their wishes.[12] Nevertheless, Brazier proposes that these interests should simply be taken as a starting point, and we

[8] Harris ibid 540 and 548; John Harris, 'Organ procurement: dead interests, living needs' (2003) 29(3) J Med Ethics 130, 130; Charles A Erin and John Harris, 'An ethical market in human organs' (2003) 29 J Med Ethics 137, 137.

[9] McGuinness and Brazier (n 3) 306.

[10] Harris (n 7) 533 and 548.

[11] Brazier (n 2) 550-551.

[12] Brazier (n 7) 32-33.

should then consider when and for what purposes it is justifiable to override them.[13] Unlike Harris' approach, where interests are pitted against each other in a zero-sum manner, Brazier does not suggest that personal and family interests should *always* trump other interests.

The interests in the debate over organs are different to the interests that arise for foetal tissue use. A person may express many interests and preferences during their life, such as religious or spiritual views. They may express direct wishes about what they would like to happen to their body after death, such as cremation or organ donation. McGuinness and Brazier argue that the wishes of the person should be respected after their death and should be prioritised over other interests.[14] The same argument cannot be applied to the deceased foetus. It is not possible to identify the preferences of the foetus regarding the use of its tissue after death. The foetus does not experience memories or express interests in the same (or in any) way as a person.[15] This is because it is a gradually developing being that has not yet reached full cognitive function. Even if a foetus could have personal interests in what happens to its body after death, which it likely cannot, it would not be able communicate these. Richard Miller suggests that 'of abortuses, rational premortem wishes would have to be presumed or hypothesized', but does not offer a basis for identifying such wishes.[16] Simply guessing what the wishes of the foetus would be without an evidential basis would not be useful. Because the personal interests of

[13] Brazier (n 2).

[14] McGuinness and Brazier (n 3).

[15] See Chapter 2.

[16] Richard B Miller, 'On Transplanting Human Fetal Tissue: Presumptive Duties and the Task of Casuistry' (1989) 14 J Med Philos 617, 623.

the foetus are not identifiable, they cannot feasibly be taken into consideration as we would do so for deceased persons. Because of this, any *conclusions* from the debate over managing conflicting interests in human organ use cannot apply here.

It should not be forgotten that the deceased foetus has a special moral status.[17] This should be reflected and protected by a commensurate legal status which should protect this material from being used in ways that undermine its moral status. This legal status should take precedence over all interests: otherwise, it becomes an empty status. Yet this status alone does not help us determine what should be done with each individual deceased foetus. It tells us how the foetal body *should not* be used, not how it *should* be used. The focus in this debate should instead be on external interests.

In some conflicts, external interests may be considered as being equally important, and so it would be unjustified for one set of interests to completely override all others. In these cases, a compromise is often sought to find a middle ground between conflicting views. For example, abortion law frameworks in England and Germany have been described as a compromise because they both permit legal abortion but place limits on when it can be accessed.[18] These approaches seek to find a middle ground between the two polarised sides of the abortion debate: abortion on demand and a complete prohibition on abortion. The Human Fertilisation and Embryology Acts (HFEAs) 1990 and 2008, which govern the storage and use of gametes and embryos outside the body for fertility treatment

[17] See Chapter 2.

[18] Christina P Schlegel, 'Landmark in German Abortion Law: The German 1995 Compromise Compared with English Law' (1997) 11(1) IJLPF 36; Kerstin Nebel and Steffen Hurka, 'Abortion: finding the impossible compromise' in Christoph Knill, Christian Adam, and Steffen Hurka (eds), *On the Road to Permissiveness? Change and Convergence of Moral Regulation in Europe* (OUP 2015) 58.

and research, have struck a similar balance. As Hale LJ in *Mrs U v Centre for Reproductive Medicine* explains:

> The new scientific techniques which have developed since the birth of the first IVF baby in 1978 open up the possibility of creating human life in ways and circumstances quite different from anything experienced before then. These possibilities bring with them huge practical and ethical difficulties. These have to be balanced against the strength and depth of the feelings of people who desperately long for the children which only these techniques can give them, as well as the natural desire of clinicians and scientists to use their skills to fulfil those wishes. Parliament has devised a legislative scheme and a statutory authority for regulating assisted reproduction in a way which tries to strike a fair balance between the various interests and concerns.[19]

The HFEA framework balances the interests of parents, gamete donors, the welfare of future children, and many others.[20] Other areas of English law also use balancing exercises to weigh competing interests and factors, such as the best interests exercise which is used to make medical decisions for a person lacking capacity.[21] The compromise approach can be appropriate when there is no compelling reason to prioritise one set of interests over others, and there may be good reasons to try and accommodate all interests or at least as many as possible. A compromise should be found if the conflicting interests are equal. If they are not, another approach must be adopted, such as those put forward by Brazier and Harris: one set of interests should be prioritised over others, either completely (under Harris' approach) or as a starting consideration which may be overridden by other interests in certain scenarios (under Brazier's approach).

[19] *Mrs U v Centre for Reproductive Medicine* [2002] EWCA Civ 565, [2002] Lloyd's Rep Med 259 at [24].

[20] See for example Human Fertilisation and Embryology Act (HFEA) 1990 section 13(5).

[21] Mental Capacity Act 2005 section 4.

3.2.1 An argument for utilitarianism

Brazier argues that we must consider the consequences that occur when interests are satisfied or denied. In the debate surrounding human organ use, Brazier posits that families will suffer severe and irreparable harm when their interests are denied:

> Relatives of people whose organs were removed without consent have expressed to me fears that at the Resurrection their beloved husband or father will not be resurrected because he was not buried whole. Or he will endure eternity disfigured and disabled … The pain such a belief must produce is acute and life-destroying … For those people whose faith or personal beliefs attach significance to bodily integrity after death, the hurt done after death may haunt their lives.[22]

The consequences that arise when foetal tissue is used in line with certain interests and against others must also be considered. These are captured by utilitarianism, which accounts for the harmful and beneficial consequences of an act. Under classic utilitarianism, the morally correct outcome is the one that maximises pleasure and minimises pain for the greatest number of people.[23] This is known as the 'greatest happiness principle' or 'principle of utility'.[24] Utilitarianism is often applied in the medical context because it provides a principled basis for determining how to allocate scarce medical resources by identifying and weighing up the beneficial and harmful consequences that result from different decisions. As Alastair Campbell explains:

> By calculating the amounts of pleasure and pain accruing we should be able to decide whether to legislate for the donation of more organs or not, and whether to extend treatment facilities or not.[25]

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[22] Brazier (n 2) 560 and 565.

[23] Jeremy Bentham, *An Introduction to the Principles of Morals and Legislation* (Clarendon Press 1876).

[24] Eleanor Mansfield, 'Utilitarianism and the allocation of NHS medical resources' (1994) 1 UCL Juris Rev 136, 139.

[25] Alastair V Campbell, *Medicine, Health and Justice: The Problem of Priorities* (Churchill Livingstone 1978) 39.

Whilst the ultimate goal of utilitarianism is to maximise utility, the way that this is conceived will differ depending on the version that is adopted.[26] Classic utilitarianism focuses purely on maximising pleasure and minimising pain. However, Brad Hooker notes that modern schools of thought propose that other desirable and undesirable outcomes must also be considered within utilitarianism, such as 'knowledge, friendship, autonomy, [and] achievement' and that utility could be construed as 'the fulfilment of desire or the satisfaction of preferences'.[27] Desirable outcomes can and should encapsulate the satisfaction of interests, societal welfare, and the fostering of other relationships, including between family members, parents, and loved ones. The interests of various groups in the use of foetal tissue, as well as other consequences that arise from the satisfaction or dissatisfaction of these interests, can therefore be directly considered under utilitarianism. This is also recognised by Craig Purshouse, who argues that the satisfaction of interests should be the goal that is maximised by utilitarianism.[28]

Classic utilitarianism's focus on the maximisation of pleasure is criticised by Ronald Dworkin for failing to treat people as true equals.[29] It does not respect people as human beings and instead treats them as means to the maximisation of social welfare. One form of utilitarianism, act-utilitarianism, determines whether an act itself is morally right based on whether it maximises utility. As Hooker explains, its application implies 'that killing an innocent person, or stealing, or

[26] Nigel Simmonds and Joshua Neoh, *Central Issues in Jurisprudence* (6th edn, Sweet & Maxwell 2022) 18–19.

[27] Brad Hooker, 'Rule-Utilitarianism and Euthanasia' in Hugh LaFollette (ed), *Ethics in Practice: An Anthology* (4th edn, Wiley Blackwell 2014) 76, 77.

[28] Craig Purshouse, 'Utilitarianism as tort theory: countering the caricature' (2018) 38 LS 24, 27.

[29] Ronald Dworkin, *Taking Rights Seriously* (5th impression, Duckworth 1987) 275-276.

breaking a promise would be morally right if the expected and actual utility of the act would be greater, even if just slightly greater, than that of any alternative act.'[30] Therefore, under act-utilitarianism, it would be morally correct to use foetal bodies in ways that undermine their special liminal status if it resulted in the greatest utility. As argued in the previous chapter, such uses should not be permitted because they will lead to the erasure of the special status of humans, which in turn harms *all* human beings.[31]

Collective goals, such as the protection of the special status of all humans, should be considered valuable and desirable outcomes under the principle of utility because, as Nigel Simmonds and Joshua Neoh rightly state, 'they have positive consequences for the lives of individuals.'[32] A similar argument is made by Fatima Kola in the context of torture. Kola argues that torture is so 'abhorrent, and the right not [to] be tortured is so intrinsic in the concept of individual dignity, that to permit it is to make an ultimate concession to the idea that security trumps rights.'[33] The inherent issue in act-utilitarianism is that, because acts are assessed on a case-by-case basis, less weight is placed on the furtherance of collective goals. Therefore, in some instances the utility produced by using foetal tissue in disrespectful ways might be slightly greater than that of any other act, even if it undermines collective goals, and so would be considered morally correct. The application of act-utilitarianism here therefore fails to duly respect the status of human bodies and treat them as equals. As Dworkin argues, in order to achieve true equality between

[30] Hooker (n 27) 78.

[31] See 2.3.

[32] Simmonds and Neoh (n 26) 19.

[33] Fatima Kola, 'Torture and terrorism: a case study' (2007) 13 UCL Juris Rev 85, 105-106.

individuals under utilitarianism, they must be treated as ends in themselves rather than as means to an end.[34] This must also apply to bodies and tissue after death because, as argued in Chapter 2, these share the same special moral status by virtue of being human.

Rule-utilitarianism avoids this issue by focusing on the utility of rules and assessing acts in relation to said rules. Under rule-utilitarianism, acts are morally justified if they are in accordance with rules that have been created to promote the greatest utility.[35] Acts are not assessed on a case-by-case basis, and instead consideration is given to how a rule should be formulated to promote the greatest utility overall. Collective goals are thus afforded more weight under this assessment. For example, a rule outlawing murder would result in greater good than the absence of it. Because of this rule, the act of murder would therefore still be prohibited even in rare cases where it produced greater utility in those circumstances, thereby preventing individuals from being treated as means to maximise social welfare. As Hooker explains:

> For unlike act-utilitarianism, rule-utilitarianism agrees with common conviction that individual acts of murder, torture, promise-breaking, and so on can be wrong even when they produce somewhat more good than their omission would produce.[36]

The law has an established interest in creating rules that maximise societal welfare (and other desirable outcomes) and minimise harms, without treating individuals or bodies as means. This is evident in the laws that protect individuals against the infliction of physical and psychiatric harm under criminal and tort law. Intentional

[34] Dworkin (n 29) 275-276.

[35] See Hooker (n 27) 78.

[36] Ibid.

violent acts are criminalised and carry harsh punishments.[37] The unintentional infliction of harm is also penalised, such as under the tort of negligence and the crime of gross negligence manslaughter.[38] Harm is a crucial criterion for the tort of negligence – the tort will not be made out if a person has not suffered material harm.[39] This is what the law seeks to protect against. This is echoed by Purshouse, who sees 'the law of tort as serving a protective function'.[40] Brazier similarly argues that primary functions of the torts of assault and battery are to prevent violence, protect individuals from harm, and protect welfare interests.[41]

Furthermore, it has been argued by Purshouse that such rules under tort law are underpinned by rule-utilitarianism. Purshouse posits that it is 'undeniable that many judges rely on utilitarian reasoning when deciding tort cases and that 'utilitarianism can provide a convincing explanation of tort law' as one that maximises the satisfaction of people's interests:

> [H]aving rules that protect people's interests through the law of tort enables us to predict how people will behave and arguably leads to good *consequences*. If judges decided each tort case from scratch based upon what they believed would have the best outcomes, then ultimately the law would not achieve the satisfaction of people's interests. The law would become unpredictable and the result in each case would depend upon the moral opinions of the judge deciding it.[42]

[37] See for example Offences Against the Person Act 1861 sections 18 and 20-23; *DPP v Little* [1992] QB 645.

[38] See for example *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [2015] AC 1430; *R v Adomako* [1995] 1 AC 171.

[39] *Dryden v Johnson Matthey plc* [2018] UKSC 18, [2019] AC 403.

[40] Purshouse (n 28) 26.

[41] Brazier (n 2) 564.

[42] Purshouse (n 28) 25 and 32; see also *Tomlinson v Congleton BC* [2003] UKHL 47, [2004] 1 AC 46 per Lord Hobhouse at [81].

This argument suggests that rule-utilitarianism already provides a unifying basis for the management of private interests under English tort law. Relying on this, it can be suggested that the adoption of rule-utilitarianism for the management of interests in foetal tissue use would be a principled development of the law.

The law's protection extends beyond harms to living human beings. Damage to property is protected against under the torts of negligence and private nuisance, as is the interference with peaceful possession of property by the crime of theft and civil remedies under property law.[43] These protections extend to human bodies and tissue. In the case of *R v Kelly*, body parts were taken from the Royal College of Surgeons and subsequently used by an artist without the college's knowledge or permission.[44] The Court of Appeal recognised that property rights could be held in the body parts, allowing them to fall within the definition of property under section 4 of the Theft Act 1968 and thereby permitting a conviction of theft to be upheld against the appellants. Certain interferences with corpses are also prohibited.[45]

Brazier extends this further still, arguing that familial interests in organ use should also be protected:

> The knowledge which we now share about the impact organ retention has had on bereaved relatives must begin to build a case that families are entitled to be protected from conduct which may injure them.[46]

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[43] *Spartan Steel & Alloys Ltd v Martin & Co (Contractors) Ltd* [1973] QB 27; *St Helen's Smelting Co v Tipping* (1865) 11 HL Cas 642; Theft Act 1968 section 1; see for example the torts of trespass and conversion: Torts (Interference with Goods) Act 1977 section 1.

[44] *R v Kelly* [1999] QB 621.

[45] See for example Sexual Offences Act 2003 section 70.

[46] Brazier (n 2) 567.

The Human Tissue Act (HTA) 2004 protects familial interests by requiring their consent for the donation of tissue from a relative or loved one (although there are some exceptions to this rule).[47] Therefore, rule-utilitarianism aligns with the existing collective goal under the law of protecting interests against harm, which encompasses the protection of interests in human tissue. Moreover, it would not allow foetal tissue to be used in ways that would subvert its special moral status. It is evident that rule-utilitarianism provides a compelling normative basis for determining what rule or rules would be morally justified for determining how competing interests in foetal tissue use should be managed.

The whole or partial satisfaction of interests is a desirable outcome under the principle of utility. However, when interests are in conflict, the prioritisation of one set of interests will come at the cost of others potentially suffering harm from the dissatisfaction of their interests. Under rule-utilitarianism, the morally correct rule is the one that promotes the greatest utility overall. If it could be said that all interests in foetal tissue would be equally harmed if they were overridden and would receive equal benefit if these interests were met, then it would be morally unjustified to allow one set of interests to override others, and a compromise should instead be found.[48] Alternatively, if desirable outcomes would be maximised from the prioritisation of one set of interests over others, then we must create a rule that requires this.

Utilitarianism has been employed to defend the use of human organs for transplantation treatment even against personal (antemortem) or family

[47] An explanation of these rules is given later in this section.

[48] See 3.2.

objections.[49] Harris argues that the benefits of providing patients with organs for life-saving treatment outweigh the 'illusions' of pain caused to family members who would object to donation.[50] Sinead O'Gorman extends this application of utilitarianism to the use of foetal brain cells.[51] O'Gorman argues that after death, the foetus cannot experience any pleasure from the use of its cells, whereas a patient will positively benefit from their use in transplantation treatment. [52] Therefore, we should 'not object to the use of foetal brain cells which would otherwise be wastefully disposed of.'[53] Furthermore:

> According to utilitarianism the mother of the foetus will already be experiencing pain and thus to utilise parts of the foetus is unlikely to add to this significantly, however, even if this may cause pain, when balancing this act against the potential pleasure gained by the transplant patient, the scales would tip in favour of the latter.[54]

O'Gorman suggests that parents will not be significantly (further) distressed by tissue use, and that any distress will *always* be outweighed by the potential pleasure gained by patients.[55] Similar utilitarian based claims have been made about the use of human organs.[56] However, these arguments do not sufficiently account for the

[49] Cynthia Kapoor, 'The removal of organs from cadavers: a utilitarian perspective' (1994) 1 UCL Juris Rev 104.

[50] Harris (n 7) 548.

[51] Sinead L O'Gorman, 'Foetal Brain Cell Transplants: A Utilitarian Perspective' (1996) UCL Juris Rev 84.

[52] O'Gorman ibid 95.

[53] Ibid.

[54] Ibid 96.

[55] Ibid.

[56] See Harris (n 7); Kapoor (n 49).

harm that can be caused to parents when their interests in foetal tissue use are overridden.

Parental interests

Parents have close personal and physical relationships with the living foetus. They may view themselves as the parents of their unborn future child and experience grief after its death.[57] The loss of any child can be deeply traumatic for parents.[58] As Campbell and Michaela Willis point out, a parent's love for their child – and their body – does not disappear upon death: 'The physical body of the person loved is fully part of the love that parent feels for child or wife for husband. This embodiment of the person does not suddenly disappear in death'.[59] The love between parent and child is enduring. After death, the close personal relationship between the foetus and the parents persists and carries over to the deceased body. Moreover, McGuinness and Brazier argue that, compared to other bodies, the deceased bodies of young children are a more significant representation of the former individual:

> When an adult or an older child dies, the family share a set of memories of what that person did and said. The physical memory remains, but is supplemented by other kinds of recollection. With the baby or small child, that physical memory may be all that there is. **The body is the baby**.[60]

[57] Danielle Fuller and others, 'Death Before Birth: Preliminary project findings for meeting with representatives of the Department of Health and Social Care' (24 August 2018) <https://testprojectwebsiteblog.wordpress.com/wp-content/uploads/2019/03/summary-of-project-findings-report-for-dhsc.pdf> accessed 26 July 2025; Middlemiss (n 1).

[58] Brazier (n 2) 567.

[59] Alastair V Campbell and Michaela Willis, 'They stole my baby's soul: narratives of embodiment and loss' (2005) 31 Med Humanit 101, 103.

[60] My emphasis added: McGuinness and Brazier (n 3) 304.

The parents' relationship with and love for their deceased child may therefore be *more* tied to their physical body than is the case for other loved ones. O'Gorman suggests that a parent's grief over the death of the foetus is unlikely to be significantly exacerbated by the subsequent use of its tissue.[61] This is not always the case. Parents feel a continued need to protect the bodies of their children after death.[62] As Naomi Pfeffer observes, women feel responsibility and a duty of care towards the foetal body.[63] The parents of Alexandra, a stillborn baby whose organs were retained as part of the events of the Organ Retention Scandal, were immensely distressed at not being able to protect their child from being 'desecrated'.[64] The mother expressed that,

> [A]s a parent … she would have done anything and everything in her power to protect her child. That was what she was there to do even more so in death because it was [the] only thing she could do for her child at that stage … she did not do it and she has to live with that.[65]

This relationship is reflected by the law, as the duty to bury or dispose of the body of the deceased foetus (if it is born on or after twenty-four weeks of gestation) is conferred on the parents.[66] If the foetus is used without their knowledge or in a way that they perceive as violating the body or memory of their child, parents may feel

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[61] O'Gorman (n 51) 96.

[62] Sheila McLean, *Independent Review Group on the Retention of Organs at Post-Mortem: Final Report* (Edinburgh: Scottish Executive, November 2001) Appendix 2: Preliminary Report, 75 at [2].

[63] Pfeffer (n 5) 2551-2553.

[64] Michael Redfern, *The Royal Liverpool Children's Inquiry Report* (HC 2001, HC12-II, London: The Stationery Office 2001) (hereafter Redfern Report) 407 and 406-8.

[65] Ibid 408.

[66] Before twenty-four weeks of gestation, the tissue is legally recognised as the tissue of the mother and other laws relating to the disposal of human bodies do not apply: Human Tissue Authority (HT Authority), *Code of Practice A: Guiding principles and the fundamental principle of consent* (June 2023) 28-29 at [141]-[142]; Births and Deaths Registration Act 1953 section 41 (as amended by the Stillbirth (Definition) Act 1992 section 1(1)); affirmed in *AB v Leeds Teaching Hospitals NHS Trust* [2004] EWHC 644 (QB), [2005] QB 506 at [272].

like they have failed to protect them. This in turn may cause them distress or deepen their grief.[67] As Brazier argues, the pain can be 'acute and life-destroying … The image of the newly dead person remains fixed in the minds of most bereaved families. Mutilation of the body becomes a mutilation of that image.'[68] This was exemplified during the Organ Retention Scandal, when many families were deeply distressed when they discovered that the bodies of their stillborn babies or children's organs had been retained without their knowledge or even against their direct wishes.[69] The parents of Alexandra felt that 'Their trust has been betrayed, they have been deceived and their child desecrated. They remain angry.'[70]

This harm was explicitly recognised in *AB v Leeds Teaching Hospitals NHS Trust*.[71] In this case, the court acknowledged that the retention of organs from children and stillborn babies can cause great distress to parents which in some cases may amount to psychiatric injury.[72] One of the claimants, Mrs Shorter, learned that the brain of her stillborn baby Laura had been retained following a post-mortem examination. The court held that this caused Mrs Shorter to suffer 'psychiatric injury … over and above the pre-existing pathological grief disorder which followed Laura's stillbirth.'[73]

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[67] Pfeffer (n 5) 2551 and 2553.

[68] Brazier (n 2) 560-561.

[69] See for example parents evidence included in the Redfern Report (n 64) 391-443.

[70] Ibid 407.

[71] *AB* (n 66).

[72] Ibid at [239] and [108]-[110].

[73] Ibid at [110].

The use of the foetus can still be distressing even if the relationship between the foetus and pregnant person is very different to the loving relationship set out above. If a person does not want to be pregnant, they may seek a termination. They may also want to control what happens to foetal tissue after the abortion for various reasons. Some may want the tissue to be completely destroyed.[74] If the tissue is used in medical research, they may view the foetus as having 'a biographical existence beyond the abortion' which undermines their choice to be child free.[75] Some have reported having nightmares about the fate of the foetus, or feeling like the foetus is 'haunting' them.[76] Parents' reproductive autonomy may be further threatened by the possibility of using foetal ovaries in reproductive treatment, which can enable infertile women to become pregnant.[77] This use could undermine people's choice to be not only child free but (genetic) grandchild free. This particular use of foetal ovaries is currently banned in England and Wales.[78] Certain aspects of this process – realising that they have an unwanted pregnancy, choosing to abort, and the physical process of undergoing abortion treatment – can be distressing.[79] Further distress may be caused if they cannot control what happens to the resulting foetal tissue.

[74] Pfeffer (n 5) 2551; Amanda J Myers, Patricia A Lohr, and Naomi Pfeffer, 'Disposal of fetal tissue following elective abortion what women think' (2015) 41 J Fam Plann Reprod Health Care 84, 87.

[75] Pfeffer ibid 2550.

[76] Ibid 2550-2551.

[77] Jonathan M Berkowitz, 'Mummy was a fetus: motherhood and fetal ovarian transplantation' (1995) 21 J Med Ethics 298.

[78] HFEA 1990 section 3A (as amended by the Criminal Justice and Public Order Act 1994).

[79] See 1.3.1; Pfeffer (n 5).

These views are not universally held. They were expressed by participants in pilot studies about foetal tissue management in which many varying opinions were expressed. Nevertheless, it is important to recognise that these views are held by some people, and the harm they may experience warrants consideration.

The personal autonomy interests of genetic parents are also engaged when foetal tissue is used in research which may reveal genetic information about them, such as the presence of a genetic disease. Graeme Laurie illustrates how interests can be harmed by the unauthorised disclosure of such information:

> Information concerning an individual's genetic make-up is of a highly personal and sensitive nature. To discover that one is likely to develop a debilitating condition in later life or that this might be passed to one's children must be an intense and possibly devastating experience. Exposure to such knowledge can alter self-perception and challenge notions of identity, and could adversely affect an individual in her social, professional and familial milieux. The mere availability of genetic information serves to heighten concerns about the uses to which the information might be put, uses which might in turn compromise the interests of the person…[80]

It is unlawful for a person's personal tissue to be used without their consent, including for genetic testing.[81] To do so would interfere not only with their rights to personal and bodily autonomy but their interests in genetic privacy. Yet as exemplified in *ABC v St George's Healthcare NHS Trust*, genetic information about a person may also be revealed if tissue from a relative is used for genetic testing.[82] The discovery of a debilitating genetic condition may be just as distressing when discovered in this way. As Chunshui Wang argues, consideration should be placed

[80] Graeme Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (CUP 2002) 90.

[81] Human Tissue Act (HTA) 2004 section 1(1); note that some exceptions to this consent requirement exist.

[82] *ABC v St George's Healthcare NHS Trust* [2017] EWCA Civ 336, [2017] PIQR P15; see also *ABC v St George's Healthcare NHS Trust* [2020] EWHC 455 (QB), [2020] PIQR P13.

on the familial dimension of genetic testing because family members can be harmed when the genetic privacy of another is intruded upon.[83] However, a person is usually unable to legally prevent their relatives' tissue from being used in particular ways because to do so would interfere with another person's personal and bodily autonomy rights. Yet the deceased foetus does not exercise such competing rights. Therefore, parents' genetic privacy interests come back into play and the harm they may suffer warrants consideration. The importance of protecting genetic privacy is highlighted by Calvin Wai-loon Ho and Terry Sheung-hung Kaan:

> In ethics, privacy is the handmaiden of autonomy. It arises from the principle of respect for persons by conferring on an individual an ethical right to require consent to be obtained prior to the disclosure of her or his personal information.[84]

These interests are enshrined under Article 10 of the Convention on Human Rights and Biomedicine (although it should be noted that this Convention has not been signed or ratified by the UK):

> Article 10 – Private life and right to information
>
> 1 Everyone has the right to respect for private life in relation to information about his or her health.
>
> 2 Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.[85]

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[83] Chunshui Wang, 'Genetic Privacy: A Challenge to Genetic Testing in China' in Terry Sheung-hung Kaan and Calvin Wai-loon Ho (eds), *Genetic Privacy: An Evaluation of the Ethical and Legal Landscape* (Imperial College Press 2013) 125.

[84] Calvin Wai-loon Ho and Terry Sheung-hung Kaan, 'The Notion of Genetic Privacy' in Kaan and Ho ibid 1, 2.

[85] Council of Europe, 'Chart of signatures and ratifications of Treaty 164' <https://www.coe.int/en/web/conventions/full-list?module=signatures-by-treaty&treatynum=164> accessed 23 July 2025.

The disposition of the foetal body also engages the personal, religious, and spiritual interests of the parents. As Brazier observes, they will be harmed if these are overridden:

> How the mortal remains of that person are laid to rest (or otherwise disposed of) is of overwhelming importance for the health and future of that family. The injury done to a family whose religion requires burial of the body intact, or cremation of every speck of bodily material, when organs are taken without their permission is a violation of religious freedom. It is not just that. It harms the surviving relatives, whose ability to work through the gradual process of bereavement is impaired. They believe that they have (albeit through no conscious act of theirs) let that relative down. They failed to safeguard his and their fundamental values. The injury done to families whose personal values require burial or cremation intact is no different.[86]

The harm that can be caused to parents clearly goes beyond the distress that follows foetal death or elective termination.[87] It is multifaceted, devastating, and may even amount to psychiatric injury.[88] This harm has not always been duly recognised. Campbell and Willis observe that the emotions expressed by families during the Organ Retention Scandal were criticised and downplayed:

> In the retained organs controversy, families were criticised for letting their feelings run away with them, and it was suggested that the media were deliberately manipulating emotions to get a good story, with headlines such as 'They stole my baby's soul'. According to The Times, this outpouring of emotion badly damaged medicine … So now the families, traumatised by the deception and concealment of the organs controversy, must bear the blame for the problems of pathology![89]

[86] Brazier (n 7) 32.

[87] Contrary to the argument presented by O'Gorman: O'Gorman (n 51) 96.

[88] *AB* (n 66) at [110].

[89] Campbell and Willis (n 59) 103.

We should not, as Harris argues, consider these interests and harms as 'illusions'.[90] Rather, we should recognise and accept them for what they are. As Campbell and Willis cogently argue:

> These are all the responses of people in close human relationships. It is pointless to suggest that these narratives of anger, grief, and loss are one sided or irrational. They are what they are: the living memory of emotional trauma, which will be forever part of the identity of those experiencing them. There is no 'real' or 'better' or 'more rational' self, floating above the emotions of our daily bodily lives. There is only the lived self and there is only the one narrative of our bodily experiences, a narrative that is ours alone.[91]

For all other interests in foetal tissue use – including those of public health and other family members – the aforementioned issues that apply to parents do not arise either at all or in the same way. As Brazier notes above, other family members may be distressed if foetal tissue is used in a way that does not align with their interests.[92] Nonetheless, they lack the close relationship that the parents have with the foetus. Very few individuals are able to develop a meaningful relationship with the foetus during its short life. The foetus is unable to have an independent existence or develop the means to communicate with others before death. This distinguishes the foetus from other family members who have independent existences, can communicate, and can form meaningful bonds with other family members before death. In contrast, most people will have very limited physical and personal interactions with the foetus compared to the parents. Because of this

[90] Harris (n 7) 548.

[91] Campbell and Willis (n 59) 103.

[92] Brazier (n 7) 32.

limited relationship, the level of distress they experience will not be 'life-destroying' or amount to psychiatric harm when foetal tissue is used against their interests.[93]

It is therefore necessary to draw a distinction between the interests of parents and those of others. In some areas, the law already does so by prioritising parental interests over others. The close relationship between parent and child is recognised in the laws governing tissue donation. Under the HTA 2004, tissue from the body of a child or stillborn foetus must be donated by a parent or a person with parental responsibility for them.[94] Consent for donation can only be given by another – such as another family member – if no parent is able to do so due to death or incapacity.[95] Under the HFEAs 1990 and 2008, *in vitro* embryos can only be stored, used for reproductive treatment, or donated for use in research with the consent of the parents.[96]

The use of foetal tissue in line with public health interests undoubtedly produces considerable medical benefits. It can be used to further medical research and develop treatments that improve outcomes for patients. These include using foetal brain cells for transplantation treatment for Parkinson's, the creation of stem cells, and research into the causes of miscarriage.[97] The development of successful medical treatments contributes to the overall improvement of public health. Foetal

[93] Brazier (n 2) 560; *AB* (n 66).

[94] HTA 2004 sections 2(7)(b)(i)-(ii) and 27(4)(b).

[95] Ibid.

[96] HFEA 1990 Schedule 3.

[97] See for example Jeffrey H Kordower and others, 'Neuropathological Evidence of Graft Survival and Striatal Reinnervation after the Transplantation of Fetal Mesencephalic Tissue in a Patient with Parkinson's Disease' (1995) 332 N Engl J Med 1118; Naomi Pfeffer, 'How work reconfigures an 'unwanted' pregnancy into 'the right tool for the job' in stem cell research' (2009) 31(1) Sociol Health Ill 98; see 1.3.

tissue can be used to benefit individual patients undergoing transplantation treatment and benefits wider public health interests through advancements in medical research.[98] Tissue is also often used to create stem cells, which in turn are used in life-saving or life-extending transplantation treatment. Examples include bone marrow and liver cell transplantation.[99] However, whole foetal organs will rarely be used for life-saving organ transplantation. Deceased organ donation can occur in two ways:

> A. Donation following neurological determination of death (DNDD) occurs after the certification of death using neurological criteria on a fully supported intensive care patient, and has previously been termed donation after brain death.
>
> B. Donation after circulatory determination of death (DCDD) occurs after the certification of death using cardiorespiratory criteria, usually following the withdrawal of intensive organ support and had previously been termed non-heart-beating donation and donation after circulatory death.[100]

Foetuses can only donate life-saving organs after they have been born alive or have been successfully resuscitated after stillbirth. At this point they would cease to be a foetus and would become a legally recognised neonate, and so the laws governing the use of neonatal organs would therefore apply to the majority of life-saving organ donation from (former) foetuses.[101] Therefore, when assessing the beneficial and harmful consequences that arise from foetal tissue use, we must consider that the use of deceased foetal tissue will rarely be life-saving. It is evident that the

[98] See 1.3.

[99] Tetsuya Ishii and Koji Eto, 'Fetal stem cell transplantation: Past, present, and future' (2014) 6(4) World J Stem Cells 404, 406.

[100] Elinor Charles, Angie Scales, and Joe Brierley, 'The Potential for Neonatal Organ Donation in a Children's Hospital' (2014) 99(3) Arch Dis Child Fetal Neonatal Ed F225, F225-F226.

[101] *AG's Reference* (n 56).

medical benefits of foetal tissue use must carry less weight in this debate than they do in the debate over human organs.

Furthermore, whilst public health interests will benefit from foetal tissue use, they will not be directly harmed if their interests are denied. If tissue is not supplied for medical use, it will only constitute a failure to confer a benefit. As Brazier argues, the harm to a parent when organs are removed against their wishes 'is much more direct and immediate than the possible impediment to research into cystic fibrosis resulting from non-retention of organs'.[102] This distinguishes public health interests from those of parents, the latter of which *will* be harmed if their interests are overridden by the former. As Lord Reed states in *CN v Poole*, neither private individuals nor public bodies 'owe a duty of care to confer benefits on individuals' under English law.[103] Furthermore, there is generally no duty to rescue a stranger under English law and certainly no legal duty to donate tissue even for use in life-saving treatment.[104] This was confirmed by Judge LJ in *St George's Healthcare NHS Trust v S* in the context of living donors:

> [H]ow can a forced invasion of a competent adult's body against her will even for the most laudable of motives (the preservation of life) be ordered without irremediably damaging the principle of self-determination? When human life is at stake the pressure to provide an affirmative answer authorising unwanted medical intervention is very powerful. Nevertheless, the autonomy of each individual requires continuing protection even, perhaps particularly, when the motive for interfering with it is readily understandable, and indeed to many would appear commendable: hence the importance of remembering Lord Reid's warning against making 'even minor concessions.' If it has not already done so medical science will no doubt one day advance to the stage when a very minor procedure undergone

[102] Brazier (n 2) 560.

[103] *CN v Poole BC* [2019] UKSC 25, [2020] AC 780 *per* Lord Reed at [28].

[104] See for example *Stovin v Wise* [1996] AC 923. Note there are some exceptions to this rule. For example, the law may impose a duty to act on a person if they have voluntarily assumed responsibility for another. However, these exceptions have not been, and are unlikely to be, applied in the context of foetal tissue donation.

> by an adult would save the life of his or her child, or perhaps the life of a child of a complete stranger. The refusal would rightly be described as unreasonable, the benefit to another human life would be beyond value, and the motives of the doctors admirable. If, however, the adult were compelled to agree, or rendered helpless to resist, the principle of autonomy would be extinguished.[105]

This was well illustrated in the Pennsylvanian case of *McFall v Shimp*.[106] The plaintiff in this case suffered from a rare bone marrow disease. The defendant was a possible bone marrow match but refused to act as a donor for the plaintiff. The plaintiff applied for an injunction to compel the defendant to donate bone marrow, but this was denied by the court. They held that whilst the defendant's refusal was 'morally indefensible', he could not be forced to act as a donor.[107] As Michele Goodwin argues, 'to compel an individual to submit to an invasion on her body is an incredibly dangerous legal construct'.[108]

There is a distinction to be drawn between these examples and foetal tissue donation, because to compel such donation would not interfere with either the parents' or foetus' bodily autonomy rights.[109] However, particular uses may undermine the special moral status of the foetus. These cannot be permitted even if, in the example given by Judge LJ above, the interference with the body is minor and the benefit gained by the patient is substantial. Furthermore, a person cannot be compelled to donate things that are separate from their body, such as the hair

[105] *St George's Healthcare NHS Trust v S* [1998] 3 WLR 936, 953 *per* Judge LJ.

[106] *McFall v Shimp* 10 Pa D & C 3d 90 (1978); this case was briefly discussed in *St George's Healthcare NHS Trust* ibid 953.

[107] *McFall v Shimp* ibid at [91].

[108] Michele Goodwin, *Black Markets: The Supply and Demand of Body Parts* (CUP 2006) 65.

[109] Their body would not need to be interfered with for its retrieval. Also, it should not be considered their personal tissue: see Chapter 2. The body of the foetus cannot exercise autonomy after death.

on their hairbrush. It is evident that no legal duty will arise – nor should it – to compel a parent to donate foetal tissue, even for use in life-saving treatment.

Whilst foetal tissue use can undoubtably lead to extraordinary medical benefits, we cannot conclude, as O'Gorman suggests, that the pleasure it creates will *always* outweigh the great harm that can be caused to parents.[110] Rather, if foetal tissue is used for *non-lifesaving* medical treatment against the interests of parents, the benefits will not outweigh the *life-destroying* harm suffered by parents. However, it is not possible to predict whether, how, and to what extent parents will be harmed by the subversion of their interests in each individual case. Scenarios could arise where the medical benefits of foetal tissue use will outweigh the harm caused to parents who refuse donation. Take the following example:

> Research Group A develops a treatment that uses a small number of foetal brain cells to treat several fatal neurological diseases. They take tissue samples from Foetus B to provide life-saving treatment for five terminally ill patients. The parents of Foetus B had refused to donate the tissue but are only mildly dismayed to find that samples were taken and used against their wishes.

In this theoretical scenario, the life-saving benefits for the five patients outweighs the minor harm caused to the parents. Under act-utilitarianism, it would be morally justified for the foetal tissue to be used to further public health interests in this case rather than in accordance with parental interests. However, in practice, we cannot accurately predict the balance of benefits and harms in individual scenarios. There are many variables which affect the various beneficial and harmful consequences of foetal tissue use, and it is not possible to quantify these. We cannot predict whether and to what extent parents will be harmed, nor whether they will experience distress immediately after or at a future timepoint. What we do know

[110] O'Gorman (n 51) 95-96.

for certain is that parents *can* experience great harm, and in the majority of cases this will outweigh the benefits. Even in the case of life-saving transplantation treatment, a single operation usually involves using tissue from multiple – 'as many as six' – foetuses.[111] Here, the public health benefits of providing treatment for one patient are outweighed by the harm caused to multiple sets of parents who object to donation and would be harmed if their objections were not respected.

Furthermore, any treatment or benefit to an individual patient is focused on that person alone. The utility that this produces for an individual pales in comparison to the utility of furthering collective goals. The use of foetal tissue in medical research is a collective goal that promotes public interests and provides greater utility in this respect. Yet the status of the foetal body is not directly considered in either of these uses. In contrast, parents feel a duty of care towards the foetal body and therefore there is a protective element to their decision-making and interests in the use of its body. The mother of Alexandra expressed that 'as a parent … she would have done anything and everything in her power to protect her child. That was what she was there to do even more so in death because it was [the] only thing she could do for her child at that stage.'[112] For many, the parental desire to protect their deceased child will be bound up with their familial relationship of love and care. Nevertheless, this desire to protect the foetus extends to those who do not view it as a child. As one woman in Pfeffer's research expressed: 'my initial reaction was well there's no way I'd do anything to my

[111] Ibid 85; see also Ishii and Eto (n 99) 406.

[112] See the discussion earlier in this section about Alexandra, a stillborn baby whose organs were retained during the events of the Organ Retention Scandal: Redfern Report (n 64) 408.

aborted fetus, you'd have that ownership thing even though you're aborting it … it's still mine'.[113]

Myers, Lohr and Pfeffer observe that 'For some women, not knowing what happened to the fetal tissue after abortion invoked an incipient duty of care.'[114] The following interests were also shared by participants in their study:

> As soon as it's come out of the body [I would want it] to be somehow destroyed there and then rather than be put into containers and taken away. Because then it's something that belongs to someone else, taken. [18-S]

> Now I want to know where it is, which is really strange because obviously I'm never going to know … you feel protective, even though I knew I weren't keeping it. [16-M][115]

Under rule-utilitarianism, a rule should be created which maximises overall utility. Respecting the special liminal status of the foetus is a collective goal that must be maximised, and this will only be achieved by prioritising the interests of the parents. Furthermore, it is evident that the greatest pleasure and least pain will be caused by respecting the interests of the parents. A rule must therefore be created to prioritise these interests over others.

3.2.2 Should parental interests be overridden by other interests?

Although Brazier argues that the interests of the person and their loved ones should be prioritised for the use of organs, she proposes that they should only be taken as a starting point, and that there may be cases where these can be justifiably

[113] Pfeffer (n 5) 2548.

[114] Myers, Lohr, and Pfeffer (n 74) 87.

[115] Ibid 87.

overridden.[116] Here, it will be considered whether parental interests can be justifiably overridden by other interests.

The status of the deceased foetus

As stated earlier in this chapter, the legal status of the deceased foetus must take precedence. Only after this should the interests of the parents be prioritised. The interests of the latter may have to be limited in order to protect the legal status of the foetus. Certain uses of the deceased foetus which undermine its special status should not be permitted, regardless of any interests in such uses. To protect this status, legal or regulatory limits should be placed on the options that the parents have when deciding how this material is used. It is outside the scope of this thesis to consider what specific uses of foetal tissue may undermine its special status. Research on this is needed to determine what limits should be put in place.[117] However, as an example, if we decided that using foetal bodies in artwork would always undermine its special status, then any interests the parents have in using the foetus in artwork must be overridden.

Public health interests

Whilst a rule prioritising parental interests may maximise desirable outcomes in scenarios concerning small numbers of affected persons – such as the health interests of five patients versus two parents – it may no longer hold up when public health interests affecting the public at large are significantly harmed. For example,

[116] Brazier (n 2).

[117] See the Introduction for an explanation of the scope of this thesis.

public health interests are engaged in the management of deceased bodies and tissue. There is a legal duty for human bodies to be buried or cremated after death.[118] As Loane Skene points out, there are 'public health reasons why [bodies] should be promptly disposed of'.[119] If the disposal of the foetal body is not carried out in a timely manner by the parents, this will negatively impact public health interests. This harm could affect several members of the public or even the public at large. Where a greater number of people are harmed, this could outweigh the harm caused to parents, which in turn would justify overriding the interests of the latter and upholding those of the former regarding expedited disposal. Two examples of this are discussed later in this chapter in the sub-section below and in 3.3.

The use of foetal tissue for medical advancements and improvements in public health are nevertheless important. These interests should be promoted whenever they do not conflict with parental or other overriding interests. To do so, focus should be given to how foetal tissue donation can be facilitated and encouraged. This will be discussed in the next chapter.

[118] There is a legal requirement to bury or cremate the body of the foetus of twenty-four weeks of gestation or greater (known in law as a stillborn child): *Buchanan v Milton* [1999] 2 FLR 844; Births and Deaths Registration Act 1953 section 41 (as amended by the Stillbirth (Definition) Act 1992 section 1(1)); *AB* (n 66). Younger deceased foetuses must also be disposed of: see for example HT Authority, *Guidance on the disposal of pregnancy remains following pregnancy loss or termination* (March 2015, updated in September 2024).

[119] Loane Skene, 'Proprietary rights in human bodies, body parts and tissue: regulatory contexts and proposals for new laws' (2002) 22(1) LS 102, 119.

State interests

The state has interests in facilitating and maintaining the practical day-to-day operation of law and policy.[120] It may be necessary for the state to set limits on the use of foetal material or the exercise of parental interests to permit law or regulation to operate in a functional or desirable way. An example of this is the legal requirement to register stillbirths, which applies to foetuses that are miscarried on or after twenty-four weeks of gestation.[121] Registration allows data about stillbirths to be collected, which in turn can be used for advancements in public health, specifically in pregnancy, miscarriage, and neonatal care.[122] Stillbirth registration classifies deceased foetuses differently depending on the gestational age at which they died. Those that die at or after twenty-four weeks of gestation are registered as a stillbirth and identified under the law as a 'child'.[123] Foetuses that die before this timepoint are not given the same legal recognition. Parents are instead given the option to request a 'baby loss' certificate to record the existence and death of the younger foetus or embryo, which is 'an official but not legal document', so there is no record of its existence in law.[124] These baby loss certificates, which are issued by the UK government, were introduced in February 2024. Prior to this,

[120] State interests were not considered in the previous section because the state clearly lacks a personal or tangible connection to the foetus. These interests also cannot be personally harmed by tissue use.

[121] See definition of 'still–born child': Births and Deaths Registration Act 1953 section 41 (as amended by the Stillbirth (Definition) Act 1992 section 1(1)).

[122] See for example University of Oxford, 'Continuing inequalities contribute to wide variation in rates of stillbirths and neonatal deaths across UK' (14 September 2023) <https://www.ox.ac.uk/news/2023-09-14-continuing-inequalities-contribute-wide-variation-rates-stillbirths-and-neonatal> accessed 23 July 2025.

[123] (n 121).

[124] Department of Health and Social Care, 'Baby loss certificate launched to recognise parents' grief' (22 February 2024) <https://www.gov.uk/government/news/baby-loss-certificate-launchedto-recognise-parents-grief> accessed 23 July 2025; UK Government, 'Request a baby loss certificate' <https://www.gov.uk/request-baby-loss-certificate> accessed 23 July 2025.

parents could be issued a commemorative certificate from a hospital or a charity such as Sands, but these certificates were not official records.[125]

It can be distressing for some parents if foetuses are not recognised equally because of differences in gestational age.[126] One woman who was diagnosed with fetal anomaly at twenty-one weeks *intentionally delayed* her termination until after twenty-four weeks of gestation just so that her 'daughter' would be recognised in law as a stillborn baby.[127] She felt so strongly that her daughter should receive proper legal recognition that she carried her for a further three weeks.[128] Another woman felt that 'a fake certificate' was unhelpful and she would have preferred her foetus to be properly registered in a formal system.[129] In one case, a set of twins were stillborn either side of the twenty-four-week threshold and so only one of them was legally recognised as a stillborn child.[130]

The twenty-four-week limit for stillbirth registration is an arbitrary one. The foetus is a gradually developing liminal being, who at twenty-four weeks of gestation cannot be morally or otherwise distinguished from the being that existed immediately before it.[131] Arbitrary limits exist in several areas of law. Consider the

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[125] Lisa Rowland, 'Registration of stillbirth' (Commons Library Research Briefing, 4 February 2025) 4 <https://researchbriefings.files.parliament.uk/documents/SN05595/SN05595.pdf> accessed 23 July 2025; Sands, 'Bereavement Support' <https://shop.sands.org.uk/en/products/bereavement-support> accessed 23 July 2025.

[126] Fuller and others (n 57) 11-12.

[127] Ibid 11-12.

[128] Ibid. Foetal tissue of less than twenty-four weeks of gestation is classified as tissue from the mother: HT Authority, *Code of Practice A* (2023) (n 66) 28 at [141].

[129] Fuller and others (n 57) 11.

[130] The case of the twins was highlighted by MP Tim Loughton: Baby Loss HC Deb 13 October 2016, vol 615, cols 468-519, 505-506.

[131] See Chapter 2.

example of English abortion law, which has sought to reach a compromise between the two polarised sides of the abortion debate.[132] The law must draw arbitrary lines to achieve this compromise. If a compromise was considered the best approach for regulating abortion, then it would be necessary and justified to draw an arbitrary line to achieve this aim.[133] Therefore, in assessing whether it is justifiable for the law to override parental interests with arbitrary limits, we must ask whether these limits are necessary for the operation of the law or necessary to prevent interference with other legal rights.

Let us imagine that the twenty-four-week limit was removed and the registration of stillbirths was expanded to include the deaths of all embryos and foetuses, regardless of gestational age, to reflect the potential social recognition of the foetus as a baby at any stage. This expansion would allow the parents of the aforementioned twins to register and recognise them both equally under the law.[134] Their interests, and those of other parents, would no longer be overridden in this regard. Allowing the legal registration of younger foetuses would not negatively affect the stillbirth registration system, because its main purpose is to record data on births and deaths. Adding *more* data does not undermine this purpose and will further contribute to public health knowledge.

However, if stillbirth registration was expanded to become *mandatory* for all deceased embryos and foetuses, as it currently is for older foetuses, this would constitute an unwanted intrusion into the lives of parents and especially pregnant

[132] (n 18).

[133] This thesis is not arguing that a compromise, or the current Act, is the best approach for regulating abortion. It is just making a point about the necessity of arbitrary limits.

[134] (n 130).

people. In rare cases, registration may be required under the current law for foetuses that are born alive and then die after abortion.[135] If this is expanded, more abortions may be registered in this way and thus recognised as the death of a 'child'.[136] Miscarriage is very common in the early stages of gestation.[137] Introducing a legal requirement for people to register these early miscarriages would intrude on their personal lives and their choice about whether to speak about their early miscarriage or not. It is also not always obvious when someone has had a miscarriage, as early miscarriage experiences can feel like 'a late period with heavy bleeding' which is distinct from a later miscarriage where a foetal body may be identifiable.[138] It would not be feasible for the law to ensure that all miscarriages are discovered and registered without introducing a more authoritarian regime that intimately observes people's bodies. This requirement may cause distress to parents who do not see the very early miscarried foetus as a 'child' worthy of legal recognition.[139] It would also constitute a gross interference with the bodily autonomy rights (and public health interests in promoting these rights) of every person who has the capacity to become pregnant.

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[135] See generally Courts and Tribunal Judiciary, *Chief Coroner's Guidance No 45 Stillbirth, and Live Birth Following Termination of Pregnancy* (February 2023) <https://www.judiciary.uk/guidance-and-resources/chief-coroners-guidance-no-45-stillbirth-and-live-birth-following-termination-of-pregnancy/> accessed 23 July 2024.

[136] (n 124).

[137] Early pregnancy loss occurs in '10% of all clinically recognized pregnancies': American College of Obstetricians and Gynaecologists, 'Early Pregnancy Loss' (Practice Bulletin, No 200, November 2018) <https://www.acog.org/clinical/clinical-guidance/practice-bulletin/articles/2018/11/early-pregnancy-loss> accessed 23 July 2025; Allen J Wilcox and others, 'Incidence of Early Loss of Pregnancy' (1988) 319(4) New Engl J Med 189.

[138] NHS Inform, 'Miscarriage' <https://www.nhsinform.scot/illnesses-and-conditions/pregnancy-and-childbirth/miscarriage/> accessed 23 July 2025.

[139] (n 121).

As of February 2024, the loss of younger foetuses (before twenty-four weeks of gestation) can now be formally registered on a voluntary basis through a government scheme, which issues parents with a 'baby loss' certificate to record the existence and death of the foetus.[140] The introduction of baby loss registration may be considered an appropriate way of formally recognising the existence of the foetus for many parents. This new system has been introduced following recommendations by the Pregnancy Loss Review, who hope it will suitably recognise the interests of parents and improve upon previously available offerings of informal and unofficial angel baby certificates and memory boxes.[141] The new system is not perfect. It does not appear to completely meet the interests of some parents and may still cause distress. In the example of the twins, each twin would still be registered in a different way.[142] The new certificate is 'an official but not legal document', so there remains no recognition of a foetus' existence in law before twenty-four weeks of gestation.[143] Nonetheless, this is an improvement on the previous state of affairs where no official recognition was given for the loss of younger embryos and foetuses. The system is relatively new, and time will tell whether it satisfies parental interests. If it does not, then alternative approaches should be considered.

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[140] (n 124).

[141] Department of Health and Social Care, *The Independent Pregnancy Loss Review - Care and support when baby loss occurs before 24 weeks gestation* (July 2023) (hereafter Pregnancy Loss Review); HT Authority, *Guidance on the disposal of pregnancy remains* (n 118); Louise Austin and others, 'Effective Communication Following Pregnancy Loss: A Study in England' (2021) 30 Camb Q Healthc Ethic 175, 181.

[142] (n 130).

[143] (n 124).

Data collection is not the only function of stillbirth registration. This registration allows bereaved parents to access financial support such as maternity, paternity, and bereavement leave. Altering the twenty-four-week limit would affect who could access these benefits.[144] This may be changed anyway, as the Employment Rights Bill proposes to extend bereavement leave measures to cover parents who suffer a miscarriage before twenty-four weeks of gestation in England and Wales.[145] Questions about whether these benefits should extend to parents who have experienced pregnancy loss at an earlier timepoint fall outside the scope of this thesis. Whilst parents may be distressed if they cannot obtain legal recognition for their losses prior to twenty-four weeks of gestation, it would cause greater harm to introduce a mandatory requirement for all deceased embryos and foetuses to be registered as stillbirths. It is therefore justifiable for the arbitrary legal limit to remain in place, even if this overrides parental interests.

3.3 What if parental interests are in conflict?

Parents may disagree between themselves about how foetal tissue should be used. One may want tissue to be donated to medical research, whilst the other may be vehemently opposed to any use of the foetus outside of burial. If a conflict arises between parents, how should this be resolved? Unlike the conflict of interests

[144] See for example UK Government, 'Register a stillbirth' <https://www.gov.uk/register-stillbirth> accessed 23 July 2025.

[145] UK Parliament, 'Employment Rights Bill' <https://bills.parliament.uk/bills/3737> accessed 23 July 2025; Women and Equalities Committee, *Equality at work: Miscarriage and bereavement leave* (2024–25, HC 803).

described above, parental conflicts will be more difficult to resolve because the harm that can be caused to their interests may be more equal.

A conflict of parental interests over the fate of a living foetus arose in the case of *Paton v British Pregnancy Advisory Service Trustrees*.[146] A husband sought an injunction to prevent his wife from obtaining, and to prevent the British Pregnancy Advisory Service from performing, an abortion without his consent. He 'contended that he had the right to have a say in the destiny of the child he had conceived.'[147] The court held that the husband lacked any right under law or equity to prevent his wife by injunction from obtaining a lawful abortion. The Abortion Act 1967 does not confer on the husband (or genetic father, or any other parent) any right of consultation or consent, and no such rights arise under the common law.

A similar case arose in *C v S*.[148] Here, the genetic father of a foetus applied on his own behalf, and as father and 'next friend' of the foetus, for an injunction to prevent the genetic mother from undergoing an abortion and to prevent the health authority from providing her with abortion treatment.[149] Unlike in *Paton*, in *C v S* it was alleged by the plaintiff that the proposed abortion would be illegal as it would contravene section 1 of the Infant Life (Preservation) Act 1929. The court held that neither the genetic father nor the foetus had the legal standing to obtain an injunction to prevent what would be a lawful abortion. This case confirmed the

[146] *Paton v British Pregnancy Advisory Service Trustrees (BPAS)* [1979] QB 276.

[147] Ibid 278.

[148] *C v S (Foetus: Unmarried Father)* [1988] QB 135.

[149] Ibid 137.

position in *Paton* that neither a husband nor genetic father has any legal standing to control, or special rights over, the foetus before live birth.

In each of these cases, the conflict is not simply about the parents' interests in what happens to the foetus. The pregnant person's bodily autonomy rights are also engaged whilst the foetus resides inside them. If the pregnant person is prevented from obtaining a lawful abortion, their personal and health interests in not continuing the pregnancy and not procreating will be disregarded, and their right to determine what happens to their body will be violated. The same cannot be said of the father or any other parent. The latter are comparably less affected – and certainly less physically affected – by any decisions about the fate of the living *in utero* foetus. The pregnant person is primarily affected by such decisions, and so it is evident that their interests and rights must win out over those of any other parent. As recognised in *Paton v UK*, this is especially pertinent when an abortion is sought 'in order to avert the risk of injury to her physical or mental health.'[150] As Emily Jackson argues:

> The simple answer is that we must give most protection to people's right to self-determination when their bodily integrity is at stake. So while it is understandable that a male progenitor's opinion about how his partner's pregnancy should proceed may be profoundly important to him, his point of view can be ignored without violating his interest in making decisions about his body. On the other hand, were we to give his preference priority, his partner would effectively be compelled to submit herself, against her will, to the physical strain of pregnancy and childbirth. Thus we can interfere with a man's desire for his pregnant partner to carry her pregnancy to term because to respect it would cause *greater* harm to his partner's freedom to make critical choices about her body and her life.[151]

[150] *Paton v UK* (1981) 3 EHRR 408 at [26].

[151] Emily Jackson, *Regulating Reproduction* (Hart 2001) 321.

The primacy of the pregnant person's rights is well recognised in law. The Abortion Act 1967 does not grant any other parents the right to be consulted about or to interfere with the pregnant person's access to abortion treatment. Similarly, it was recognised in *Evans v Amicus Healthcare Ltd* that one of the principles underpinning the HFEA 1990 – which governs the provision of fertility treatment – was 'of female self-determination' and of 'giving the woman full control of the pregnancy' after an embryo has been implanted into her.[152] In other cases, the courts have refused to extend common law protections to cover the *in utero* foetus where this would override the bodily autonomy rights of the pregnant person.[153]

However, disputes over deceased foetal tissue must be distinguished from those in *Paton* and *C v S*.[154] The foetus has a separate existence from the pregnant person after its death, and so the disposition of the foetal body will no longer impose upon their bodily autonomy rights. Furthermore, the pregnant person's interests in not procreating or not continuing a pregnancy will cease to apply after foetal death. When these factors are removed, the interests of the parents are placed on equal footing. Harm that may arise from foetal tissue use can affect all parents. For example, the personal autonomy interests of both genetic parents will be engaged when genetic information is obtained from foetal tissue.

Indeed, when a foetus or child has a separate existence outside the body of the pregnant person, the law gives equal weight to parental interests. Under the HTA 2004, it appears that tissue from a deceased child or stillborn foetus (of

[152] *Evans v Amicus Healthcare Ltd* [2004] EWCA Civ 727, [2005] Fam 1 *per* Thorpe and Sedley LJ at [67].

[153] See for example *Re MB (Caesarean Section)* [1997] 2 FLR 426; *Re F (In Utero)* [1988] 2 WLR 1288.

[154] *Paton v BPAS* (n 146); *C v S* (n 148).

twenty-four weeks of gestation or greater) can be donated with the consent of any parent.[155] A notable exception to this is for tissue donation from the deceased foetus of less than twenty-four weeks of gestation. The consent of the pregnant person is required for this, on the basis that it is recognised as *their* personal tissue.[156] As argued in the previous chapter, this classification should be removed from the law. For living *ex utero* embryos, the continuing consent of all gamete providers must be in place for their creation, storage, and use in treatment or research.[157] The consent they provide may be varied and withdrawn at any stage before the embryos are used.[158]

If parental interests are held to be equal under the law, how should conflicts between them be resolved? The HTA framework provides little guidance on what should happen if a conflict between parents arises over the use of foetal tissue. The HTA Code of Practice on Consent recommends that 'careful thought should be given as to whether to proceed if a disagreement arises between parents or other relatives.'[159] The HTA Code of Practice F Part Two on Deceased Organ and Tissue Donation further recommends that:

> Where there is disagreement between people in different positions on the ranked list, it is recommended that the [Specialist Nurse] seeks to provide those people with the time and information they need to come to an agreement.[160]

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[155] HTA 2004 sections 2(7)(b)(i)-(ii) and 27(4)(b); HT Authority, *Code of Practice A* (2023) (n 66) 20 at [90]-[91]; see the discussion in 1.3 about who can give consent for the donation of tissue from a stillborn foetus under the HTA 2004.

[156] Ibid 28-29 at [141]-[142].

[157] HFEA 1990 Schedule 3 at [1]-[8].

[158] HFEA 1990 Schedule 3 at [4].

[159] HT Authority, *Code of Practice A* (2023) (n 66) 20 at [92].

[160] HT Authority, *Code of Practice F part two: Deceased organ and tissue donation* (June 2023) 25 at [139].

The minimal guidance provided by the HTA framework leaves several key questions unanswered. How much time should parents be given to reach an agreement? It is surely not desirable for hospitals to store foetal bodies indefinitely if parents are at an impasse. Most crucially, what is missing is a clear indication of what should happen if a disagreement remains unresolved. Some parents may never reach an agreement. In such a case, the HTA framework does not clarify whether tissue should be donated anyway (against the interests of one parent) or if donation should be refused (against the interests of another). Unlike in *Paton*, parental interests in *ex utero* embryonic and foetal tissue are given equal weight under the law, so it is not clear which set of interests should override the other in the event of an unresolved conflict.[161] For parental disputes over the donation of tissue from living children, the HTA Code of Practice on Consent recommends that 'the matter should be referred to court for approval.' [162] Yet no such recommendation is made for deceased donation.

The case of *Evans v Amicus* involved a dispute between two progenitors about the use of their created embryos. While this case concerned *ex utero* living embryos, rather than deceased embryonic or foetal tissue, it is currently the most analogous case under English law and may shine a light on how similar disputes may be managed.[163] The claimant, Natallie Evans, had undergone IVF treatment with her partner, Howard Johnston, to create embryos from their gametes. The embryos represented Evans' last chance of bearing a genetically related child. After

[161] *Paton v BPAS* (n 146).

[162] HT Authority, *Code of Practice A* (2023) (n 66) 27 at [132]; see also HT Authority, *Code of Practice F* (n 160) 18 at [102].

[163] *Evans v Amicus* (n 152).

the couple separated, Evans sought to have the embryos implanted into her. Johnston objected to this and wrote to the clinic to withdraw his consent for the future use and storage of the embryos. Evans applied for a declaration that Johnston had not and could not withdraw or vary his consent. The case was dismissed by both the Family Division of the High Court and the Court of Appeal. In the appeal, it was recognised that one of the primary principles underlying the HFEA 1990 was 'the requirement for informed consent, capable of being withdrawn at any point prior to the transfer of the embryos to the woman receiving treatment'.[164] On this basis, Thorpe and Sedley LJJ held that Johnston could withdraw his consent prior to treatment and there was 'no available way of reading down the Act so as to make the withdrawal of Mr Johnston's consent immaterial to the continuation of Ms Evans's treatment.'[165]

The HFEA 1990 conferred the right of consent on both parties, and both were entitled to exercise their right to withdraw or vary that consent even when it overrode the interests and positive consent of the other. Evans had also argued that the HFEA 1990 violated several of her rights, including her Article 8 right to private life under the European Convention on Human Rights (hereafter the Convention). Article 8 protects a person's 'right to respect for [their] private and family life, [their] home and [their] correspondence.'[166] After the appeal was dismissed, Evans applied to the European Court of Human Rights (ECtHR). In *Evans v UK*, the court clarified that 'private life' was a broad term that encompasses:

[164] Ibid *per* Thorpe and Sedley LJJ at [23].

[165] Ibid at [58].

[166] European Convention on Human Rights Article 8(1).

> [A]spects of an individual's physical and social identity including the right to personal autonomy, personal development and to establish and develop relationships with other human beings and the outside world, [and therefore] **incorporates the right to respect for both the decisions to become and not to become a parent**.[167]

The ECtHR held that both parents' Article 8 rights were engaged, and that it was not possible to protect and uphold both of their rights and interests when they directly conflicted.[168] Article 8 rights can only be justifiably interfered with on the following grounds:

> There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.[169]

The court held that the Article 8 rights of one parent could be interfered with if it was necessary for the protection of the other parent's rights, and that the approach taken under the HFEA 1990 (which did exactly that) was justified as it fell within the state's broad margin of appreciation.[170]

The Article 8 rights of all parents are also clearly engaged in conflicts over the use of foetal tissue. However, the nature of the interests and rights that are engaged in this context are different from those arising in *Evans* in several ways. Unlike *Evans*, which concerned the interference with the claimant's right to private life, foetal tissue disputes capture parents' rights to respect for private *and family* life under Article 8. After implantation, the foetus lives a life and is recognised as

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[167] My emphasis added: *Evans v UK* (2006) 43 EHRR 21 at [57].

[168] Ibid.

[169] European Convention on Human Rights 8(2).

[170] *Evans v UK* (n 167).

having parents under the law, who then become responsible for determining what happens to the foetal body after death.[171] A foetus that is miscarried after twenty-four weeks of gestation is recognised in law as a 'child'.[172] Some parents will socially recognise the foetus as a child at an earlier stage and may grieve their death after pregnancy loss. It was confirmed in *Hadri-Vionnet v Switzerland* that a parent's rights to respect for private and family life encompasses the use of the foetus in rituals surrounding death.[173] In this case, the ECtHR held that the applicant's Article 8 rights had been interfered with because she had not been able to attend the funeral of her stillborn baby and its remains had been transported to a graveyard in an unsuitable manner.[174] Parents' interests in using the foetal body in rituals around death will therefore be protected under their Article 8 rights, although their rights in this regard may conflict if they disagree on which religious or secular rites should be observed.

The ECtHR in *Evans v UK* recognised Article 8 as encompassing 'the right to respect for both the decisions to become and not to become a parent.'[175] In the *Evans* cases, and cases in other jurisdictions that dealt with similar facts, the courts have considered how these competing rights and interests should be weighed. In *Evans v Amicus*, Arden LJ concluded that:

> The interference with Ms Evans's private life is also justified under article 8(2) because, if Ms Evans's argument succeeded, it would amount to interference with the genetic father's right to decide not to become a parent. **Motherhood could surely not be forced on Ms Evans and likewise fatherhood cannot be forced on**

[171] HTA 2004 sections 2(7)(b)(i)-(ii) and 27(4)(b); HFEA 2008 sections 33-47.

[172] (n 124).

[173] *Hadri-Vionnet v Switzerland* App no 55525/00 (ECtHR, 14 February 2008).

[174] Ibid.

[175] *Evans v UK* (n 167) at [57].

> **Mr Johnston**, especially as in the present case it will probably involve financial responsibility in law for the child as well.[176]

The ECtHR also considered the case of *AZ v BZ*, in which the Supreme Court of Massachusetts considered that, per public policy, 'forced procreation is not an area amenable to judicial enforcement' and that 'freedom of personal choice in matters of marriage and family life' should not be impinged upon.[177] They found in favour of the partner who did not want the embryos in question to be used in fertility treatment. The same approach was taken by the Supreme Court of New Jersey in *JB v MB*.[178]

Procreation rights are not engaged in foetal tissue donation in the same way. After death, there is no possibility of the foetus becoming a living child against the wishes of any parent. However, some women have expressed not wanting the foetus to be used in a way that would give it 'a biographical existence' after an abortion, as this would undermine their choice to be child free.[179] As Pfeffer observes:

> Where the aborted fetus somehow persists beyond the abortion there is a danger that 'it's still haunting you' (FG2F4), and that it might prevent a woman from 'getting on with her life' and coming to terms with the abortion.[180]

Furthermore, if foetal ovarian tissues were used in reproductive treatment, the consequence would be that a parent of the foetus would be forced into becoming a

[176] My emphasis added: *Evans v Amicus* (n 152) *per* Arden LJ at [111].

[177] *AZ v BZ* 431 Mass 150, 725 NE 2d 1051, 1058-1059 (2000).

[178] *JB v MB* 170 NJ 9, 783 A2d 707 (2001).

[179] Pfeffer (n 5) 2550.

[180] Ibid 2550.

genetic grandparent against their wishes.[181] These interests are tied to the decision of not becoming a parent and are therefore protected under Article 8. The approaches of the courts in the aforementioned cases have weighed heavily in favour of the partner who does not want the embryos to be used. On this reading, it would be justified for the Article 8 rights of a parent who does not want to donate foetal tissue for certain uses to be protected even where this interferes with the competing Article 8 rights of another parent who does want it to be donated.

In certain disputes, the embryos in question have represented a parent's last chance of having a genetically related child. This was considered a decisive factor by the Israeli Supreme Court in *Nachmani v Nachmani* and in the dissenting judgments in *Evans v UK*.[182] In the latter, it was suggested that to deny the parent this last opportunity by upholding the other parent's objection 'could lead to irreparable harm or to the destruction of the essence of one party's rights'.[183] In contrast, the use of deceased foetal tissue cannot constitute someone's last opportunity to have a genetically related child. It might represent the last opportunity to have a genetically related *grandchild* through the use of foetal ovarian tissue, but this should not be permitted in the face of the other parent's objection and whilst it remains outlawed.[184] Nonetheless, if the foetus had been their last opportunity to have a genetically related child, then the death of the foetus will be especially distressing to them, and they may have strong feelings about how

[181] Whilst this use is outlawed in England and Wales, it remains a possibility that warrants consideration: see 3.2.1; Berkowitz (n 77).

[182] *Nachmani v Nachmani* 50(4) PD 661 (1995); *Evans v UK* (n 167).

[183] *Evans v UK* ibid at [O-19].

[184] See 3.2.1; Berkowitz (n 77); HFEA 1990 section 3A (as amended by the Criminal Justice and Public Order Act 1994).

its body is used. It would be wrong to assume, however, that the other parent would not also be greatly distressed by the death of the foetus and have strongly held wishes about the disposition of its body. This loss of opportunity does not give one parent a greater claim to have their interests recognised over that of other parents.

Furthermore, when foetal tissue is used in medical research, genetic information about it and its genetic parents may be revealed.[185] As recognised in *Evans v Amicus*, under the HFEA 1990 *ex utero* embryos are considered 'the genetic material of two individuals', and indeed the dispute in this case centred on the parents' control of their material.[186] In Arden LJ's view, their rights in this regard must be protected:

> [Under the HFEA 1990] the right of withdrawal [of consent] is granted in recognition of the dignity to which each individual is entitled. Such must include an individual's right to control the use of their own genetic material. In my judgment, it would be contrary to public policy for courts to enforce agreements to allow use of genetic material.[187]

Once *in utero*, an embryo begins to develop into a unique human being. It becomes so much more than, and can no longer be accurately described as, just the parents' reproductive material. After death, parental interests must therefore be limited by a requirement to respect the individual foetus' special moral status, and so parents should not be given rights to treat foetal tissue as if it were their own personal tissue. However, they should be given the power to object to certain uses of it that would interfere with their genetic privacy, because to do so would not interfere with anyone's bodily autonomy rights. In the absence of competing rights from the

[185] See 3.2.1.

[186] *Evans v Amicus* (n 152) *per* Arden LJ at [80].

[187] Ibid *per* Arden LJ at [120].

foetus, save the requirement to respect its special status, the interests of one parent in donating foetal tissue for genetic research must be outweighed by another parent's refusal because of their genetic privacy interests.[188]

Finally, under the HFEA framework, the welfare of any future children must be taken into account in decisions about the use of embryos and the provision of fertility treatment.[189] As Arden LJ explained in *Evans v Amicus*, 'it is the policy of the 1990 Act that children should not be brought into the world simply to satisfy the wishes of their genetic parents, or other human beings.'[190] This is no longer a relevant consideration after the death of the foetus, and so this will not operate to override the interests or rights of parents in the use of foetal tissue. Regard need only be given to respecting its special moral status when determining how its tissue should be used.

In the *Evans* cases, it was held that a parent's objection to embryo use must be protected even at the cost of interfering with the procreation interests of another parent. A consistent thread that ran through the judgments was the harm that can be caused by forcing someone to procreate against their will. In the High Court, Wall J affirmed that the power to withdraw consent must be available to all parents regardless of their sex or situation:

> If a man has testicular cancer and his sperm, preserved prior to radical surgery which renders him permanently infertile, is used to create embryos with his partner; and if the couple have separated before the embryos are transferred into the woman, nobody would suggest that she could not withdraw her consent to

[188] See 3.2.1.

[189] HFEA 1990 section 13(5).

[190] *Evans v Amicus* (n 152) *per* Arden LJ at [85].

> treatment and refuse to have the embryos transferred into her. The statutory provisions, like Convention rights, apply to men and to women equally.[191]

For the same reason, foetal tissue should not be used against the wishes of a parent. Although parental rights and interests in foetal tissue use are different from those that arise in disputes over embryos, they nonetheless also warrant protection for the reasons stated above. Following *Evans*, parents cannot be forced into decisions that violate their Article 8 rights. They must therefore be permitted to object to particular uses of foetal tissue. This may have the effect of interfering with the Article 8 rights of any parent who seeks to use foetal tissue in particular ways. However, Article 8 does not confer on parents a positive right to use foetal tissue in a particular way. Neither does English law. They have no rights to use the tissue of another as they wish, whether to obtain genetic information or to become a genetic grandparent. It is evident that they lack any legal or any other justified basis on which to dictate the use of foetal tissue without the agreement of other parents.

The law should be slow to confer positive rights on a person to use the body of another. As illustrated in *Evans*, parents do not have a right under the HFEA 1990 to use their embryos. Similarly, whilst family members may be asked to donate the tissue of a deceased relative, they do not have a protected right which ensures that they will be given this opportunity or that any donation will be accepted. It would be a departure to extend the law for foetal tissue donation in this regard, and there is no justifiable basis for doing so. Simply put, it is not their tissue to use as they please.

[191] *Evans v Amicus Healthcare Ltd* [2003] EWHC 2161 (Fam) *per* Wall J at [320].

Distinguishing between uses of the foetal body

Deceased bodies naturally decompose. Rituals around death and other forms of disposal are performed both to manage decomposition and to honour the former individual. These acts are both socially expected and legally required (unless bodies are used otherwise).[192] Other uses of bodies – such as in research, art, and medical training – are non-natural (albeit not unwanted) departures from the natural disposition of being laid to rest or disposed of. It is more likely that parents will be harmed, or will experience greater harm, if foetal tissue is used against their interests for non-natural uses, and less so by natural and socially expected uses. Firstly, some may lack knowledge about how foetuses are used in medical research or other applications which can provoke 'concerns about mishandling'.[193] Secondly, some women have expressed concerns about the 'lack of control' they would have after donation and the 'ethical responsibility' they would feel for how foetal tissue is used.[194] As Pfeffer observes: 'an invitation to donate an aborted fetus to medical research in general and stem cell research in particular places a woman at the juncture of a host of concerns over which she has no authority.'[195]

Thirdly, parents may perceive the foetus as being mutilated if it is used in a particular way rather than being laid to rest. Some women would find it too upsetting to donate tissue from a stillborn foetus (as opposed to one that is

[192] See for example Skene (n 119) 119; *AB* (n 66).

[193] Pfeffer (n 5) 2553. Pfeffer's study also highlighted a 'lack of knowledge about how aborted fetuses are treated as scientific objects in the stem cell laboratory' amongst participants: Pfeffer (n 5) 2544; see also Chapter 4.

[194] Ibid 2552.

[195] Ibid 2552.

electively terminated), especially to non-therapeutic research.[196] Others worry that the use of tissue would 'allow the fetus a biography beyond the abortion, that it might even develop or resurrect it.'[197] Such uses can therefore cause parents great distress. In contrast, there is more public knowledge about how foetuses and other bodies are used in rites such as burial and cremation. These practices are socially accepted and expected. There are several different ways to honour and dispose of bodies, and certain methods may cause distress if they do not align with the wishes of the parents. For example, one woman in Middlemiss' research considered it disrespectful that foetuses are often cremated together in a group alongside placentas and other conception tissue.[198] Another was extremely upset to be told that she was not allowed to attend the funeral for her baby after experiencing pregnancy loss.[199] A similar issue arose in *Hadri-Vionnet v Switzerland*, where a stillborn baby had been buried without the parents being consulted.[200] The ECtHR held that this had unlawfully interfered with their Article 8 rights.

Parents may wish to donate foetal tissue to 'a good cause… [which] is gonna make a difference to the quality and to society and human beings' to allow 'something good' to come from the pregnancy loss.[201] They may have a vested interest in advancing research in areas such as pregnancy complications and

[196] Ibid 2549.

[197] Ibid 2550.

[198] Middlemiss (n 1) 304-305.

[199] Ibid 306-307.

[200] *Hadri-Vionnet* (n 173).

[201] Pfeffer (n 5) 2549-2550.

miscarriage care.[202] As Pfeffer explains, those 'who undergo an abortion might see redemption in allowing scientists to extract value out of a fetus that they have rejected.'[203] If they are denied the opportunity to donate tissue this will harm their interests. Nevertheless, the outcome is that the foetus will be used in a socially expected way. This will cause less harm that the opposite situation where, for example, a foetus is not laid to rest in line with parental wishes but is perceived as being 'chopped up' and 'pulled apart' in a laboratory after donation.[204] For these reasons, non-natural uses of the foetus may cause greater harm to parental interests than natural uses. Therefore, the law should not recognise positive rights to donate foetal tissue and should instead protect parental objections to donation.

Parental objections and Article 8 rights

The HFEA framework staunchly protects a parent's legal right to withdraw or vary their consent for the use of embryos and does not permit this right to be overridden in any circumstance.[205] In *Evans v UK*, the applicant argued that exceptions to this rule should be allowed where its enforcement would cause disproportionate harm to another parent.[206] This was not accepted by the ECtHR. They held that states enjoy a wide margin of appreciation in this area which permits them to impose 'bright line' rules without exceptions in order to achieve a balance between

[202] Ibid 2549; Fionn Anderson and others, 'Attitudes of women to fetal tissue research' (1994) 20 J Med Ethics 36.

[203] Pfeffer ibid 2549.

[204] Ibid 2552.

[205] HFEA 1990 Schedule 3 at [4]; *Evans v Amicus* (n 152); *Evans v UK* (n 167).

[206] *Evans v UK* ibid.

competing Article 8 rights.[207] The approach under the HFEA framework fell within this margin of appreciation. The court considered that to require UK legislation to allow exceptions would undermine the legitimate principle of protecting consent rights and would be difficult to manage:

> The fact that the law allowing either party to withdraw his or her consent up until the point of implantation of the embryo did not permit of exception (a 'bright line' rule), did not in itself render it disproportionate. If exceptions were permitted, the principle which Parliament legitimately sought to achieve, of ensuring bilateral consent to implantation, would not be achieved. Complexity and arbitrariness would result, and the domestic authorities would be required to balance individuals' irreconcilable interests, as in the present case.[208]

The ECtHR held that states were entitled to a wide margin of appreciation regarding the regulation of IVF treatment because it 'gives rise to sensitive moral and ethical issues against a background of fast-moving medical and scientific developments.'[209] The same can be said of the use of foetal tissue, which raises unique ethical questions and can be used in rapidly developing applications in medical research and treatment.[210] It is therefore likely that states would be afforded a wide margin of appreciation for laws governing foetal tissue use which would justify the implementation of a bright line rule. Following *Evans v UK*, it would thus be proportionate under the Convention for legislation to draw a bright line in law to *always* protect parental objections to foetal tissue use even when this interferes with the Convention rights of another parent.

[207] Ibid at [50]-[55].

[208] Ibid at [55].

[209] Ibid at [62].

[210] See 1.3.

In contrast to the protection given under the HFEA framework, the HTA framework does not give equal weight to the interests of both parents in the same way. Consent is only required from one parent for deceased tissue donation.[211] Therefore, only that parent can vary or withdraw their consent.[212] Whilst the HTA Code of Practice on Consent recommends that 'where appropriate, both parents are involved' in the decision to donate foetal tissue, this is not a legal requirement and it remains the case that consent is only required from one of them.[213] Greater emphasis is also placed on involving 'the mother' over other parents.[214] If another parent who was not the one to give consent changes their mind about tissue donation at a later stage, they do not have the legal standing to challenge the continued storage and use of donated tissue. There is no consent for them to vary or withdraw, and they are not otherwise afforded the legal power to object under the HTA 2004. All parents can potentially be harmed by the use of foetal tissue against their interests. A governing framework must therefore place parents on equal footing by protecting their interests equally and giving each of them the power to object to tissue donation.

Disputes over disposal arrangements

Even if the foetal body is not donated and is used in rituals around death, parents may disagree about *how* it should be laid to rest. For example, Parent A may want to hold a secular funeral for the foetus whereas Parent B may want to carry out

[211] HT Authority, *Code of Practice A* (2023) (n 66) 10 at [33] and 20 at [90].

[212] Ibid 13 at [51]-[52].

[213] Ibid 29 at [142].

[214] Ibid.

religious burial rites. The harm caused to each parent when their interests regarding natural uses of the foetal body are denied is more equal and therefore more challenging to manage than disputes over both natural and non-natural uses. Although this chapter has argued that the law should uphold parents' objections to non-natural uses of the foetal body, there must be a limit to which the law should do so for natural uses. If both Parent A and Parent B are permitted to object to each other's intended arrangements, the end result would be that no decisions about the management of the body would be made, and it would remain unburied. This would contravene the legal requirement for bodies to be buried or otherwise disposed of.[215] The legal position is explained by Hale J (as she was then) in *Buchanan v Milton*:

> There is no right of ownership in a dead body. However, there is a duty at common law to arrange for its proper disposal. This duty falls primarily upon the personal representatives of the deceased … An executor appointed by will is entitled to obtain possession of the body for that purpose … Where there is no executor, that same duty falls upon the administrators of the estate.[216]

When a foetus of twenty-four weeks of gestation or greater dies, known as a stillborn child under the law, it will die intestate. When a person dies intestate, the law recognises a hierarchy of persons who will be appointed as the administrators of their estate.[217] Parents are recognised as the administrators for the stillborn foetus, which grants them the right to possess the body for the purposes of arranging for its disposal.[218] These laws do not apply to foetuses of a younger age,

[215] (n 118).

[216] *Buchanan* (n 118) 845-846 *per* Hale J.

[217] Non-Contentious Probate Rules 1987 rule 22.

[218] Ibid rule 22(1)(c); Births and Deaths Registration Act 1953 section 41 (as amended by the Stillbirth (Definition) Act 1992 section 1(1)).

because they are legally classified as the pregnant person's personal tissue rather than a deceased person or body.[219] Foetal tissue of a lower gestational age must still be disposed of, but the parents do not have the legal power to direct how this is carried out and their consent is not required for its disposal. The Human Tissue Authority (HT Authority) has produced guidance which recommends that the pregnant person's 'wishes regarding disposal options should be respected and acted upon.'[220] These rules clearly do not adequately recognise and protect the interests of *all* parents in the disposition of the body of the younger foetus.

Earlier in this chapter it was argued that the legal requirement for stillbirth registration – which only applies to foetuses of twenty-four weeks of gestation or greater – should not be extended to all foetuses where this is necessary for the protection of state and public health interests.[221] For the same reasons, the legal requirement to bury foetuses of twenty-four weeks of gestation or greater should not apply to all foetuses. Crucially, parents should not be *legally* required to choose formal methods for disposing of the body of the younger foetus because they may not wish to recognise its existence in this way. Nonetheless, the law should enact provisions which ensure that parental interests in how younger deceased foetuses are disposed of are followed.

Rule 22(1)(c) of the Non-Contentious Probate Rules 1987 appoints all parents as administrators of the stillborn foetus' estate but does not clarify how disputes between parents about burial arrangements should be settled. A small

[219] HT Authority, *Code of Practice A* (2023) (n 66) 28-29 at [141]-[142]; *AB* (n 66).

[220] HT Authority, *Guidance on the disposal of pregnancy remains* (n 118) 2 at [8].

[221] See 3.2.2.

number of these disputes have been brought before the courts. In the case of *Re JS (Disposal of Body)*, a child and her mother sought to cryopreserve the body of the former after her death.[222] A disagreement arose between them and the child's father about whether he could view her body after death.[223] Despite JS' clear wishes, the law does not permit a person to control how their body is used after death.[224] Moreover, as a child she was unable to create a will to grant her mother alone the power to control the disposition of her body.[225] Therefore, the right to direct the disposal of her body would have fallen to both parents.[226] Jackson J made it clear that the role of the court was not to decide how the body should be used or make directions to this effect but was only to 'resolve disagreement about who may make the arrangements.'[227] This was also outlined in the earlier case of *Anstey v Mundle*.[228] In *Re JS*, Jackson J held that the court had the power to make an order

> [A]ppointing the mother as the sole administrator of her estate in place of the mother and father jointly, and specifying that the mother shall thereby have the right to make arrangements for the disposal of the body, and to decide who should be permitted to view it.[229]

[222] *Re JS (A Child) (Disposal of Body: Prospective Orders)* [2016] EWHC 2859 (Fam).

[223] Ibid at [21].

[224] *Williams v Williams* [1882] LR 20 ChD 659; ibid at [35] and at [47]-[48].

[225] Wills Act 1837 section 7.

[226] Non-Contentious Probate Rules 1987 Rule 22(1)(c); *Re JS* (n 222) at [50].

[227] *Re JS* ibid at [49].

[228] The court in *Anstey* 'concluded that the Court could not determine or direct where or how the deceased would be buried, but could declare who had the power and duty to bury the deceased, among the various contending parties': summarised by Hayden J in *Re K (A Child) (Disposal of Body: Court's Power to Authorise)* [2017] EWHC 1083 (Fam), [2017] 4 WLR 112 at [9]; *Anstey v Mundle* [2016] EWHC 1073 (Ch); see also *Hartshorne v Gardner* [2008] EWHC 3675 (Ch).

[229] *Re JS* (n 222) at [41].

Jackson J concluded that the courts could make this order based on either section 116 of the Senior Courts Act 1981 – which permits courts to alter who is appointed as the administrator of an estate – or based on the court's inherent jurisdiction.[230]

The court may also appoint another person, other than the parents, as an administrator. This occurred in *Re K (A Child) (Disposal of Body: Court's Power to Authorise)*, where neither of the parents made an effort to bury the body of their child for several months after his death.[231] Hayden J made an order for the local authority to make the necessary arrangements regarding the body's disposal.[232] The decision in this case closely aligns with a local authority's statutory duty regarding deceased bodies under section 46(1) of the Public Health (Control of Disease) Act 1984:

> It shall be the duty of a local authority to cause to be buried or cremated the body of any person who has died or been found dead in their area, in any case where it appears to the authority that no suitable arrangements for the disposal of the body have been or are being made otherwise than by the authority.

The disposal of a body could also be delayed when there is a dispute between parents regarding disposal methods. When such delays occur, the body is left to degrade and, in the words of Hayden J in *Re K*, is not shown 'proper respect and decency'.[233] This undermines the respect that is owed to the deceased foetus' body because of its special moral status, which cannot be borne. The law must therefore enact ways of managing parental disagreements to avoid such delays. Furthermore, delays in burying bodies also engage public health interests in maintaining

[230] Ibid at [52]-[53].

[231] *Re K* (n 228).

[232] Ibid at [4]; *Re JS* (n 222).

[233] *Re K* ibid at [10].

environmental health and public hygiene standards, as well as state interests in maintaining public health standards and compliance with burial laws. As espoused by Hayden J in *Re K*: 'as a matter of public policy, a body should be disposed of with due dispatch.'[234] Ben Saunders also notes that 'something must be done with cadavers, for they cannot simply be left to rot wherever they happen to be.'[235] For this reason, it is necessary and justifiable for state and public health interests to override those of the parents regarding disposal decisions.

In the event of intractable disputes, statute and common law provides guidance for how a court should reach a decision about who should be appointed as the administrator for the management of a body. Several cases have made orders under section 116(1) of the Senior Courts Act 1981, which reads as follows:

> If by reason of any **special circumstances** it appears to the High Court to be **necessary** or **expedient** to appoint as administrator some person other than the person who, but for this section, would in accordance with probate rules have been entitled to the grant, the court may in its discretion appoint as administrator such person as it thinks expedient.[236]

In *Re Clore (Deceased) (No 1)*, Ewbank J gave the term 'special circumstances' a broad definition which could extend to any 'circumstances which the court thinks are relevant'.[237] This definition was adopted by Hale J in *Buchanan v Milton*.[238] She identified six special circumstances as arising in this case, as summarised by Hayden J in *Re K*:

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[234] Ibid at [10].

[235] Ben Saunders, 'Opt-out, mandated choice and informed consent' (2023) 37 Bioethics 862, 866.

[236] My emphasis added.

[237] *Re Clore (Deceased) (No1)* [1982] Fam 113, 117.

[238] *Buchanan* (n 118) 846-847 and 855.

> One was the nature of the adoption, the fact that the Applicant had given up the deceased at a very young age; secondly, the deceased's Aboriginal heritage and the importance attached to correct burial procedures; thirdly, the initial agreement reneged upon after death; fourthly, the deceased's daughter's interest in knowing that, in due course, things were done in accordance with her father's Aboriginal heritage; fifthly, the interest of other members of the Australian family; and finally, the deceased's wishes.[239]

In *Re JS*, Jackson J found 'the nature of the family breakdown' and 'JS' wishes' to be special considerations.[240]

Other cases have made orders that instead rely on the inherent jurisdiction of the court.[241] In *Hartshorne v Gardner*, Sonia Proudman QC (sitting as the judge) identified a non-exhaustive list of factors to be considered in the exercise of the court's jurisdiction.[242] These were summarised and relied on in the judgment of Klein J in *Anstey v Mundle*:

> [O]ne, the deceased's wishes; two, the reasonable requirements and wishes of the family who are left to grieve; three, the location with which the deceased was most closely connected; and, four, to quote the judgment, 'the most important consideration is that the body be disposed of with all proper respect and decency and if possible without further delay.[243]

For either approach, there is a developing body of case law containing relevant legal considerations that future courts can rely on in order to guide their management of parental disputes over the disposal of foetal bodies.

Nonetheless, the interests of the parents should be upheld as far as this is possible. Because their competing interests carry equal weight, a bright line rule

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[239] *Re K* (n 228) at [16].

[240] *Re JS* (n 222) at [54].

[241] See for example *Hartshorne* (n 228); *Re JS* ibid.

[242] *Hartshorne* ibid.

[243] *Anstey* (n 228) at [25]; *Hartshorne* ibid.

favouring one parent over others should not be adopted. A resolution should instead be reached on a case-by-case basis. The primary aim for the courts should be to assist the parents in reaching an agreement. If this cannot be achieved, the role played by the law and by the courts should remain limited, as was the case in *Re JS* and *Anstey v Mundle*.[244] The powers of the court should not be extended to permit them to direct how the body is disposed of. Instead, the existing common law rules should apply, which permit a court to dictate which person should take responsibility for making these arrangements. Where possible, this should include at least one of the parents, or if this is not possible, the local authority.

Arguments against giving equal recognition to parental interests

Difficult cases may arise where it does not seem reasonable to prioritise the interests of all the parents of a deceased foetus. This is illustrated by the following example of an abusive genetic parent:

> Izzy falls pregnant as a result of being raped by Joe. Izzy chooses to continue the pregnancy, but Joe later physically assaults Izzy and causes her to miscarry.

Whilst Joe is the genetic parent of the foetus, he has not shown the care we might expect from a parent; instead, he has inflicted significant pain on Izzy by repeatedly abusing her and forcing her to become pregnant against her will and to miscarry. In such a case, it does not seem reasonable to allow Joe to have a say in the disposition of the foetal tissue that results from the miscarriage. One way to avoid him from having this input would be to only prioritise the interests of the pregnant person. Under such a rule Izzy alone would make the decision about the

[244] *Anstey* ibid; *Re JS* (n 222).

disposition of foetal remains and Joe would not have any legal standing to object to this. Whilst this approach may produce an ideal result in the case of Izzy and Joe, privileging the interests of the pregnant person in all cases would be harmful to other parents. It would come at the cost of ignoring the interests of all other parents. Many other cases will not reflect the dynamic in the given example, and some will instead involve a loving partner:

> Kat and Lee hope to start a family together and both feel grief when Kat suffers a miscarriage partway through pregnancy. She is rushed to hospital where she receives treatment to ensure that all the tissue is extracted. After the procedure, a researcher asks her to consider donating the foetal tissue to medical research, which she agrees to. When Lee joins her at the hospital, he is distraught when he learns about the donation. He objects to the use of foetal tissue in medical research on religious grounds and wanted to have a Catholic funeral for the remains. Kat had been unaware of Lee's wishes but chooses not to withdraw the donation because she wants the tissue to be used in research to help others.

Here, there are two loving parents and partners who have different religious and personal views surrounding the management of the foetal remains. If only Kat's interests are prioritised, then Lee's will be overlooked, and he may be harmed by the use of the foetal tissue against his interests. This is just one example of the varied dynamics and relationships that will surround decisions about the use of foetal tissue. The important point here is that there will be many cases where other non-abusive parents have strong interests in how foetal tissue should or should not be used and they may be harmed if these are not taken into consideration. Framing the law around an unusual hard case is not a good approach when the consequence is to deny the inclusion of other parents' interests (and potentially cause them harm) in many other cases. Take another example:

> Maeve unexpectedly dies due to complications from an ectopic pregnancy. Her husband Nick is distraught to lose both his wife and unborn child. Because only the interests of Maeve (as the pregnant person) would have been taken into account

> regarding tissue disposal, Nick is left with no legal control over the disposition of the foetal remains.

Even if legal priority is given only to the pregnant person, many couples would discuss and reach a joint decision about how to manage foetal remains. However, the interests of other parents such as Nick cannot be legally prioritised following the death of the pregnant person. This is why they must be taken into account.

In the case of Izzy and Joe, the issue of giving equal legal recognition to Joe's interests could be resolved in two ways. Firstly, legal grounds could be established on which parents lose their legal interest in the disposition of foetal tissue. These may include the infliction of bodily harm and sexual assault on the pregnant person. However, there is often a long delay between when a crime is committed and when it is brought to court, and there are many difficulties in prosecuting sexual assault. Without a legal conviction, these grounds would not assist individuals like Izzy. A second avenue would be to allow one parent to bring a claim to permit them alone to be appointed as the administrator for the management of the deceased foetal body, as discussed earlier in this section and in cases such as *Re JS* and *Re K*.[245] A criminal conviction would not be needed here – Izzy would simply need to demonstrate to the court that she alone should be granted the power to direct the disposal of the tissue. The application pathway for this could be streamlined and made easier for parents to ease the burden of a complex court claim.

Finally, even if Izzy could not prevent Joe's interests from carrying legal weight, the primary consequence of this would be that she might be prevented from

[245] *Re JS* (n 222); *Re K* (n 228).

donating foetal tissue for a particular use, as he would have the legal standing to object to this. Joe would not have the power to dictate how else the foetal tissue would be used, such as the method of disposal, because any conflict between Izzy and Joe in this respect would result in a legal dispute (as described above) where Izzy could be granted the power to determine the disposal of the foetal body. The desire to donate foetal for a particular use, such as in medical research, may be important to Izzy, and she may be distressed if she is prevented from doing so. However, looking at the bigger picture, this negative consequence is relatively minor, especially when compared to the alternative approach of denying all other parents a legal interest in foetal tissue. On balance, recognising a legal interest for all parents will cause the least harm and must be preferred under rule-utilitarianism.

Another difficult, and perhaps more usual case may arise regarding the identification of other parents. Take the following example:

> Orla unexpectedly falls pregnant and seeks a termination. She tells the clinical team providing her abortion care that she does not know who the genetic father is. Her care team are unsure about whether this is true or whether she just does not want to identify him.

It is not possible for the interests of the genetic father, or any other parent, to be taken into account if they are not identified and notified about the existence of foetal tissue. This is a challenge to the proposition that their interests should be considered. However, under the current law, the pregnant person cannot be compelled to identify other parents regarding the management of the pregnancy or foetal tissue, and it would not be appropriate to add in a requirement for this here. The pregnant person is entitled to their privacy. Moreover, they may well be unaware of the identity of the genetic father. Whilst those seeking consent for the use of foetal tissue should ask the pregnant person whether there are other parents,

they can only act in good faith upon the information they receive. The legislative provisions that establish the legal grounds for respecting parental interests must be worded so as to allow exceptions for donees acting in good faith regarding their knowledge about the existence of other parents.

3.3.1 Who is a parent?

Whose interests should count as parental interests in conflicts over foetal tissue use? The law recognises people as parents for various reasons. For living children, there are public and legal interests in knowing who is responsible for taking care of them day-to-day and who has the authority to make welfare decisions about them such as for medical care and schooling. Those with these responsibilities are recognised as parents or as having parental responsibility under the law.[246] For couples undergoing fertility treatment, such as IVF, the HFEA 2008 recognises who will act as the parents of the future child after its birth.[247] Furthermore, the HFEA 1990 requires that the welfare of the future child is considered in treatment decisions.[248] These Acts provide clarity about who will be recognised as a parent of the future child. When children are conceived in other ways – not by methods governed by the HFEA framework – parents are legally identified upon live birth.[249] That is the point at which they must act as a parent to the living child.

[246] See Children Act 1989 section 2.

[247] HFEA 1990 section 13(5) and HFEA 2008 sections 33-47.

[248] Ibid.

[249] Children Act 1989 section 2(1).

For foetal tissue donation, parents only need to be identified insofar as to determine who should have a say in donation. If the foetus was conceived using fertility treatment, the law will have already identified the parents under the HFEA framework.[250] For all other foetuses that die *in utero*, parents will not have been pre-identified by law except for the pregnant person. Section 33(1) of the HFEA 2008 provides that 'The woman who is carrying or has carried a child as a result of the placing in her of an embryo or of sperm and eggs, and no other woman, is to be treated as the mother of the child.' For example, in *AB v Leeds Teaching Hospitals NHS Trust* the claimant Mrs Shorter was recognised as the parent of her stillborn foetus after she experienced pregnancy loss.[251]

The HTA 2004 requires consent to be given by a parent for the donation of deceased foetal tissue.[252] Yet it does not define who counts as a parent. The HTA Code of Practice on Consent only states that consent for tissue donation from a stillborn foetus or child may be given by 'a parent' or 'a person with parental responsibility' under the Children Act 1989.[253] Section 2 of the Children Act 1989, which outlines who has parental responsibility for children, identifies the people who would attain this upon the birth of the child or would be recognised as parents at the time that the pregnant person undergoes fertility treatment.[254] It does not explicitly recognise or provide guidance about who would have parental

[250] HFEA 2008 sections 33-47.

[251] *AB* (n 66) see for example at [98]; see also *Hadri-Vionnet* (n 173).

[252] HTA 2007 section 27(4).

[253] HT Authority, *Code of Practice A* (2023) (n 66) 26-27 at [129]-[130].

[254] Upon birth: see for example Children Act 1989 section 2(1). Upon artificial insemination: Children Act 1989 section 2(1A)(a) and HFEA 2008 section 42.

responsibility for the foetus before and after its death either generally or specifically for the purposes of having the authority to donate its tissue.

In contrast, the HFEA 2008 explicitly recognises various categories of parent. These include the pregnant person, their spouse or civil partner at the time of treatment, and a partner or other person who meets the 'agreed female parenthood conditions' or the 'agreed fatherhood conditions'.[255] Definitions are also given for who should not be treated as a parent, such as sperm and egg donors.[256] It remains unclear whether the HTA 2004 would recognise all or some of these categorises of parent for foetal tissue donation. It is desirable for those recognised as parents under the HFEA framework to remain so under the rules governing foetal tissue donation. If these people could be parents of an embryo and a future child, then they must also be parents of the foetus who dies *in utero*. It would not be legally consistent for someone's legal parental status to cease upon the death of the foetus but to continue if it lives.

The pregnant (or gestational) person must of course be recognised as a parent. They have the closest physical tie to the foetus before death and they are well recognised in law as its parent during and after pregnancy.[257] This includes surrogates, who become pregnant with the intention of allowing the child to be raised by another. The laws recognising the pregnant person as a parent during pregnancy do not make any distinction as to whether they would continue to

[255] Pregnant person: HFEA 2008 section 33; their spouse or civil partner at the time of treatment: sections 35 and 42; and a partner or other person who meets the 'agreed female parenthood conditions' or the 'agreed fatherhood conditions': sections 36-37 and 43-44.

[256] HFEA 2008 sections 41 and 47.

[257] HFEA 2008 section 33; *AB* (n 66); *Hadri-Vionnet* (n 173).

parent the future child after live birth. For example, section 33(1) of the HFEA 2008 simply provides the definition of a 'woman who is carrying or has carried a child'. No genetic link or future intention to care for the child after birth are required for any pregnant person to be recognised as a parent before birth or before the implementation of a parental order or adoption order.[258] During pregnancy, any physical interference with the foetus would constitute a violation of the pregnant person's bodily integrity rights. After death, foetal tissue may be mixed up with non-foetal products of conception, which comprises tissue from both the pregnant person and the foetus.[259] If these tissues cannot be separated, then non-foetal products of conception may be donated and used alongside foetal tissue. Therefore, even if the pregnant person is not genetically related to the foetus, their personal rights and interests over the use of their personal tissue will be engaged and could be harmed by its use.

Genetic links between parent and child can be incredibly important to some people. In *Evans*, the claimant sought permission to use the embryos she had created with the defendant because they represented her last chance of having a genetically related child.[260] The law, however, does not place much weight on genetic links when recognising who should be a parent or have parental responsibility. Section 2(1) of the Children Act 1989 assigns parental responsibility to married spouses or civil partners regardless of whether a genetic link exists between parent and child. The HFEA 2008 also recognises that married or civil partners of the pregnant person at the time of treatment can be parents of the future

[258] See for example HFEA 2008 sections 33(1)-(2).

[259] See 2.6.

[260] *Evans v Amicus* (n 152).

child, regardless of the presence of a genetic link.[261] This much is also recognised outside the context of fertility treatment. In *Paton*, the husband was recognised as the 'father' of the unborn foetus.[262] Other non-legal partners – those who do not have a legal union with the pregnant person – may be recognised as parents under the HFEA 2008.[263] Furthermore, sperm and egg donors are not treated as parents under the Act, despite their clear genetic link, unless other requirements under Part 2 of the Act are satisfied.[264]

Social and intending parents can become legally recognised parents after a parental order has been obtained, which is 'an order providing for a child to be treated in law as the child of the applicants'.[265] Social and intending parents of *living* children are therefore well recognised under the law. Nonetheless, the interests of genetic parents also receive some legal recognition and protection. A parental order will only be granted if one of the applicants has a genetic link to the child by virtue of their gametes being used to create the embryo.[266] Moreover, in *Evans* the courts were reluctant to allow parenthood to be forced on an unwilling genetic parent.[267] A genetic parent will be harmed if they are forced to become a genetic parent or grandparent against their wishes.[268] In addition, their genetic privacy interests will

[261] HFEA 2008 sections 35 and 42.

[262] *Paton v BPAS* (n 146) 279-280; *Paton v UK* (n 150) at [2] and [25].

[263] HFEA 2008 36-37 and 43-44.

[264] Ibid sections 41 and 47.

[265] HFEA 2008 section 54(1) and sections 54-55 generally.

[266] Ibid sections 54(1)(b) and 54A(1)(b).

[267] *Evans v Amicus* (n 152) *per* Arden LJ at [111].

[268] See 3.2.1 and 3.3.

be engaged (and thus may be interfered with) if genetic information about them can be obtained from foetal tissue use.

Each of these categories denotes people who would be considered parents of the foetus at both a social and legal level under the HFEA framework. Therefore, their Article 8 rights to private and family life will be engaged when foetal tissue is used. This has been explicitly recognised for the pregnant person and their married partner in *Paton v UK* and the genetic parents in *Evans v UK*.[269] There is a very real possibility that all of these parents may be harmed, in the ways described above, by the use of foetal tissue against their interests.[270]

Those seeking to obtain legal parenthood under a parental order cannot do so until six weeks after the live birth of the child.[271] Parental orders can be applied for after the first six weeks and within six months of the birth.[272] Therefore, it appears that they would not be recognised as a parent before this point, which as described above is not the case for the other aforementioned categories of parent, who may be legally recognised before birth. The HTA 2004 explicitly recognises that the stillborn foetus has parents:

> It is recommended that, whenever possible, the consent process for the examination of stillbirths and neonatal deaths involves the mother, and that, where appropriate, both parents are involved.[273]

[269] *Paton v UK* (n 150); *Evans v UK* (n 167).

[270] See 3.2.1 and 3.3.

[271] HFEA 2008 section 54(7).

[272] Ibid section 54(3).

[273] HT Authority, *Code of Practice A* (2023) (n 66) 29 at [142].

However, the Act does not give a definition for who would be recognised as a parent of a stillborn foetus. Without explicit recognition, it appears that social and intending parents would not be legally recognised under the HTA 2004 or elsewhere under the law. Nevertheless, as argued above, the Article 8 rights of social and intending parents will also be engaged when foetal tissue is used, and will be harmed if it is used against their interests. Therefore, there is a need for their interests to be recognised and protected in the same way as other parents under the law.

The law will only recognise a maximum of two parents for a living embryo or child.[274] More than two people may have parental responsibility for a child, but this does not apply to embryos and foetuses before live birth. The role of the law here is to identify who should count as a parent for the purposes of donation. Any practicalities about how many parents a living child should have in law, and whether this should be limited, do not apply. The foetus will not become a living child to whom these rules would apply, so the law on foetal tissue donation does not need to strictly align with them or abide by such limits. The law governing the donation of foetal tissue can thus afford to be more expansive regarding how many parents are identified for a deceased foetus. All the aforementioned categories – social, genetic, and gestational parents – should be recognised. In many cases, only two parents will be identified. But in some cases, a greater number of parents will be involved. Take the following example:

> Abi is married to Beth. Abi agrees to act as a surrogate for Carlos and Dom, an unmarried couple. Abi's egg and Carlos' sperm is used to create the embryo, which is implanted into Abi via IVF. Carlos and Dom intend to obtain a parental order

[274] See for example HFEA 2008 sections 33-47. A maximum of two people can apply for a parental order: HFEA 2008 section 54.

> to be recognised as the legal parents of the future child. During the pregnancy, Abi and Beth establish a relationship with the growing foetus. Abi then suffers a miscarriage at twenty-six weeks and is asked to donate foetal tissue to medical research.

It is not necessary, nor would it be justified, to only recognise two people in the scenario as the foetus' parents. All of these parents – Abi as the gestational parent, Beth as the partnered social parent, Carlos as the genetic parent, and Dom as the intending social parent – may be harmed if foetal tissue is used against their interests. To choose just two of these to the exclusion of the other would undermine their Article 8 rights and disregard the harm they could experience. All four should be recognised as parents and have the power to object to foetal tissue donation.

3.4 How should interests be protected?

Interests must be protected by clear and enforceable rules. This could take the form of non-legal regulation through the creation of best practice guidelines. Examples of such guidelines include the Codes of Practice on the use of foetal tissue issued by the Polkinghorne and Peel Committees.[275] Codes can be very detailed, and the rules within them may be overseen, enforced, and updated over time by a regulatory authority.[276] Several detailed Codes on the use of human tissue have been produced by the HT Authority, including on consent, post-mortem examination, anatomical examination, public display, and medical research.[277]

[275] John Polkinghorne, *Review of the Guidance on the Research Use of Fetuses and Fetal Material* (Cm 762, 1989) (hereafter Polkinghorne Report and Code of Practice); John Peel, *The Use of Fetuses and Fetal Material for Research* (London HMSO, 1972).

[276] For example, the HT Authority.

[277] HT Authority, 'Codes of Practice' <https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/codes-practice> accessed 23 July 2025.

The HT Authority has powers to 'monitor, inspect, and regulate' organisations using human tissue.[278]

However, the current and previous governance of foetal tissue under non-legal regulation has been inadequate.[279] The Polkinghorne Code of Practice did little to prevent or remedy the retention of foetal tissue as part of the Organ Retention Scandal.[280] As a further example, guidance published by the HT Authority recommends that, at minimum, the following methods for disposing of foetal tissue should be offered: 'cremation, burial, and incineration.'[281] Pregnant people should be informed of these options, 'given the opportunity to discuss them, and supported in an individual and sensitive manner to ensure that [they] can make a decision that is right for [them].'[282] These minimum requirements have not consistently been met in practice since the publication of the guidance in 2015. Several women have reported not receiving sufficient information about different burial methods.[283] Some parents have felt 'unclear' about their options or have been asked in a way which 'implied that there was a right answer and a wrong answer.'[284] The lack of recordkeeping of disposal methods prevents us from

[278] HT Authority, 'Who are the HTA?' <https://www.hta.gov.uk/about-the-HTA/who-are-hta> accessed 23 July 2025.

[279] See 1.4.

[280] Ibid.

[281] HT Authority, *Guidance on the disposal of pregnancy remains* (n 118) 1 at [2] and 4 at [26].

[282] Ibid 3 at [8].

[283] Taken from a study published in 2021: Middlemiss (n 1) 304-305.

[284] Taken from a report published in 2023: Pregnancy Loss Review (n 141) 53 at [132].

recognising how often hospitals are providing care that falls below the guideline standards.[285]

The lack of recordkeeping and oversight more generally for foetal tissue has also been insufficient. There is also little consistency in local practices for foetal tissue collection. As Julie Kent observes:

> [L]ittle is known about the use of fetal tissue in [stem cell (SC)] science outside the scientific community … Companies seldom provide information about the source of fetal derived SCs and obscure their origins by referring to them as 'adult SCs' or tissue specific (somatic) SCs. The scientists interviewed had NHS research ethics committee approval for their research, most were willing to discuss the collection procedure but didn't want their activities advertised … This study showed that arrangements for the collection of fetal tissue varies and lacks transparency.[286]

Kent also raises concerns about her observations of safety and staff training:

> Safety issues have been a focus of attention in the IVF clinic where embryos are being collected for SC derivation, but according to this clinician, the same safety concerns have not been widely discussed in relation to the procurement of fetuses in the abortion clinic. Indeed, I can confirm that such methods of donor selection or training of staff seeking consent were not widely evident.[287]

Whilst these concerns were observed in the small number of subjects in Kent's study, it is possible that they may be more widespread because there are no national guidelines about safety issues or staff training for foetal tissue collection and use.

It is evident that that non-legal protections for foetal tissue use have previously failed to provide sufficient protection for interests and are unable to enforce punitive measures or provide sufficient remedies when regulatory provisions are contravened. The regulation of embryos and gametes for fertility

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[285] Middlemiss (n 1) 304; Julie Kent, 'The fetal tissue economy: From the abortion clinic to the stem cell laboratory' (2008) 67 Soc Sci Med 1747, 1748.

[286] Kent ibid 1749.

[287] Ibid 1750.

treatment under the HFEA framework, which include the Codes of Practice issued by the Human Fertilisation and Embryology Authority, has been more successful.[288] This is in part due to it being underpinned by a comprehensive legislative framework.[289] In the words of Lord Bingham in *R (Quintavalle) v Secretary of State for Health*, the HFEA framework 'opted for a strict regime of control … [and] no activity within this field [of fertility treatment] was left unregulated.'[290]

Legal controls provide stronger and more robust protection for interests. The law does this well for managing conflicting interests in human tissue use under the HTA framework. It requires consent to be provided by a family member or loved one for the donation of human tissue, which allows the consenter's interests to be prioritised over those of others.[291] The law also operates in this role in other areas of medical law, including disagreements between families and medical professionals about the medical care of children. The law acts as the final decision-maker in difficult cases, such as those for Charlie Gard and Alfie Evans, where parents and medical professionals disagree on what medical treatment should be provided to children.[292] Yet legal controls may not be enough unless they contain robust protections. In contrast to the HFEA framework, the governance of foetal tissue under the HTA framework has been inadequate.[293] As a further example,

[288] (n 277).

[289] HFEAs 1990 and 2008; see Chapter 1.

[290] *R (Quintavalle) v Secretary of State for Health* [2003] UKHL 13 at [13].

[291] Consent must be obtained from someone in a qualifying relationship: HTA 2004 sections 2, 3, and 27(4).

[292] *Yates v Great Ormond Street Hospital* [2017] EWHC 972 (Fam); *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 308 (Fam).

[293] See 1.4.

Brazier describes the HTA 1961 as 'a toothless tiger imposing fuzzy rules with no provision for sanctions or redress.'[294] When the provisions of the 1961 Act were contravened during the events of the Organ Retention Scandal, it offered no recourse to the affected parents under criminal or civil law. Some form of redress, such as the criminal sanctions introduced by the HTA 2004, is needed to protect interests.[295] Chapter 5 will discuss what form this legal framework should take in order to sufficiently protect interests.

3.5 How should foetal tissue be classified?

Should the prioritisation of parental interests extend to the question of how the foetus is classified under law? Parents refer to the deceased foetus in a variety of ways. At one end of the spectrum, it is described as a depersonalised thing with little to no status: 'a bunch of cells', 'dead matter', 'a thing', or 'an accident'.[296] At the other end, the foetus is socially conceptualised as a baby, regardless of gestational age.[297] Others place it somewhere in the middle of the spectrum, by recognising it as a 'foetus', or alternating between terms and struggling to adopt a

[294] Brazier (n 7) 31.

[295] See for example HTA 2004 section 5(7)(a)-(b).

[296] Pfeffer (n 5) 2549.

[297] In the eyes of one woman, 'they're all a baby at whatever age they are': ibid 2547.

fixed conceptualisation of the foetus due to its liminal nature.[298] They may also be described as 'wanted' or 'unwanted.'[299]

Distress can be caused when an individual's conceptualisation of the foetus is denied. This can occur when a foetus is socially conceptualised as a baby, but this is not reflected by, nor is space made for this conceptualisation, in its legal classification. In an example given above, one woman intentionally delayed her termination by three weeks (to reach the twenty-four week threshold) so that her daughter would be legally recognised as a stillborn baby, to align with her social conceptualisation of her daughter.[300] Another woman considered it disrespectful for both her foetus (of less than twenty-four weeks of gestation) and her placenta, the latter of which was removed separately, to be included in the same legal category, and believed it would be more appropriate for the foetus to be recognised as a dead body.[301] Danielle Fuller and others have observed that the validation of the baby's existence is important for women who have experienced pregnancy loss at *all* gestational ages.[302] One woman in Middlemiss' study was horrified to

[298] Ibid 2548-2549; see 2.4.1 and 2.4.2 for a discussion of the liminal nature of the foetus; see Karolina Kuberska and others, 'Death Before Birth: Liminal Bodies and Legal Frameworks' in Chris Dietz, Mitchell Travis, and Michael Thomson (eds) *A Jurisprudence of the Body* (Palgrave Macmillan 2020) 149.

[299] The terms 'wanted' and 'unwanted' are used for clarity of discussion and to highlight the range of possible conceptualisations of the foetus. Yet, as Pfeffer notes, 'women may have mixed feelings … [and] both terms fail to capture the fluidity of women's feelings about the fetus': Pfeffer (n 5) 2547.

[300] Fuller and others (n 57) 11-12.

[301] Middlemiss (n 1) 304-305.

[302] This study involved participants who had experienced miscarriage, stillbirth, or termination for foetal abnormality, and so is not representative of the views of those who have sought a termination for other reasons: Fuller and others (n 57).

discover that the body of her son, who died at seventeen weeks of gestation, was referred to as 'medical waste' in his medical notes.[303]

Distress may also occur if the law insists that the foetus is a baby if a parent conceptualises it as a nothing or 'a bunch of cells'.[304] The recognition of a baby gives it a 'biography' which undermines a person's choice to be child free.[305] A baby is a social and legal person, so conceptualising the foetus in this way suggests that it has social or even legal personhood. This in turn could insinuate that an aborted foetus is a person who has been killed, providing an implied moral commentary on abortion which would be unwelcome to those who have undergone elective termination.[306] If the law denies or overrides personal interests in the conceptualisation of the foetus – whether this is as a baby, as a clump of cells, or as something in-between – this can be distressing.

Parental interests can also be harmed by the way the deceased foetus is classified, as well as by how it is used. For this reason, their interests in its classification warrant consideration. Nevertheless, these interests can and must be overridden by the respect given to the special liminal status of the deceased foetus and by any overriding state interests. As argued in Chapter 2, the foetus should not be forced into fixed legal categories which deny its liminal nature. Therefore, the law must recognise all deceased foetuses within a single legal category. The establishment of a single legal category will also align with parental interests, as it will avoid the distress that is caused to parents when foetuses are recognised

[303] Middlemiss (n 1) 299.

[304] Pfeffer (n 5) 2549.

[305] Ibid 2547 and 2550.

[306] See Chapter 2 for a discussion of personhood and abortion.

differently depending on gestational age. Studies by Pfeffer, Aimee Middlemiss, and the Death Before Birth project indicate that social conceptualisations of the foetus are not based on gestational age and can apply at all stages.[307] For example, one woman identified the foetus as a baby as early as the first week after conception.[308] Another did so at six weeks of gestation.[309] In the eyes of one woman, 'they're all a baby at whatever age they are'.[310] As research by Fuller and others demonstrates, 'How women and their families feel about this issue does not depend on whether a pregnancy ended prior to 12 weeks or much later.'[311] Some may conceptualise the foetus as becoming a baby later in gestation, in line with its gradual growth, but there is no social consensus amongst pregnant people about whether the foetus becomes a baby at all or at what point this occurs. This is a social reflection of the liminal nature of the foetus. As with moral status, there are no fixed social categories which can accurately reflect this liminality, and so the law should also avoid creating multiple fixed categories for the foetus. Instead, the law should adopt a single category that is inclusive of all foetuses at all points in gestation.

Equal legal recognition of all foetuses within a single legal category may appear to have implications for abortion law. In England and Wales, abortion is permitted on a number of grounds, one of which only permits abortions before

[307] Pfeffer (n 5) 2547; Fuller and others (n 57); Middlemiss (n 1) 307-309.

[308] Pfeffer ibid 2547.

[309] See Case Study 5 – Simran: Pregnancy Loss Review (n 141) 173.

[310] Pfeffer ibid 2547.

[311] Fuller and others (n 57) 11.

twenty-four weeks of gestation.[312] The Abortion Act 1967 makes it easier to access legal abortion before twenty-four weeks of gestation and much harder to access it after this threshold, because this represents the point of viability when the foetus may be able to survive independently outside the womb. It is also the result of a compromise being struck for the governance of abortion in England and Wales.[313] The removal of the twenty-four-week threshold from the legal governance of the deceased foetus does not directly undermine the use of this threshold for the living foetus in abortion law. The former only affects how the foetus is categorised after death, not during life, and abortion law does not regulate any activities involving the foetus after death. No change will be made to the governance of the living foetus. Therefore, removing the twenty-four-week threshold from the legal governance of the deceased foetus does not directly undermine the use of this threshold for abortion law. These laws can exist concurrently. Therefore, state interests in maintaining legal consistency and coherency do not need to intervene on this basis.

This single legal category should identify the foetus by using neutral terminology. The law should not use terminology that does not reflect the liminal nature of the foetus. Therefore, it should not use terms such as *baby* or *person* because the foetus does not have the moral status of a person. Furthermore, these terms may cause distress to parents who do not see it as a baby. The law should also avoid terms at the other end of the spectrum, such as 'a bunch of cells', because this also does not reflect its special moral status, and the use of these terms may

[312] Abortion Act 1967 section 1(1)(a)–(d).

[313] See 3.2.

also cause distress.[314] Although some parents will conceptualise the foetus in this way, this is not sufficient to inform its classification under the law. Instead, the law should use a neutral term, which does not signify a fixed moral status. Such a term can apply equally to all foetuses within a single legal category and can encompass its liminal nature at all gestational ages.

The neutral legal term should be *foetus*. This term represents the middle ground between the two extreme ends of the terminology spectrum of *baby* and *nothing*. Middlemiss argues that *foetus* is not a neutral term because it was not widely used by participants in her study and it is not ordinarily used in social contexts when a pregnancy is wanted.[315] This argument may hold true in the context of Middlemiss' study, which interviewed women who experienced miscarriage and focused on the social personification of the foetus. However, it does not hold true in a broader context. Pfeffer's research, which interviewed women with mixed views and experiences, observed that women do use the term *foetus*.[316] The law should adopt a term that includes all foetuses and pregnancies – not just ones where the pregnancy is wanted and the foetus is conceptualised as a baby. So, in the broader context that includes the interests of all parents, a single legal classification of foetus is appropriate.

The term *foetus* is primarily used in medical terminology.[317] The suitability of using medical terminology must be questioned, because it may indicate that the

[314] Pfeffer (n 5) 2549.

[315] Middlemiss (n 1) 300.

[316] Pfeffer (n 5) 2547-2551.

[317] See for example ibid 2547.

law is being overly and unnecessarily medicalised. Anna Nelson, Elizabeth Chloe Romanis, and Kerry Petersen have criticised certain areas of law, including those governing childbirth in the UK and abortion in Australia, for becoming overly medicalised.[318] Petersen argues that medicalisation can result in 'legal gatekeeping' which can limit and deny the interests of pregnant people seeking abortion.[319] When considering the legal regulation of foetal tissue, we should be careful not to allow it to be overly medicalised if this may result in the interests of parents not being upheld. This is important because the adopted legal terminology will refer to the deceased foetus generally, even when it is not used in medical research or treatment. To avoid accusations of medicalisation, the law could create a new term which is separate from medical associations. But this is unnecessary. The term foetus is used socially. It is widely known outside of medical terminology, whereas other medical terms such as myocardial infarction are not widely known and alternative social terms such as heart attack are used to describe the same condition. The same can be said for the ulnar nerve, which is more commonly known as the funny bone. It may make sense for the law to create new terminology or adopt social terminology to avoid using unrecognisable medical terminology, but that is not the case here. Therefore, despite its use in medical terminology, the term foetus is socially and legally appropriate and is not an exclusively medical term.

The use of a single, clear term is desirable for legal clarity and coherency. It does not require legislators or researchers to identify what legal category should apply to a foetus, and what laws the use of that foetal tissue should be governed by,

[318] Anna Nelson and Elizabeth Chloe Romanis, 'The Medicalisation of Childbirth and Access to Homebirth in the UK: COVID-19 and Beyond' (2021) 29(4) Med L Rev 661; Kerry Petersen, 'Abortion: Medicalisation and Legal Gatekeeping' (2000) 7(3) J Law Med 267.

[319] Petersen ibid 272.

because there is only one classification and one set of rules. The term *foetus* is also easily recognised by researchers who already use this term in practice. This will make it easier for them to understand and follow the law in practice. The term foetus also aligns with the terminology used in other laws in England and Wales: both the Abortion Act 1967 and HFEA 2008 refer to the foetus.[320] It is also widely used in the common law.[321]

Nevertheless, there should be a separation between the terminology used in law and the terminology used in practice. The term foetus will not always match the social conceptualisations of the foetus held by parents, such as those who consider it to be a baby, and its use may therefore cause distress. Austin and others argue that the language that is used can have a significant impact on donors' 'emotional state and their decision-making processes'.[322] This can be avoided if the terminology used in practice is more flexible and can be adapted to fit individual conceptualisations. For example, if a researcher approaches parents about donating foetal tissue, they should be flexible in the language they use and adopt the terminology preferred by the parents. Members of the pregnant person's clinical care team should also adapt their terminology in the same way when asking parents about what should happen to the foetal body, such as regarding methods of disposal. A requirement for flexible, patient-centric language could be captured by best practice guidelines, such as in the Codes of Practice produced by the HT

[320] Abortion Act 1967 section 5(2); HFEA 1990 sections 3A(1) and 37(5).

[321] See for example *C v S* (n 148); *Paton v BPAS* (n 146); *St George's Healthcare NHS Trust v S* (n 106).

[322] Austin and others (n 141) 179 and 176-177.

Authority. This will allow the law to use a single, clear term to refer to the foetus whilst ensuring that the interests of parents are prioritised in practice.

Similarly, flexible, patient-centric language should be used to refer to those being asked to give consent for foetal tissue donation. This thesis has consistently used the term parent to identify these individuals collectively for the purposes of clarity in discussions. However, as recognised in the Introduction, some people will not consider themselves to be a parent after pregnancy loss and would object to being referred to in this way. When approaching donors to discuss donation, researchers should adopt the terminology that the donors prefer.

In conclusion, recognising all deceased foetuses under one legal category aligns with the liminal nature of the foetus and the interests of parents. For clarity and coherency, the law should adopt the term foetus because this neutral terminology represents the middle ground within the range of conceptualisations of the foetus whilst also being a socially and legally recognisable term. This terminology should not necessary be used in practice, and researchers should adapt their language to suit the interests of the parents.

3.6 How should foetal tissue use be governed in line with these interests?

Classifying all deceased foetuses under one legal category will affect the legal governance of foetal bodies used in rituals around death. Under the current HTA framework, the methods available for interring or disposing of the body of the deceased foetus of less than twenty-four weeks of gestation are different to the methods available for older foetuses and other deceased human bodies. For

younger foetuses, the methods include group cremations with other foetuses and conception tissue, incineration with clinical waste, and hospitals funerals which the parents may not be allowed to attend.[323] Methods are also not universally available – different options are offered at different hospitals.[324] The disparity between interment methods offered for foetuses before and after twenty-four weeks of gestation can be distressing. This is especially the case if the available methods do not suit the parents' interests or conceptualisations of the foetus. One example of this is the woman who intentionally delayed her termination by three weeks to ensure her daughter would have a proper burial.[325] Amanda Myers, Patricia Lohr, and Pfeffer explain how the available options do not meet the interests of pregnant people:

> '[S]ensitive disposal' [under the HTA framework] fails to take into account the potentially differing needs of women ending an unplanned or unwanted pregnancy as compared with those experiencing the loss of a wanted pregnancy.[326]

This disparity should be rectified. All burial or disposal options offered by a hospital for other human bodies should be made available for younger foetuses, as far as is possible. This should include the option for the parents to attend any hospital ceremonies or the option to arrange a funeral themselves. Parents should not be required to choose a more formal method of interring the foetus, such as burial or cremation, because they may not wish to recognise the foetus in this way.

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[323] HT Authority, *Guidance on the disposal of pregnancy remains* (n 118) 1 at [2] and 4 at [26]; Middlemiss (n 1) 304–308.

[324] HT Authority, *Guidance on the disposal of pregnancy remains* ibid; Middlemiss ibid.

[325] Fuller and others (n 57) 11-12; Sheelagh McGuinness and Karolina Kuberska, 'Death Before Birth: Report to the Human Tissue Authority on disposal of pregnancy remains (less than 24 weeks' gestational stage)' (Spring 2017) 18-19 <https://deathbeforebirthproject.wordpress.com/research/> accessed 27 July 2025.

[326] Myers, Lohr, and Pfeffer (n 74) 85.

They may prefer to allow the hospital to choose an interment method, or request that the tissue is incinerated. These other methods should still be permitted. However, burial methods should also be available for those who want them. Appropriate options should also be offered for those experiencing abortion or miscarriage outside of a hospital or clinic, such as at home.

Parents should also not be required to dispose of their foetal remains in a particular way; rather, the argument presented here is that hospitals should offer a wider range of such methods. Other methods may be chosen by parents (provided that the method of disposal is not prohibited under laws protecting public health interests and burial laws).[327] For example, Austin and McGuinness observed a woman who experienced miscarriage at home and chose, along with her husband, to flush the remains down the toilet.[328]

McGuinness, Karolina Kuberska, and Fuller point out that the availability of these options, such as allowing parents to attend hospital funerals, is not prevented by legal obstacles.[329] They can already be provided within the existing legal framework. There is, however, no legal requirement to facilitate this. In 2017, McGuinness, Kuberska, and Fuller recommended that a standardised approach should be developed regarding which internment options are offered and that local NHS Trust policies should be updated to facilitate the attendance of parents at

[327] See 3.2.2 and 3.3.

[328] Louise Austin and Sheelagh McGuinness, 'Reproductive loss and disposal of pregnancy remains' (2019) 70(1) NILQ 131, 143.

[329] Sheelagh McGuinness, Karolina Kuberska and Danielle Fuller, 'Pregnancy loss: consistent bereavement care pathways needed' (Policy briefing 47: October 2017) 2 < https://www.bristol.ac.uk/media-library/sites/policybristol/briefings-and-reports-pdfs/2017-briefings--reports-pdfs/PolicyBristol_Briefing_October_2017_Pregnancy_Loss.pdf> accessed 24 July 2025.

hospital ceremonies.[330] However, research by Middlemiss in 2020 indicates that these issues remain outstanding.[331] The Pregnancy Loss Review in 2023 also observed that some parents have felt 'unclear' about their options regarding foetal remains or have been asked about it in a way which 'implied that there was a right answer and a wrong answer.'[332] Therefore, local policy change is not enough. The law should introduce a positive requirement for hospitals to offer all internment methods for younger foetuses. This could create issues in practice if it is not feasible for hospitals to accommodate the foetal body in the same way as other bodies. Therefore, this positive legal requirement should be broadly conceived – they should be required to do so as far as is practicable – and further guidance should be provided in best practice guidance documents produced at the national regulatory level, such as in a Code of Practice from the HT Authority. This guidance should advise hospitals on how to adapt methods of internment to make them suitable for younger foetuses, and when to offer appropriate alternatives. This should include allowing parental attendance at all hospital memorial services. Therefore, the legal framework should both require *and* facilitate the availability of all possible interment methods for all foetuses.

3.7 Conclusion

In conclusion, parental interests in the use of foetal tissue must be prioritised by the law when interests conflict. This is because they will experience the greatest

[330] McGuinness and Kuberska (n 325).

[331] Women are still reporting being prevented from attending hospital services and being offered different disposal options: Middlemiss (n 1) 305-308.

[332] Pregnancy Loss Review (n 141) 53 at [132].

overall harm if foetal tissue is used against their interests. Nonetheless, their interests should only be taken as a starting point and can be overridden when it is necessary for the protection of the status of the deceased foetus or for state or wider public health interests. All other interests remain important and should be promoted by the law when they do not conflict with parental or other overriding interests. If a dispute arises between parents, then the law should first protect parental objections to any non-natural uses of the foetus. If parents cannot agree on how the foetal body should be laid to rest, a resolution should be found by the courts on a case-by-case basis. The role of the court should be limited to appointing who should be given responsibility for determining how the body is disposed of. Furthermore, limits should not be placed on the number of parents that can be identified – all gestational, genetic, and social parents should be recognised as having parental interests in the use of foetal tissue.

Parental interests must be considered when determining the classification of foetal tissue under the law. To reflect the liminal status of the foetus, all foetuses should be included within one legal classification regardless of gestational age. This legal classification should use the neutral term *foetus*. However, in practice, researchers should adapt the terminology they use to reflect the interests of the parents. Hospitals should also be required to make methods of interring bodies available for younger foetuses, as far as is possible, and allow parents to attend hospital services.

Chapter 4: Consent for Foetal Tissue Use

4.1 Introduction

Many different formulations of permission and consent are required under medical law. These include the requirement to obtain a person's explicit informed consent before the provision of medical treatment.[1] The content of and processes for obtaining permission also vary depending on various factors. These include what permission is being sought for, the person's capacity to give consent, the level of knowledge they have, the level of knowledge they are considered to need to give valid consent for a particular activity, and the ethical issues that arise from that activity. Permission is not required for everything – some exceptions exist. For example, medical treatment can be legally performed without consent in an emergency situation where the patient lacks capacity and needs life-saving treatment.[2]

Explicit informed consent is usually required for the donation and use of human tissue, though there are some exceptions to this.[3] The Human Tissue Act (HTA) 2004 does not state whether consent must be informed, but the HTA Code of Practice on Consent issued by the Human Tissue Authority (HT Authority) does

[1] See for example *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [2015] AC 1430.

[2] On the basis that this will be in the patient's best interests: Mental Capacity Act (MCA) 2005 sections 1(5) and 4.

[3] Human Tissue Act (HTA) 2004 sections 1-3.

specify this.[4] Similarly, informed consent is often required for the recruitment of participants to research studies and clinical trials, and in *Montgomery v Lanarkshire Health Board* Baroness Hale confirmed that 'the need for informed consent was firmly part of English law'.[5]

The HTA framework also permits generic consent to be given, which is a 'broader permission, where consent may, for example, be given to allow the storage and use of tissue for an as yet unknown research project.'[6] Compared to informed consent, only broad information will be made available to the donor about the future research that the tissue might be used in if they give generic consent for its donation. The donation of organs for use in transplantation treatment is also governed differently, operating under a deemed consent model (also known as presumed consent), where adults are considered to have consented to donation unless they have explicitly opted-out.[7] Tissue may also be used in research without consent if it is anonymised before use and ethical approval has been obtained for the research.[8]

In contrast, the consent requirements under the Human Fertilisation and Embryology Acts (HFEA) 1990 and 2008 are more extensive. In *Evans v Amicus Healthcare Ltd*, it was affirmed that the 'continuing consent' of all gamete donors is

[4] Human Tissue Authority (HT Authority), *Code of Practice A: Guiding principles and the fundamental principle of consent* (June 2023) 11-12 at [40]-[44].

[5] *Montgomery* (n 1) *per* Baroness Hale at [107]; The Medicines for Human Use (Clinical Trials) Regulations 2004 Schedule 1; see also Health Research Authority (HRA), 'Informing participants and seeking consent' (updated 19 June 2024) <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/informing-participants-and-seeking-consent/> accessed 24 July 2025.

[6] HT Authority, *Code of Practice A* (2023) (n 4) 11 at [41].

[7] HTA 2004 section 3 as amended by the Organ Donation (Deemed Consent) Act 2019.

[8] HTA 2004 sections 1(8)-(9).

required for the creation, storage, and use of embryos in fertility treatment or research, and the HFEA framework permits no exceptions to this requirement.[9] In this case, continuing consent was defined as consent that remained operative 'from the commencement of treatment to the point of implant'.[10] As in this case, it is necessary for both of the gamete donors of an embryo to consent to its continued storage and use in fertility treatment. If a donor withdraws their consent, their past consent is no longer operative. Without valid consent in place, embryos cannot be used in treatment or kept in storage. Several other formulations of consent exist such as multilayered consent, dynamic consent, and vulnerable consent.[11]

The level of information that should be provided during the consent process may need to vary depending on the activity for which it is sought. When information is provided as part of the consent process for medical treatment, it must include a discussion of any risks that the patient would consider to be material.[12] The information that is provided will therefore differ based on what the patient considers to be a material risk and when medical practitioners choose to limit the information provided through the exercise of therapeutic privilege.[13] Material risks must also be discussed during the consent process for tissue

[9] *Evans v Amicus Healthcare Ltd* [2004] EWCA Civ 727, [2005] Fam 1 *per* Thorpe and Sedley LJ at [37]; Human Fertilisation and Embryology Act (HFEA) 1990 Schedule 3 [1]-[8]; see also *Evans v UK* (2006) 43 EHRR 21.

[10] *Evans v Amicus* ibid *per* Thorpe and Sedley LJ at [37].

[11] See for example Palmira Granados Moreno and Yann Joly, 'Informed Consent in International Normative Texts and Biobanking Policies: Seeking the Boundaries of Broad Consent' (2015) 15(4) Med L Int 216, 224-225; Rebecca Hewer, 'Vulnerability and the Consenting Subject: Reimagining Informed Consent in Embryo Donation' (2019) 27 Fem Legal Stud 287; Jane Kaye and others, 'Biobank Report: United Kingdom' (2016) 44 JL Med & Ethics 96, 101.

[12] *Montgomery* (n 1).

[13] For a discussion of therapeutic privilege see Aoife M Finnerty, 'The Privilege of Information – An Examination of the Defence of Therapeutic Privilege and Its Implications for Pregnant Women' (2021) 29(4) Med L Rev 639, 657.

donation.[14] Timothy Caulfield, Gerald Robertson, and Harold Vanderpool argue that the content of informed consent for xenotransplantation must contain 'special considerations … [that] exceed those in any known research setting'.[15] This should include the provision of information that is usually unnecessary for other medical treatment such as 'the possibility of media attention, psycho-social concerns, [and] the risk of compromised confidentiality'.[16]

In contrast, it has been suggested that generic consent (rather than informed consent) should be used for the donation of tissue to biobanks.[17] This is because it is unlikely that detailed information about future research uses will be known at the time of donation, so it will not be possible to provide this to donors. Whilst information could be provided at a later date, when it becomes available, Palmira Granados Moreno and Yann Joly point out that 'research would become impractical and costly due to the need to constantly recontact and re-consent participants.'[18] Caulfield and others also note that allowing a donor to withdraw their consent can be 'impractical' or even 'impossible' for biobanks to accommodate.[19] Moreno and Joly argue that generic consent, which requires the provision of only general information, is a compromise which 'enables the

[14] HT Authority, *Code of Practice A* (2023) (n 4) 11-12 at [40]-[44].

[15] Harold Vanderpool as cited by Timothy Caulfield and Gerald Robertson: Harold Vanderpool, 'Critical ethical issues in clinical trials with xenotransplants' (1998) 351 The Lancet 1347, 1348; Timothy A Caulfield and Gerald B Robertson, 'Xenotransplantation: Consent, Public Health and Charter Issues' (2001) 5 Med L Int 81, 84.

[16] Caulfield and Robertson ibid 83.

[17] Moreno and Joly (n 11).

[18] Ibid 223.

[19] Timothy Caulfield and others, 'Research Ethics Recommendations for Whole-Genome Research: Consensus Statement' (2008) 6(3) PLoS Biology 0430, 0431-0432.

development and collaboration of large-scale biobank projects.'[20] The content, formulation, and process of obtaining permission or consent varies because different contexts raise distinct ethical questions and challenges. What is suitable in one context may not be in another. Another example of this is therapeutic privilege, which is when a healthcare professional withholds information from a patient under the belief that disclosing it would cause significant harm. Its use may be viewed as justified in some contexts and yet 'hugely problematic' in others, such as in pregnancy and childbirth.[21] Furthermore, the language of *consent* is not always preferred. In Scotland, authorisation must be given for the donation of human tissue.[22] Nevertheless, the HT Authority states that the language of consent and authorisation 'are essentially both expressions of the same principle.'[23]

Arguments in favour of requiring informed consent for the donation of human tissue are often predicated on the idea that this protects the autonomy of the individual and their body.[24] However, the principle of autonomy has little relevance in the context of foetal tissue donation. In life, the foetus is unable to develop so far as to exercise personal autonomy, and it certainly cannot exercise this after death. Furthermore, foetal tissue should not be considered the personal tissue of the pregnant person, as is the case under the HTA 2004, nor should it be

[20] Moreno and Joly (n 11) 244.

[21] Finnerty (n 13).

[22] Human Tissue (Scotland) Act 2006 section 6.

[23] HT Authority, 'Legislation' <https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/legislation> accessed 24 July 2025; Muireann Quigley also argues that 'there is no discernible difference between consent and authorisation to be found': Muireann Quigley, *Self-ownership, property rights and the human body* (CUP 2018) 44, see also 42-44.

[24] See for example Jonathan Zimmern, 'Consent and Autonomy in the Human Tissue Act 2004' (2007) 18(2) KLJ 313, 325-327.

considered the material of the genetic parents.[25] As such, permission to donate foetal tissue should be sought to protect parental interests in this material rather than their autonomy rights.[26]

Despite the extensive legal commentary on different formulations of permission, very little of it considers the context of foetal tissue donation. The use of foetal tissue raises unique ethical issues that distinguish this context from the examples given above.[27] Therefore, assumptions cannot be made about whether certain formulations of permission or consent that apply in other contexts should apply here. This chapter will examine what permission should be required for foetal tissue donation and use. It will start by considering whether either of the forms of consent that apply to human tissue and organ donation under the HTA 2004 – namely explicit informed consent and deemed consent – would be suitable for foetal tissue donation.[28] It will then move on to question whether the same form of permission should be sought for each parent. Later in this chapter, consideration will be given to questions about the scope of permission and how and when it should be sought.

Questions about the donation of foetal tissue will not arise in every case of abortion or miscarriage. Telemedical abortions, where abortion medication is taken and the management of resulting tissue occurs outside of a hospital setting,

[25] HT Authority, *Code of Practice A* (2023) (n 4) 28-29 at [141]-[142]; see 2.4; see 3.3.

[26] See Chapters 2 and 3.

[27] See Chapters 1-3.

[28] HTA 2004 sections 1-3, and section 3 as amended by the Organ Donation (Deemed Consent) Act 2019.

become legally permitted in England and Wales in 2020.[29] Since then, the number of telemedical abortions taking place have increased and they accounted for 52% of abortions in 2021 and 61% in 2022.[30] Those undergoing telemedical abortion or experiencing miscarriage outside of a hospital setting are usually not approached about donating tissue to medical research, as collecting tissue in this setting presents additional challenges compared to collection within a clinic. For example, it is difficult obtain this tissue while it is still 'fresh'.[31] Naomi Pfeffer observes that foetal tissue is usually stored in a refrigerator after collection and transported to the lab as soon as possible 'by, for example, not holding on to it in the theatre or clinic until that day's list of patients is completed.'[32]

Furthermore, when foetal tissue arrives in the lab it is considered to be contaminated from the environment in which it is collected, such as by 'the air of the operating theatre or clinic'.[33] Outside of a hospital setting, it will likely take longer for donees to obtain foetal tissue from donors, and it may have become comparatively more contaminated from being in different environments. As a result, the tissue may have decomposed or degraded too much to be used in certain

[29] Abortion Act 1967 section 1(3B) as amended by the Health and Care Act 2022; Philippa Kemp, 'At-Home Early Medical Abortions Made Permanent in England and Wales' Oxford Law Blogs: Family & Medical Law Blog (5 July 2023) <https://blogs.law.ox.ac.uk/family-andmedical-law/blog-post/2023/07/home-early-medical-abortions-made-permanent-england-and> accessed 14 July 2025.

[30] UK Government, 'Abortion statistics, England and Wales: 2021' (updated 24 July 2025) <https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2021/abortion-statistics-england-and-wales-2021> accessed 26 October 2025; UK Government, 'Abortion statistics, England and Wales: 2022' (updated 9 April 2025) <https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2022/abortion-statistics-england-and-wales-2022> accessed 26 October 2025.

[31] Naomi Pfeffer, 'How work reconfigures an 'unwanted' pregnancy into 'the right tool for the job' in stem cell research' (2009) 31(1) Sociology of Health & Illness 98, 104-106; see 1.3.

[32] Pfeffer ibid 105.

[33] Ibid.

ways such as in the creation of stem cells.[34] Because of the difficulties in collecting fresh foetal tissue following abortion or miscarriage occurring outside of a clinic, the parents in these cases are less likely to be asked to give permission for the donation of foetal remains. Therefore, the discussion in this chapter about giving consent to the donation of tissue may be of less relevance in these scenarios. Instead, many parents may simply decide between themselves about how to manage the disposal of tissue without involving third parties.

In a hospital setting, parents might be asked to give permission for the use of foetal tissue in rites surrounding death such as burial and funeral services. Parents may also be approached about donating foetal tissue for use in other applications (such as for medical research), but this will not always happen and will depend on whether such groups are seeking tissue at that time. Therefore, the discussion in this chapter will likely only be relevant for scenarios where parents are asked for permission to use foetal tissue for rites surrounding death, when these are organised by the hospital or other actors, or for donation for other uses.

4.2 The form of permission

The current legal formulations of permission for the donation of foetal and other human tissue under the HTA 2004 are explicit informed consent and deemed consent. [35] We should not of course simply adopt either of these existing formulations without due consideration of whether they would be appropriate in the context of foetal tissue donation. This is especially important because the HTA

[34] Ibid 104.

[35] Ibid.

framework currently fails to respond to the unique ethical challenges raised by the use of foetal tissue.[36] Nevertheless, there are many overlapping ethical issues that arise from the use of both foetal and other human tissues which suggest that one of these formulations could be appropriate in this context.

One of the primary differences between explicit informed consent and deemed consent concerns the provision of information. The former involves the direct provision of information during the consent process, which must be engaged with in order for the consent to be valid.[37] By contrast, no individual consent process takes place under a deemed consent model. Instead, adults are presumed to have consented unless they have explicitly opted out of doing so. Veronica English and Ann Sommerville argue that the public must have sufficient knowledge about a topic in order to justify the introduction of a deemed consent framework.[38] The key outstanding question here is what role information needs to play in the donation process for foetal tissue.

4.2.1 Information and public knowledge

Foetal tissue is not a common or comfortable discussion topic in social circles. It is not 'something you can chat with your best friend about' because certain uses of it incite 'basic social revulsion'.[39] Foetal tissue has an 'unquantifiable yuk factor'

[36] See Chapter 1 and Chapter 2.

[37] HT Authority, *Code of Practice A* (2023) (n 4) 11-12 at [40]-[44].

[38] Veronica English and Ann Sommerville, 'Presumed consent for transplantation: a dead issue after Alder Hey?' (2003) 29 J Med Ethics 147, 148.

[39] Naomi Pfeffer, 'What British women say matters to them about donating an aborted fetus to stem cell research: A focus group study' (2008) 66 Soc Sci Med 2544, 2550; Jeremy Laurance, 'New fertility treatment facing ban' *The Times* (Issue 64842, 3 January 1994).

because it is derived from miscarriage or abortion which, although common experiences, carry a cultural taboo.[40] For some, abortion is seen as ordinary medical treatment.[41] For others, as Kate Greasley observes, abortion is considered 'taboo, emotive, and political.'[42] Some experiences of abortion and miscarriage are surrounded by a cultural silence and disrupt traditional social scripts.[43] As Louise Austin and Sheelagh McGuinness summarise: 'The experience of reproductive loss is often met with silence or by attempts to minimise the significance of the experience.'[44] The taboo topics of foetal tissue, miscarriage, and abortion are even avoided by the UK government and its officials.[45] Amel Alghrani observes 'The reluctance of Parliament and politicians to even discuss legislation dealing with abortion'.[46] Pfeffer also argues that:

> In British official circles reluctance to investigate women's views about donating aborted fetuses for research of every kind is explained by reference to what are

[40] Laurance ibid; Karolina Kuberska and others, 'Death Before Birth: Liminal Bodies and Legal Frameworks' in Chris Dietz, Mitchell Travis, and Michael Thomson (eds) *A Jurisprudence of the Body* (Palgrave Macmillan 2020) 149, 156-157; see 1.3.1.

[41] See 1.3.1.

[42] Kate Greasley, *Arguments About Abortion* (OUP 2017) 1.

[43] Kuberska (n 40) 154 and 165; Danielle Fuller and others, 'Death Before Birth: Preliminary project findings for meeting with representatives of the Department of Health and Social Care' (24 August 2018) <https://testprojectwebsiteblog.wordpress.com/wp-content/uploads/2019/03/summary-of-project-findings-report-for-dhsc.pdf> accessed 26 July 2025; Louise Austin and others, 'Effective Communication Following Pregnancy Loss: A Study in England' (2021) 30 Camb Q Healthc Ethic 175, 175; Elizabeth Peel and Ruth Cain, ''Silent' miscarriage and deafening heteronormativity: A British experiential and critical feminist account' in Sarah Earle, Carol Komaromy, and Linda Layne (eds), *Understanding Reproductive Loss: Perspectives on Life, Death and Fertility* (Routledge 2012) 79; see 1.3.1.

[44] Louise Austin and Sheelagh McGuinness, 'Reproductive loss and disposal of pregnancy remains' (2019) 70(1) NILQ 131, 138.

[45] See 1.3.1 and 1.4.

[46] At this time, MP Nadine Morris sought to raise the issue of reforming abortion law but noted that every time she attempted to do so she was shut down: 'one MP after another has risen to comment that this is not really the place to discuss abortion': Amel Alghrani, *Regulating Assisted Reproductive Technologies* (CUP 2018) 153-154.

> called 'sensitivities', a euphemism for the belief that women 'may prefer not to be reminded of the events that led up to the existence of the tissue'.[47]

Mary Dixon-Woods and others point out that public avoidance of these topics may stem from the prevalence of anti-abortion rhetoric, which paints abortion as murder and has 'publicly *opposed* the use of human foetal tissue in research, in particular for the ways it seemingly legitimated and encouraged abortion'.[48] The cultural associations of silence and stigma surrounding miscarriage and abortion also attach to perceptions of foetal tissue.[49] These perceptions are further complicated by the maternal-foetal relationship, both before and after pregnancy loss. It is a unique relationship that varies depending on the social narrative attributed to it. Some pregnancies are wanted, whilst others are unwanted.[50] The deceased foetus may be conceptualised somewhere on a scale between a beloved child that died before its time and 'an accident'.[51] Perceptions of the foetus may vary over time and between individuals. Some social narratives also seek to 'frame the pregnant person in opposition to the fetal subject'.[52]

Unsurprisingly, because of this cultural taboo, there appears to be little public knowledge about foetal tissue collection and use. For example, many

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[47] Pfeffer (n 39) 2545; Department of Health, *Human Bodies, Human Choices: The Law on Human Organs and Tissue in England and Wales: A Consultation Report* (Department of Health, 2002) 137.

[48] Mary Dixon-Woods and others, 'Human Tissue and 'the Public': The Case of Childhood Cancer Tumour Banking' (2008) 3 BioSocieties 57, 73.

[49] See 1.3.1.

[50] Some pregnant people describe their pregnancies in this way yet 'women may have mixed feelings … [and] both terms fail to capture the fluidity of women's feelings about the fetus': Pfeffer (n 39) 2547.

[51] Ibid 2549.

[52] Kuberska (n 40) 162; see Isabel Karpin for an argument against this oppositional framing: Isabel Karpin, 'Legislating the Female Body: Reproductive Technology and the Reconstructed Woman' (1992) 3(1) Colum J Gender & L 325.

participants in a study by Pfeffer did not know what stem cell research was or how foetal tissue was used in it:

> [P]articipants were unclear about the nature of stem cell research, that is, what exactly investigators do in the laboratory: do they work with the whole fetus, its organs or its cells; would it be 'poked about with' (FG6F7), 'pulled apart' (FG4F5), 'chopped up' (FG4F4), or 'get drawn from' (FG6F5); would the fetus serve as a research subject, that is, would it be 'alive whilst it was being experimented on' (FG1F2); is it treated as an organ donor, and if so, do investigators resuscitate them or use life-support equipment to maintain their vital functions until their organs are harvested; would 'the essence of the fetus' (FG3F1) be extracted out of it, a scenario where 'it's like you're giving it a little blood test or something' (FG3F3).[53]

Several participants also reported uncertainty about where, how, and for how long foetal tissue is stored for, as well as what it is used for, after donation.[54] One woman wondered whether tissue was collected in a 'big bag of fetuses', while others wondered if research 'requires the fetus somehow to be alive.'[55] Research by Amanda Myers, Patricia Lohr, and Pfeffer observed that 'A majority of the women we interviewed did not know what happened to the fetal tissue after abortion.'[56]

Research by Julie Kent highlights this lack of knowledge by comparing it to the public knowledge of other types of research and tissue donation.[57] One scientist, who used both pre-implantation embryos (donated following in vitro fertilisation (IVF)) and aborted foetuses in his research, thought that the women donating these

[53] Pfeffer (n 39) 2552 and 2550-2552.

[54] Ibid 2550-2551.

[55] Ibid 2549 and 2551.

[56] Amanda J Myers, Patricia A Lohr, and Naomi Pfeffer, 'Disposal of fetal tissue following elective abortion what women think' (2015) 41 J Fam Plann Reprod Health Care 84, 86.

[57] Julie Kent, 'The fetal tissue economy: From the abortion clinic to the stem cell laboratory' (2008) 67 Soc Sci Med 1747.

materials 'were different kinds of donors'.[58] Those donating the former were 'very well informed' whereas donors of the latter 'just want to get the termination over and done with; they're not really thinking about it at all'.[59] Even a pro-life activist that Kent interviewed, who was well informed about the collection of pre-implantation embryos, knew very little about foetal tissue collection.[60]

This lack of information pervades many other experiences and uses of foetal tissue and so is not limited to knowledge about donating it to research. A 'Lack of information was a common theme' in interviews with women experiencing miscarriage, who were 'frequently… not offered comprehensive information upon confirmed diagnosis' and instead 'offered euphemistically-phrased information'.[61] This applies to information about the experience of miscarriage, such as 'staff talking about pain in understated language', as well as what happens to the foetal tissue afterwards.[62] This is underscored by a stark account from one woman:

> And I didn't know what to do. I didn't know how [to] cope with what was happening. I was in pain. So it sounds awful but the baby ended up falling into the toilet. And [I couldn't] stay in the bathroom so [I] went back into the bedroom and my husband [who] was in the bathroom with me the whole time and helping me to pass the baby [he] had a look at the baby and tried to get it out of the toilet so that we could do something with the body. Um, but he came back in the bedroom a couple of minutes later and just said [the] baby had sort've disintegrated. The body'd split apart and um there was nothing much he could do about getting it out

[58] Ibid 1748-1749.

[59] Ibid.

[60] Ibid 1749.

[61] Austin and McGuinness (n 44) 143; Fuller and others (n 43) 8; Aimee Middlemiss, 'Pregnancy remains, infant remains, or the corpse of a child? The incoherent governance of the dead foetal body in England' (2021) 26(3) Mortality 299, 304-305.

[62] Fuller and others ibid 8.

> of the toilet. [A]nd then we, we had a terribly awful practical talk about what did we do next so we ended up flushing the toilet.[63]

These accounts are taken from a small number of research studies and so may not provide conclusive answers to the question of what level of knowledge the public, and especially parents, have about foetal tissue use. Nevertheless, this research does clearly demonstrate that many parents, and pregnant people in particular, lack basic knowledge about pregnancy loss and foetal tissue use. In many cases, this is because the detailed information known to the clinical care team is not shared with them.[64]

Parents may struggle to find out further information about tissue use even if they seek it out directly because of the cultural silence and taboo surrounding it. As Kent points out:

> It is difficult to trace the extent of use of fetal tissue in research in Britain because no formal records are kept or publicly available and there is no national oversight of such research … little is known about the use of fetal tissue in [stem cell] science outside the scientific community.[65]

Pfeffer observed that scientists and companies have been reticent to 'advertise' their work using foetal tissue for fear of backlash and 'concerns about being the target of anti-abortion activists.'[66] Kent has observed that: 'Companies seldom provide information about the source of fetal derived [stem cells (SCs)] and obscure their origins by referring to them as 'adult SCs' or tissue specific (somatic) SCs.'[67] Pfeffer

[63] Austin and McGuinness (n 44) 143.

[64] Fuller and others (n 43) 8-9.

[65] Kent (n 57) 1748-1749; see also Pfeffer (n 31) 100.

[66] Pfeffer ibid 100.

[67] Kent (n 57) 1749.

also notes the challenges she faced when seeking more information about foetal tissue collection and use:

> The empirical research reported here, at times felt less like social science and more like investigative journalism. There is no published information on how aborted fetuses reach the stem cell or any other laboratory because the work of reconfiguring an 'unwanted' pregnancy into a source of stem cells proceeds in a contentious and highly sensitised environment, and much of it is hidden.[68]

In contrast, there is far more public knowledge and transparency about the management and donation of human organs and tissue. Prior to the introduction of the new opt-out framework for human organ donation in 2019, which permits donation for transplantation on the basis of deemed consent, the government carried out a public information campaign about it.[69] Organ donation is widely encouraged by public bodies, and this was also the case in the lead up to the change in the law.[70] Public discourse about organ donation notably does not carry the taboo associated with foetal tissue, miscarriage, and abortion.[71] Furthermore, the events of the Organ Retention Scandal, which highlighted the importance of transparency and information provision in tissue and organ donation, may remain in the public consciousness.[72] Although foetal bodies were also found to be retained during this scandal, the media coverage and public outcry primarily focused on stories about the organs of children and loved ones, as did the resulting HTA

[68] Pfeffer (n 31) 99 and 99-100.

[69] Organ Donation (Deemed Consent) Act 2019; see for example: NHS Organ Donation, 'Organ Donation Campaigns' <https://www.organdonation.nhs.uk/get-involved/organ-donation-campaigns/> accessed 24 July 2025; NHS Organ Donation, 'Organ and tissue donation – a vital lesson that can help to save lives' <https://www.organdonation.nhs.uk/get-involved/news/a-vital-lesson-that-can-help-to-save-lives/> accessed 24 July 2025.

[70] Ibid.

[71] See 1.3.1.

[72] See 1.2.

framework.[73] Therefore, historical misuses of foetal tissue are unlikely to be remembered in the same way.

Prior to the introduction of the HTA 2004, the regulations governing foetal tissue did not sufficiently consider the relevance of public knowledge when making recommendations about consent requirements.[74] This is perhaps unsurprising, as Pfeffer points out that some of the Polkinghorne Committee's recommendations were not evidence-based but instead 'formed largely in response to claims made by opponents of abortion'.[75] Furthermore:

> [T]he [first] investigation into women's views about donating aborted fetuses for research was provoked by the failure on the part of the committee that drew up the Polkinghorne Guidelines to find out what women of reproductive age thought about the controversy responsible for its engagement.[76]

The results of that investigation – a study by Fionn Anderson and others – undermined some of the recommendations from the Polkinghorne Code of Practice:

> It would not be permissible to give the mother any indication of the exact use, indeed it would be impossible [under the Polkinghorne Code] because the doctor who gained her consent to research (the source) is prohibited from communicating in any way with the user. While many of the women we asked agreed to giving general consent, a significant minority (32 per cent) felt they would want some detail about the proposed research and would like the opportunity to ask questions. There seems no reason to deny more specific information to those women who want it. With both the woman and the doctor ignorant of the precise use of the

[73] See 1.2 and 1.4.

[74] John Polkinghorne, *Review of the Guidance on the Research Use of Fetuses and Fetal Material* (Cm 762, 1989) (hereafter Polkinghorne Report and Code of Practice); see 1.4 for a discussion of the Polkinghorne Code of Practice.

[75] Pfeffer (n 39) 2545.

[76] Pfeffer (n 39) 2545 referencing the following study: Fionn Anderson and others, 'Attitudes of women to fetal tissue research' (1994) 20 J Med Ethics 36.

> tissue it is hard to imagine circumstances in which consent would be either sought or given.[77]

Future governance can avoid such mistakes by creating rules informed by the relevant factors and comprehensive research on said factors, such as the level of public knowledge.

Because of the lack of public information, there is a much lower chance that parents will have a fully formed informed opinion about the use of foetal tissue prior to pregnancy loss. They may not have thought about it at all or lacked basic information on which to form a preliminary opinion. This indicates that the provision of information could have a significant impact on what decision they make. It also suggests that they may need some time to parse this new information and reach a decision. A similar conclusion is drawn by Austin and McGuinness regarding experiences of miscarriage and the subsequent disposal of foetal tissue.[78] They argue that 'clear and comprehensive information' must be provided about these experiences to avoid unnecessary distress.[79] This information may not only reduce distress but also allow parents to reach a decision that accurately reflects their interests.

Furthermore, existing research supports the theory that the provision of information may drastically change individuals' views on foetal tissue donation. Research by Pfeffer 'observed a clear pattern where participants changed their position on the core question of the rights and wrongs of donating a fetus for stem cell research as they gained information and thought more carefully about the

[77] Anderson ibid 39.

[78] Austin and McGuinness (n 44) 143.

[79] Ibid.

implications of such a decision.'[80] Participants' discussions changed from having initial enthusiasm for donation to expressing deep concerns, and 'By the end of the focus groups, participants had co-produced a tendency to refuse.'[81] More research is needed on parental views about donation and whether these might change following the provision of information. Nevertheless, these preliminary views are enough to indicate that information provision *could* fundamentally change a parent's interests in foetal tissue use. For some, information will be instrumental in decision making. It will allow them to fully understand how foetal tissue might be used in order to determine whether it would be in their interests to donate it.

Information may be directly wanted by some parents, regardless of its impact on their views. For example, some women expressed a desire for the foetal tissue to be destroyed after abortion, and that anything less than a confirmation of this would be distressing.[82] As one woman put it:

> You'd want to know whether it was dead as well. I mean you'd want to know what they tell you when they'd killed it. You wouldn't want for it to be living for ages not knowing if this thing that you produced is still alive or not, would you? I'd be really horrified.[83]

For another, it was important to know that the foetus was not 'taken' by anyone else:

> As soon as it's come out of the body to be somehow destroyed there and then rather than be put into containers and taken away. Because then it's something that belongs to someone else, taken.[84]

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[80] Pfeffer (n 39) 2553.

[81] Ibid 2553.

[82] Ibid 2550-2551; see also Myers, Lohr, and Pfeffer (n 56) 87.

[83] Pfeffer ibid 2551.

[84] Myers, Lohr, and Pfeffer (n 56) 87.

It therefore may be important for some parents to receive detailed information about what will happen to the tissue, such as during and after its use for medical or other purposes. Participants in Myers, Lohr, and Pfeffer's study expressed dissatisfaction about not being provided with information about how the foetus would be disposed of:

> I've always wondered what happened to the fetus afterwards. [1-S]
>
> I feel cheated because nobody sat with me and talked to me about, well, anything at all, let alone how the fetus would be disposed of. [2-S]
>
> But it was really one of the points I dwelt on for quite a while … you know, I thought it was going to sit somewhere in some kind of cold room or something you know? Like this really … some kind of really impersonal place. [21-S][85]

Six participants in the study specifically 'took part in the research in order to find out about providers' disposal methods, two of whom wanted to check the veracity of (inaccurate) information on the Internet.'[86] Interests can also vary depending on the particular uses of foetal tissue: some might agree to donate to therapeutic research but not to non-therapeutic research.[87] Potential donors would be unable to make this distinction without being provided with sufficient information about the research they are being asked to donate material to. The provision of information would directly satisfy the interests of many parents as well as facilitate their decision-making capabilities by allowing them to engage with detailed information that is not publicly available or commonly known.

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[85] Note that this is in the context of disposing of foetal tissue after abortion, not after it has been used in research: ibid 87.

[86] Ibid.

[87] In a study by Pfeffer, participants considered research which benefitted public health to be therapeutic, whereas non-therapeutic research included the development of 'cosmetics … biological weapons, "sticking an ear on a mouse" … and reproductive cloning': Pfeffer (n 39) 2550.

4.2.2 Consent following bereavement

In theory, providing information as part of a consent process is desirable. However, obtaining informed consent in practice can be difficult in the context of abortion and miscarriage. Obtaining consent from bereaved family members for tissue donation is difficult. Obtaining *informed* consent is more so. When grieving the recent death of a loved one, it may be jarring or distressing to be asked to consent to the removal of their body parts. Being asked to engage with and understand detailed information, which may not be pleasant to read in normal circumstances, may be further distressing or overwhelming. Studies on human tissue donation by families suggest that 'during the period of stress around the death, many bereaved are not able to process the information'.[88] As Jonathan Zimmern argues:

> There are similarly serious questions to be asked about the competence of a bereaved parent to make difficult decisions about post-mortems, tissue donation for research or transplantation immediately following the death of a child.[89]

The practicality of providing and understanding information following bereavement is further complicated by the context of abortion, miscarriage, and foetal tissue collection. As one bereavement midwife points out: 'when you lose a baby initially you are in a state of shock, grief, sadness and denial. You cannot be 100% sure that they absorb all the information.'[90] This challenge remains even if

[88] Marc PHD Cleiren and Ada J Van Zoelen, 'Post-Mortem Organ Donation and Grief: A Study of Consent, Refusal and Well-Being in Bereavement' (2002) 26 Death Stud 837, 846; Zimmern (n 24).

[89] Zimmern ibid 328.

[90] Austin and others (n 43) 183-184.

the pregnant person (or another parent) wants to receive information. As one woman put it:

> I think it's quite hard because you have that massive shock, and your brain shuts down. [A]nd I couldn't process it. I knew they needed to tell me that then because of the nature of it. I knew that you couldn't wait … I don't even know if she explained it really well … my brain was obviously still in shock mode by then.[91]

Another woman had an adverse physical reaction to being provided with information because 'it was not in a manner which was helpful at that time':

> She did start saying about what happens with the remains. And I ran out and threw up in the toilet because it was just it was so clinical the way she talked about it. And what happens. They asked [what] happens afterwards once they've done the DNC. Do we want to keep them or what they do with them? It made me feel physically sick and I ran out and I threw up in the toilet.[92]

These experiences are not limited to bereavement and miscarriage and extend to other forms of pregnancy loss, such as elective abortion.[93] The lack of social scripts surrounding pregnancy loss may make the bereavement itself harder to manage.[94] Furthermore, medication or other treatment given for abortion or miscarriage may temporarily hinder the pregnant person's ability to parse information. One woman described being 'completely off my trolley on any drugs that they could give me' when undergoing induced labour for a termination at thirteen weeks.[95]

In addition to these challenges, some will simply not *want* to receive any information: 'From an emotional side, I wouldn't like to hear the options, because

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[91] Ibid 183-184; Fuller and others (n 43) 5-6.

[92] 'DNC' refers to Dilation and Curettage (D&C) treatment to remove any remaining pregnancy tissue from the womb if this has not naturally passed following a miscarriage: Austin and McGuinness (n 44) 147-8.

[93] See for example Anderson (n 76) and Pfeffer (n 39).

[94] Myers, Lohr, and Pfeffer (n 56) 86.

[95] Fuller and others (n 43) 8.

it would make things really difficult'.[96] Only a minority of the respondents in a study by Anderson and others wanted to receive information about what happened to foetal tissue following abortion, especially if they had previously undergone abortion treatment.[97] The reasoning behind this is not explored in the study. Myers, Lohr, and Pfeffer observed that most participants in their study were 'not giving disposal any consideration at the time of the abortion, because their priority was to expedite an end to the pregnancy':

> I mean I think most people, me in particular, had so many other things going on that I just wanted to get rid of it at the time, and, sort of, without thinking too much about, 'Oh what happens now?' to it. [20-S]
>
> I didn't actually know and … It sounds really mean, but I just got it over and done with. [3-S]
>
> As far as my brain went it was you got rid of it, end of. [9-S][98]

Providing information in the context of pregnancy loss, especially in the case of bereavement, can be 'difficult' and unwanted.[99] Experiences of pregnancy loss can themselves be distressing, and it is trite to say that it is not in the interests of parents to be caused further distress through the provision of unwanted information.

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[96] Expressed by one participant in Myers, Lohr, and Pfeffer (n 56) 88.

[97] 'Less than half the women in each group would wish to know the exact details of the research but again women who had never had an abortion felt they would want more information (38 per cent v 23 per cent p<0-001) and these women were more likely to want to ask questions of the researcher (54 per cent v 33 per cent p<0-001 … a significant minority (32 per cent) felt they would want some detail about the proposed research and would like the opportunity to ask questions': Anderson (n 76) 38-39.

[98] Myers, Lohr, and Pfeffer (n 56) 86.

[99] Ibid 88.

J Kenyon Mason and Graeme Laurie suggest that information about postmortem examinations is often unpleasant.[100] The same can be said for information about the use of foetal tissue in medical research and for other purposes. Because of this unpleasantness, Mason and Laurie question the utility of providing such information at all (other than in the context of personal medical treatment):

> One wonders if it has any real value in other contexts and, in particular, whether the drive to disclose detailed information as to the nature of post-mortem examinations is desirable? It is a fact of life that the autopsy is, by its very nature, unpleasant. To seek to disclose the realities of the procedure to relatives – already no doubt in a fragile emotional state – may result in more harm than there is 'good' in the obtaining of 'informed consent'.[101]

The importance of providing information, at least for some parents, has been illustrated in this chapter.[102] However, it should be noted that many of the views in favour of receiving information were expressed outside of the context of recent pregnancy loss.[103] This is significant because some parents may want information in theory but may not be prepared to engage with it in the difficult aftermath of pregnancy loss. They may be too distressed by bereavement or under the effect of medication. Nevertheless, we cannot definitively dismiss all – or perhaps any – views in favour of receiving information on this presumptive basis. Respondents in the Death Before Birth study, which did directly consider the context of

[100] J Kenyon Mason and Graeme T Laurie, 'Consent or Property? Dealing with the Body and Its Parts in the Shadow of Bristol and Alder Hey' (2001) 64(5) MLR 710, 718.

[101] Ibid 718.

[102] See 4.2.1.

[103] Several of these studies canvassed the general views of participants and did not specifically consider views in the aftermath of pregnancy loss: see for example Pfeffer (n 39) and Anderson (n 76); the provision of information in this aftermath was not a direct consideration in a study by Middlemiss: Middlemiss (n 61).

bereavement following pregnancy loss, still expressed dissatisfaction regarding the lack of information provided to them about the experience of miscarriage and the management of foetal tissue for disposal.[104]

The aforementioned research indicates that a range of views are present. These views are based on pilot studies, and primarily focus on pregnant people, so it is unclear how widespread they are or how individual parental views might change depending on the setting. We are therefore lacking a comprehensive understanding of the importance of information provision for foetal tissue donation and how parental views are affected by distress, medication, the experience of abortion or miscarriage, and different settings. More research on this is needed. Nonetheless, we have sufficient data to conclude that parents have varied and variable views on information provision. Some do not want, or cannot engage with, information in the immediate aftermath of pregnancy loss. For others, the provision of information is very important. Others may not know if they want to know or not or may frequently change their mind.[105] Therefore, legal and regulatory controls should not be based on assumptions about whether parents want information or not. As Austin and others argue, 'effective communication means avoiding making assumptions about how people may be feeling following a loss.'[106] Even if research indicated that a majority would want to receive information, there would still be a minority who feel otherwise. For one woman, simply *knowing* about foetal tissue research was 'awful' and 'horrible'.[107]

[104] Austin and McGuinness (n 44); Austin and others (n 43); Fuller and others (n 43).

[105] Pfeffer (n 39) 2549.

[106] Austin and others (n 43) 181.

[107] Pfeffer (n 39) 2549.

Conversely, another felt 'cheated' because no one told her what happened to the foetus.[108]

4.2.3 Consent or veto?

The donation of tissue from a living person usually requires their explicit informed consent.[109] Foetal tissue should not be regarded as the personal genetic material of the parents, so there is no need to obtain their consent on this basis.[110] However, as discussed in Chapter 2, it can be difficult to separate foetal tissue from other conception tissue.[111] Therefore, conception tissue – which should be recognised as originating from both the foetus and the pregnant person – may be included in any foetal tissue that is donated. For this reason, it is difficult to see how the requirement to obtain the pregnant person's consent for the donation of their personal tissue could be met without requiring their consent for the donation of foetal tissue, on the basis that it might contain conception tissue.

By comparison, the argument in favour of obtaining explicit consent from other parents is less compelling. In the previous chapter, it was argued that the law must protect parental objections to the donation of foetal tissue for non-natural uses, such as to medical research.[112] This can be achieved by giving parents the right to veto the donation or use of foetal tissue. A veto would allow a parent to

[108] Myers, Lohr, and Pfeffer (n 56) 87.

[109] HTA 2004 sections 1-3.

[110] See 3.3.

[111] See 2.6.

[112] See 3.3.

override the positive consent given by another for the donation of tissue, thereby preventing it from being used any further for a particular use. A requirement to obtain explicit informed consent would also protect these interests; however, the process of obtaining consent requires far more from parents than granting them a power of veto. In the former, they must actively engage in a dialogue about foetal tissue use in order for it to be donated, whereas in the latter they need only exercise their veto if they object to its use. Obtaining consent from parents following pregnancy loss can cause them distress and harm.[113] It would be unjustified to require a more onerous form of permission – such as informed consent, which requires a person to read and understand detailed information – if a veto would also adequately protect parental interests and would avoid the imposition of harm. Furthermore, the interests of others, such as of researchers collecting foetal tissue, should be promoted when they do not interfere with parental or other overriding interests.[114] It would also place a burden on researchers to obtain consent from more than one parent, especially in scenarios where a foetus may have more than two parents.[115] This is another reason why parental vetos should be preferred if there is no compelling reason to require a more onerous form of consent.

A parental veto could be enshrined within a deemed consent model, which would allow foetal tissue to be donated without requiring all parents to partake in an informed discussion about donation or to provide explicit consent. This model would need to grant parents the power to veto donation before it occurs (via an explicit opt-out) or afterwards, in order to sufficiently protect their objections at

[113] See 4.2.2.

[114] See 3.2.2.

[115] See 3.3.1.

every stage. Within this model, parents could still be provided with information about particular uses of foetal tissue so that they can use this to decide whether to exercise their veto.

A deemed consent model may need to be limited to certain uses of foetal tissue. For example, in a study by Anderson and others only two percent of the women interviewed 'felt reluctant' to donate foetal tissue to 'research into clinical problems affecting the fetus and neonate'.[116] In contrast, many of the participants in a study by Pfeffer specified certain fields of research to which they would refuse to donate tissue including cosmetics, biological weapons, 'sticking an ear on a mouse', and reproductive cloning.[117] Furthermore, after receiving information during the study 'participants had co-produced a tendency to refuse' to donate tissue to stem cell research.[118]

However, as demonstrated earlier in this chapter, there appears to be a dearth of public information about foetal tissue use. Because of the lack of social scripts to facilitate discussions around it, it is unlikely that this will change in the near future. English and Sommerville argue that for a deemed consent framework to be justified, there must be sufficient public knowledge about the topic and public opinion must be in favour of this framework.[119] As Ben Saunders explains, if an opt-out model is introduced without this, then deemed consent may not be informed.[120] Obtaining uninformed deemed consent is unjustified because, as

[116] Anderson (n 76) 37.

[117] Pfeffer (n 39) 2550.

[118] Ibid 2553.

[119] English and Sommerville (n 38) 148.

[120] Ben Saunders, 'Opt-out, mandated choice and informed consent' (2023) 37 Bioethics 862, 863.

demonstrated above, information about tissue use can profoundly change a parent's view about donation and its provision is therefore crucial to protecting their interests. Furthermore, English and Sommerville notes that during the Organ Retention Scandal it was the 'lack of knowledge, information, and explanation about what that involved that was the main cause of anger and distress.'[121] They suggest that deemed consent is justified for organ donation because there is sufficient public knowledge about how and why they are used for the purposes of transplantation. They also argue that deemed consent should not apply to tissue donation for research purposes, as the public knowledge about these uses is lacking.[122] Without a sufficient level of public information for foetal tissue uses, it would not be justified to implement a deemed consent model.[123]

Because of the benefits of a veto model – namely that it avoids placing a burden on parents (other than the pregnant person) to receive information and make a decision about foetal tissue donation in the aftermath of pregnancy loss – we should aim to work towards implementing it in future. Four things must be put in place to achieve this. Firstly, the particular uses of foetal tissue that the deemed consent model could justifiably apply to must be identified. Further research is needed to ascertain this. For example, the current deemed consent model only applies to the use of organs for transplantation treatment and does not cover any other uses of organs. Secondly, public knowledge about foetal tissue use must be improved. Saunders suggests that 'extensive education campaigns' would be

[121] English and Sommerville (n 38) 148.

[122] Ibid.

[123] Ibid 148.

needed to raise public awareness about a topic.[124] This could be carried out in a similar fashion to the information campaigns about organ donations for transplantation that took place before the law moved to a deemed consent model.[125] Thirdly, the establishment of social scripts to enable the public to navigate discussions about foetal tissue use. Fourthly, public opinion must be in favour of establishing a deemed consent model for foetal tissue donation. Empirical research is needed to identify ways in which the third and fourth points can be facilitated.

As the adoption of deemed consent is not currently justified, explicit consent must be obtained. Because of the lack of public knowledge, the consent must be informed. Many argue that information is a necessary part of the consent process for human tissue donation, including Brazier who argues that it can protect the interests of bereaved relatives.[126] The case for obtaining informed consent for foetal tissue use is surely even stronger, because there is comparably less public knowledge about this. Furthermore, this requirement will similarly be capable of protecting parental interests in this context.[127]

Informed consent is an attractive option for further reasons. It aligns with current trends in medical law in focusing on the needs and interests of the patient in medical decisions about their treatment, the use of their separated material, and

[124] Saunders (n 120) 865.

[125] (n 69).

[126] Margaret Brazier, 'Retained Organs: Ethics and Humanity' (2002) 22 Legal Stud 550, 566-567.

[127] See for example Ana S Iltis, 'Organ Donation, Brain Death and the Family: Valid Informed Consent' (2015) 43(2) J Law Med Ethics 369; Brazier ibid; Onora O'Neill, 'Some limits of informed consent' (2003) 29 J Med Ethics 4.

the use of their medical information.[128] Requiring consent to be informed can also be considered *more* important for tissue donation than it is for medical treatment, because unlike the latter, the former is unlikely to involve any direct therapeutic benefit to the donor. There is also likely to be less publicly available information about specific research uses of tissue when compared to medical treatment.[129]

Not asking for consent for tissue donation can itself be distressing. Following the Organ Retention Scandal, many families were profoundly distressed by the retention of their children's organs.[130] This was caused by several factors, including them not being *asked* about donation.[131] Several families stated that they would have given permission for organs to be used if they had been asked.[132] However, they were distressed to learn that they had been used without their permission or knowledge. Research by Anderson and others observed that a majority of women would want their permission to be sought for the donation of foetal tissue for research use, and many women in Pfeffer's research expressed firm preferences about its donation.[133] Several women also expressed strong views

[128] See for example *Montgomery* (n 1); *Thefaut v Johnston* [2017] EWHC 497 (QB); Data Protection Act 2018.

[129] The NHS includes key information about medical conditions and treatment on their website: NHS, 'Conditions' <https://www.nhs.uk/conditions/> accessed 24 July 2025. There is no requirement, nor any standard expectation, for detailed information about research studies to be published online if they are not clinical trials.

[130] See 1.2 and 1.4 for a discussion of the Organ Retention Scandal.

[131] See for example parents evidence included in the Redfern Report: Michael Redfern, *The Royal Liverpool Children's Inquiry Report* (HC 2001, HC12-II, London: The Stationery Office 2001) (hereafter Redfern Report) 391-443; Sheila McLean*, Independent Review Group on the Retention of Organs at Post-Mortem: Final Report* (Edinburgh: Scottish Executive, November 2001) Section 1: Hospital Post-Mortem Examinations, 26 at [2].

[132] See parents evidence included in the Redfern Report ibid: see for example 391, 395-396, 398-399, 403, 405, and 408.

[133] Sixty-three per cent of all women in the study and seventy-one per cent of women who had never had a termination wanted their permission to be sought: Anderson (n 76) 38; see generally Pfeffer (n 39).

about how the foetal body should be treated after death, such as in burial or cremation, in research by Middlemiss and the Death Before Birth project.[134] It is evident that failing to directly ask for consent may harm parental interests.

The positive act of asking for permission also ensures that a conversation about foetal tissue use takes place. Even if parents have preferences about this, they may be reluctant to initiate the conversation due to 'squeamishness'.[135] As observed by Myers, Lohr, and Pfeffer, 'A few participants did wonder about it prior to the procedure, although only two made active enquiries with clinic staff. Two other participants reported that squeamishness had prevented them from raising the issue.'[136] This is due to the cultural stigma that pervades discourse around foetal tissue.[137] This, and other factors including the lack of social scripts for miscarriage, abortion, and foetal tissue, may discourage parents from initiating a conversation about their preferences.[138] The requirement for permission would solve this by placing the obligation of initiating this conversation on the person seeking consent. This will prevent parental interests from being accidently overlooked due to them not being vocalised.

[134] Middlemiss (n 61) 307-308; Fuller and others (n 43) 11.

[135] Myers, Lohr, and Pfeffer (n 56) 86.

[136] Ibid 86.

[137] See 1.3.1.

[138] Myers, Lohr, and Pfeffer (n 56) 86.

4.3 Obtaining informed consent

It can be possible to obtain informed consent following pregnancy loss without or with minimal distress by adjusting how this information is delivered. Several studies have tested successful methods for sensitive and effective communication during experiences of bereavement which allow detailed information to be provided and engaged with. A limited amount of this research focuses on the present context. Research by Austin and others suggests that when individuals struggle to take in verbal information following pregnancy loss, written information should be provided for the donors to read at a later date.[139] Providing information in a written format gives the parents control over when they read it and how much information they absorb.[140] Austin and others also argue that it is important to consider the language that is used because it has a significant impact on donors' 'emotional state and their decision-making processes'.[141]

At this stage, it is useful to consider research that has been conducted in similar contexts. Far more research has been conducted on effective methods of obtaining informed consent from bereaved family members for human tissue and organ donation. While the context of foetal tissue donation is unique, similar challenges may be present in other tissue donation or bereavement contexts. Some of these existing methods may therefore be effective in the context of pregnancy loss – although this would need to be evidenced – and it is likely that research questions for the latter will be informed by existing research on the former. Several studies have demonstrated that the quality and method of communication in the

[139] Austin and others (n 43) 183-184.

[140] Suggested by one participant in Myers, Lohr, and Pfeffer (n 56) 88.

[141] Austin and others (n 43) 176-177 and 179.

consent process significantly minimises distress and improves the satisfaction of family members: 'it is probably not information itself that is critical to well-being but rather the relational aspect of sharing information with the bereaved that helps cushion the shock of the drastic actions taken within a donation procedure.'[142] Simon Streit and others credit 'the success of the Spanish donation and transplantation program' to the implementation of 'policies that focus on trust and transparency':

> These include policies that support training opportunities for healthcare professionals that are focused on communication skills, family consultation, and consent, direct communication with the media, including educational programs for journalists, and round-the-clock availability for consultation. Likewise, Spanish policy supports a conservative consent policy and practice that focuses on the needs of donor families.[143]

Recommendations from other studies have focused on improving the education and training of staff to understand 'individual and family reactions to loss, grief and bereavement'.[144] An Australian study tested a successful method which balances donation requests

> [W]ith the counselling, information and practical needs of potential donor families in their shock and grief. Social work assessment, advocacy, liaison, counselling, crisis intervention and particularly communication skills have been utilised, both

[142] Cleiren and Zoelen (n 88) 846; see also for example Geke A Blok and others, 'Requesting Organ Donation: The Case of Self-Efficacy' (2004) 9 Adv Health Sci Educ 261, 261; Birgit Wulff and others, 'Post-mortem tissue donation at the Institute of Legal Medicine in Hamburg: Talking to the next of kin guidelines and first experiences' (2009) 11 Leg Med S141.

[143] Simon Streit and others, 'Ten Lessons from the Spanish Model of Organ Donation and Transplantation' (2023) 36 Transpl Int 1, 6.

[144] Wendy Walker and Magi Sque, 'Family bereavement: A case study of controlled organ donation after circulatory death' (2019) 24 Nurs Crit Care 229, 232; Blok and others (n 142); Lyndall Forbe-Smith, Mary Haire, and Mary Doneley, 'Social work practice in the donation of human tissue for transplantation: utilising social work values and competencies to achieve effective outcomes for transplant patients and donor families' (2002) 35(1-2) Soc Work Health Care 377; Jorge S López and others, 'Bereaved relatives' decision about deceased organ donation: An integrated psycho-social study conducted in Spain' (2018) 205 Soc Sci Med 37, 38.

> as an integral component of obtaining informed consent and in working with families' experience of grief and loss in sudden, traumatic bereavement.[145]

A Spanish study recommended specific staff training on the following good practices:

> [E]nsuring a private space; participation of personnel with expertise in the field of organ donation and adequate training in effective requesting; initiating the request in an empathic manner with an adequate introduction, role clarification and acknowledgement of the loss; giving time to release feelings and talk about the deceased; avoiding questions that may tacitly encourage refusal to donate; developing a supportive, trust-based relationship with the family, which includes addressing concerns and questions with sensitivity; providing information and positive arguments about the benefits of donation; providing instrumental, emotional and spiritual support; and ensuring that families do not feel harassed or pressured.[146]

The success of these methods needs to be empirically tested and proven to be effective in the foetal tissue donation context before they should be adopted there. Nonetheless, this research can provide a basis for identifying research questions for this. Examples from the studies above include improving training for all staff members involved in the consent process, especially that which focuses on the skill of sensitively *delivering* information. Once this research has been conducted, we will have a better idea of how the law can respond to issues in information provision.

Another way to accommodate parents who do not want to or are unable to engage with information would be to relax the process or content requirements for informed consent. For example, the discussion or information provision need not be detailed or extensive. This might not constitute a significant change to, and

[145] Forbe-Smith, Haire, and Doneley ibid 378.

[146] López (n 144) 38.

instead may simply reflect, current informed consent practices. As Alastair Campbell puts it:

> The clinical reality of gaining consent, however, especially in distressing situations of serious illness or traumatic bereavement, is far removed from the philosophical ideal of fully informed consent.[147]

Julie Austin concurs, suggesting that perhaps we cannot realistically expect more than this in practice:

> Desirable as truly informed consent is, to discuss anything as difficult as indications for and possible benefits of postmortem examination with someone recently bereaved is asking a great deal of both parties to the discussion. It is hard to see how 'informed' consent can be attained on this sort of occasion, even with training in communications skills for the healthcare staff expected to undertake the discussions.[148]

Yet even a requirement for relaxed (or perhaps realistic) informed consent would not account for the possibility that this information may fall on unwelcome ears. Some people will simply not want to know.[149] Others may feel that hearing the information would pressure them into making a particular decision.[150] For example, the Pregnancy Loss Review observed that some parents felt 'unclear' about their options regarding the disposal of foetal tissue or have been asked about it in a way which 'implied that there was a right answer and a wrong answer.'[151] Everyone must of course be given the option to reject the consent process itself and the

[147] Alastair V Campbell and others, 'Human tissue legislation: listening to the professionals' (2008) 34 J Med Ethics 104, 108.

[148] Julie Austin, 'Retained organs and tissues: divergence of the law and practical humanity?' (2002) 8(5) C Risk 185, 188.

[149] See for example Myers, Lohr, and Pfeffer (n 56) 86-88; Anderson (n 76) 38-39.

[150] Myers, Lohr, and Pfeffer ibid 88.

[151] Department of Health and Social Care, *The Independent Pregnancy Loss Review - Care and support when baby loss occurs before 24 weeks gestation* (July 2023) (hereafter Pregnancy Loss Review) 53 at [132].

information that comes with this. Yet some may still want to give consent *without engaging* with detailed information. Many of the women in a study by Anderson and others were willing to give consent to donate foetal tissue without detailed information.[152]

This raises the question: if a person wishes to give consent without engaging with the information provided at all, is this compatible with the idea of informed consent? At face value, we might say no. Consent without, or with very limited, information looks more like generic consent (also known as broad consent). Generic consent has been suggested as a justified form of permission in other contexts, such as in response to the challenges posed by biobank collections.[153] The existing (albeit limited) research presented in this chapter indicates that the provision of information is important to some parents. Under a generic consent model, there would be no legal obligation for detailed information to be provided and so any parents who did want this would not have their interests met.[154] Only informed consent can satisfy this. Therefore, the preliminary data does not support the conclusion that generic consent would be suitable for foetal tissue use.

The law could go in the opposite direction and require strict informed consent to reflect these interests. To satisfy the 'philosophical ideal of informed consent', detailed information must be given and understood for consent to be

[152] Anderson (n 76) 39.

[153] See for example Bernice S Elger and Arthur L Caplan, 'Consent and Anonymization in Research Involving Biobanks: Differing Terms and Norms Present Serious Barriers to an International Framework' (2006) 7(7) EMBO Reports 661; Bartha Maria Knoppers, 'Biobanking: International Norms' (2005) 33(1) J Law Med Ethics (2005) 7; Moreno and Joly (n 11).

[154] Under general consent, only general information is required to be given during the consent process, such as what types of research the material *might* be used in.

valid.[155] This model presents a similar problem. It would not align with the interests of parents who do not want detailed information, or do not want to engage with it at the time of the consent process. Take the following scenario:

> A woman wants to plan for all eventualities regarding her pregnancy. She reads up on foetal tissue uses and decides that, if a miscarriage occurs, she will donate the tissue to medical research. She experiences a miscarriage, and a researcher asks her to give informed consent to donate foetal tissue. She does not want to read and consider the information that is offered because she is distressed by the miscarriage and has already made up her mind. She asks to give consent anyway. The researcher refuses to accept the donation because she does not believe that the woman is sufficiently informed.

By requiring strict informed consent in this case, the law is overriding parental interests. In doing so, it is making the paternalistic presumption that parents cannot possibly make a sensible decision without understanding the information that is offered to them. Too much focus is placed on what the parents do with the information provided, which suggests that there are right and wrong ways of engaging with information. We should be wary of repeating the Polkinghorne Committee's mistake of regulating foetal tissue on the basis of paternalistic presumptions.[156] Such assumptions underpinned the separation principle from the Polkinghorne Code of Practice which sought to separate the pregnant person's decision to abort from their decision to donate foetal tissue.[157] As Pfeffer argues, this painted both donors and researchers in a negative light:

> It was justified by the Polkinghorne Committee on the grounds that investigators might encourage a woman, uncertain whether to proceed with a pregnancy

[155] Campbell and others (n 147) 108.

[156] Polkinghorne Report and Code of Practice (n 74); see 1.4.

[157] Polkinghorne Report ibid 9 at [4.2] and 10 at [4.6].

> termination, to go ahead with it, a view which suggests that **women are gullible and investigators are ethically suspect**.[158]

The separation principle and its inferences received strong objections from the Royal College of Obstetricians and Gynaecologists, John Keown, Pfeffer, and Kent.[159] Furthermore, Kent and Pfeffer argue that the separation principle had the effect of codifying public 'distrust' in researchers using foetal tissue.[160] Dialogue and trust between researchers and parents is a vital element for obtaining informed consent, and we should avoid the implementation of legal barriers which attempt to undermine this. The law must respond to and allow space for the interests it seeks to protect. It should not instead make paternalistic presumptions about what these interests are. Therefore, the law should not mandate how parents choose to engage with the information provided to them.

As argued above, it is difficult for individuals to have an accurate perception of foetal tissue research given the cultural silence that surrounds it.[161] This indicates that engagement with information could be very enlightening for parents. However, it must be stressed that the lack of public information does not suggest that no one would *ever* be able to find sufficient information – by their own standards of

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[158] My emphasis added: Naomi Pfeffer, 'What has happened to the review of the Polkinghorne Guidelines on research using fetal tissue?' *BioNews* (20 April 2009) <https://www.bionews.org.uk/page_91690> accessed 24 July 2025.

[159] Ibid; the perceived denigration of researchers was opposed by the Royal College of Obstetricians and Gynaecologists: Royal College of Obstetricians and Gynaecologists and Royal College of Pathologists, *Fetal and Perinatal Pathology: Report of a Joint Working Party* (June 2001) 28-29; John Keown argues that the separation principle undermines the Committee's view that abortion is not immoral: John Keown, 'The Polkinghorne Report on Fetal Research: nice recommendations, shame about the reasoning' (1993) 19 J Med Ethics 114, 118; Naomi Pfeffer and Julie Kent, 'Framing Women, Framing Fetuses: How Britain Regulates Arrangements for the Collection and Use of Aborted Fetuses in Stem Cell Research and Therapies' (2007) 2 BioSocieties 429, 436-437.

[160] Julie Kent and Naomi Pfeffer, 'Regulating the collection and use of fetal stem cells' (2006) 332(7546) BMJ 866, 867.

[161] See 4.2.1.

sufficient – to make a decision about donation outside of the information provided by researchers. Furthermore, we should not assume that such information will be important to every parent. Some may not care. Some may only want information about a specific issue. Wanting information is a choice. Not wanting information is a choice. The examples explored above showcase that a range of views surrounding the receipt of information exist. To protect parental interests, the law must recognise that they will exist somewhere on this spectrum and that their exact views cannot be predicted. If they get to choose – whether that is to give informed consent to donate, or refuse – why should we not also give them the choice to *not* be informed at that time? Why should we not trust that they may have an existing, possibly informed, opinion? It is paternalistic to presume that they must be uninformed and that they must understand the detailed information provided to them to make a valid decision.

In the context of consent for biobank donation, Tuija Takala argues that 'If we follow the Millian view on autonomy we should allow people to make foolish choices.'[162] It is not the role of the law to decide whether parents are making foolish choices regarding the information they have been given, nor to prevent them from acting in this way. Recommendations from the Royal College of Nursing and local NHS Trust policies about the management of foetal tissue after pregnancy loss recognise the importance of trusting the wishes and decisions of the pregnant person:

> The critical issue in supporting best practice is in respecting a woman's choice, based on the understanding that this is her pregnancy loss – regardless of the

[162] Tuija Takala, 'Setting a Dangerous Precedent? Ethical Issues in Human Genetic Database Research' (2007) 8 Med L Int 105, 127.

> circumstances of that loss – and that she is best placed to determine how the remains should be managed.[163]

These recommendations align with views expressed by participants interviewed by Myers, Lohr, and Pfeffer: 'In general, participants believed that information about fetal tissue disposal methods should be available to women who wish to access it, but that it should not be forced upon them'.[164] This should apply to all parents. To accommodate their varied and variable preferences, the law should not examine how and to what extent they engage with the information provided to them. The focus should be on the provision of information by the researcher rather than what the parents choose to do with that information.

This proposed formulation of informed consent is neither radical nor undesirable, even though it is a departure from the philosophical ideal of fully informed consent. It is, rather, an accepted reality. As demonstrated earlier in this section, ideal consent cannot always realistically be obtained in practice.[165] This is especially the case in challenging contexts such as bereavement. As Ana Iltis explains, ideal consent

> [R]arely, if ever, is required or met. Instead, we accept varying degrees of disclosure, capacity, understanding and appreciation, and freedom and voluntariness depending on the nature and scope of the decision at hand.[166]

Onora O'Neill argues that ideal consent is both unachievable and undesirable:

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[163] Royal College of Nursing, *Managing the Disposal of Pregnancy Remains: RCN Guidance for Nursing and Midwifery Practice* (5th edn, 2024) 6; see also Sheelagh McGuinness and Karolina Kuberska, 'Death Before Birth: Report to the Human Tissue Authority on disposal of pregnancy remains (less than 24 weeks' gestational stage)' (Spring 2017) 15 <https://deathbeforebirthproject.wordpress.com/research/> accessed 27 July 2025.

[164] Myers, Lohr, and Pfeffer (n 56) 87-88.

[165] Campbell and others (n 147) 108; Austin (n 148) 188.

[166] Iltis (n 127) 370-371.

> Genuine consent is not a matter of overwhelming patients with information, arrays of boxes to tick or propositions for signature. The quest for perfect specificity is doomed to fail since descriptions can be expanded endlessly, and there is no limit to a process of seeking more specific consent.[167]

Mark Rothstein also argues that 'too much is made of the fact that consent rarely satisfies the ideal'.[168] We should not only consider how the donor gives consent; we should focus on how the researcher asks for consent, because this

> [I]s a demonstration of respect for the autonomy and dignity of the individual, a tangible exercise in trust building, and an expression of the moral equivalence of the researcher and research subject in an otherwise asymmetrical relationship.[169]

These are positive elements which we should seek to promote in the consent process. Even the Health Research Authority recommends the use of 'proportionate consent' and warns that consent procedures

> [C]an sometimes be applied too rigidly and with too little appreciation of the risks, benefits and values that are at stake in connection with different kinds of research. This can lead to the use of excessively lengthy and complex participant information sheets which can inhibit, rather than promote, participant understanding and genuinely informed consent.[170]

Ideal consent is also difficult to consistently implement in practice. Some individuals may erroneously believe that they understand the information or may pretend that they do. The person taking consent may thus mistakenly assume that

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[167] O'Neill (n 127) 6. See also Mark Rothstein, who argues that 'A variety of studies have demonstrated that research subjects do not read written descriptions of the research contained in informed consent documents; if they read the document, they often do not understand what they read; and when asked about it later, they cannot remember what they signed. Instead of informing the potential research subject, the argument goes, informed consent documents are incomprehensible legal instruments written for the benefit of the researchers and their institutions': Mark A Rothstein, 'Ethical Issues in Big Data Health Research' (2015) 43(2) J Law Med Ethics 425, 427.

[168] Rothstein ibid 427.

[169] Ibid 427.

[170] HRA, 'HRA publishes new proportionate consent guidance' (updated 9 June 2017) <https://www.hra.nhs.uk/about-us/news-updates/hra-publishes-new-proportionate-consent-guidance/> accessed 24 July 2025.

they have succeeded in obtaining ideal informed consent in such cases. We should not blindly accept the fiction of attaining the ideal in practice. It is better to accept a realistically achievable standard, especially when it is also the best method for promoting the interests of parents.

Furthermore, if we insist on ideal consent, we could be asking too much from potential donors. Ida Helene Asmussen and Katharina Eva Ó Cathaoir argue that this is too 'demanding, requiring the patient to understand and weigh complex (and sometimes unclear) health information'.[171] O'Neill concurs, stating that 'it would be ethically wrong to require patients to handle a form as complicated as a mortgage application at a difficult time in their lives.'[172] Laurie and Emily Postan also argue that placing too many expectations on the consent and information process can create 'an oppositional dynamic [between potential donor and donee] which is more reflective of a situation where trust is absent than one in which trust is a central concern.'[173] These are undesirable elements which we should seek to minimise or avoid in any consent process.

A primary concern that is raised about this approach is whether it invites deception and coercion into the equation. If a participant lacks a comprehensive understanding of the research – simply because they did not read the information – are they more vulnerable to being deceived or coerced into giving positive consent? O'Neill points out that this concern is negated by a requirement to provide

[171] Ida Helene Asmussen and Katharina Eva Ó Cathaoir, 'Making Access to a Population of Bodies in the Name of Autonomy' (2018) 25(5) EJHL 555, 560.

[172] O'Neill (n 127) 6.

[173] Graeme Laurie and Emily Postan, 'Rhetoric or Reality: What Is the Legal Status of the Consent Form in Health-related Research?' (2013) 21 Med L Rev 371, 377.

detailed information, even if there is limited engagement with it: 'If additional accurate information is reliably available as demanded, patients will not be deceived: even a patient who decides on the basis of limited information has judged that the information was enough to reach a decision, and is not deceived.'[174]

4.3.1 The timing of consent

To avoid distress, the provision of information and request for consent could also be posed at a much later time. Perhaps hours, days, or weeks after the initial pregnancy loss. This could allow the parents some time to process their feelings and participate in the consent process without distress. The success of this – whether distress would be entirely avoided by this method – would depend on the individual, but it might be preferable for some. This could be tested through research, to determine its desirability. However, asking for the donation of foetal tissue long after it is expelled from the body of the pregnant person is not scientifically desirable. Foetal tissue degrades quickly outside of the body. Tissue may be frozen to preserve it, but many research applications require the tissue to be 'fresh', otherwise it will be too degraded to be used effectively.[175] Therefore, it is possible that many researchers would not want to obtain foetal tissue at this later stage. Furthermore, delaying the consent process may introduce practical issues regarding how long a hospital is required to store foetal tissue for.

[174] O'Neill (n 127) 6.

[175] See for example Royal College of Obstetricians and Gynaecologists and Royal College of Pathologists (n 159) 20 and 29; see 1.3.

Consent could be sought at an earlier stage: during pregnancy, before miscarriage or abortion occurs. This would allow parents to be given information at a time when they are *not* tackling the difficult context of pregnancy loss which may involve bereavement, feelings of shame, and other complex emotions. Some parents may be more willing and able to engage with information in this earlier context than they would be following pregnancy loss. This option would be especially beneficial for those who want to receive information but feel unable to engage with it in certain challenging contexts.

Would it be distressing for parents, and especially pregnant people, to be asked about foetal tissue donation during pregnancy? A discussion about potential pregnancy loss may be upsetting in the context of a wanted pregnancy. It could be an unwelcome reminder that the foetus could die instead of growing and being birthed as a living child. Furthermore, we should not assume that this period will be free from complexities – the pregnant person and other parents may be grappling with difficult questions such as whether to continue their pregnancy or other personal concerns, whether related to the pregnancy or not. It may therefore also be challenging for them to engage with information in this context. Even so, it may be the case that asking for consent at this earlier stage would be *less distressing* than asking for consent in the immediate aftermath of pregnancy loss. Research is needed ascertain this.

Allowing researchers to approach donors for consent during pregnancy has previously been met with ethical concern from the Polkinghorne Committee. The Committee created a separation principle which required that the decision to terminate a pregnancy was made before a pregnant person can be approached

about donating foetal tissue.[176] It was created in response to ethical concerns that women who were uncertain about whether to have an abortion would be encouraged by researchers to have one in order to donate tissue.[177] It prevented researchers from obtaining consent at an earlier stage during pregnancy, as they had to wait until the pregnant person had already decided to have an abortion.[178] It notably prevented them from ever obtaining consent before pregnancy loss from those who intended to keep their pregnancy but experienced spontaneous miscarriage, because no decision to end the pregnancy would have been made. The separation principle is criticised by Keown, who points out that it contradicts the Committee's position that abortion is not immoral and so cannot morally taint foetal tissue.[179] It is difficult to see why this separation is required when the basis for it is rejected by the Committee themselves.

Some do believe that abortion, and foetal tissue by consequence, carries a moral taint.[180] However, the law should not create legal limits that reflect the views of only some parents, especially if it would prevent others from experiencing the consent process at a less distressing timepoint. If individuals believe that abortion is morally tainted, then they can simply choose to not have an abortion. The separation principle is not justified and should not be reinstated. Therefore,

[176] Polkinghorne Report and Code of Practice (n 74) 4-5 at [2.5]-[2.8].

[177] Ibid; Pfeffer (n 39) 2545.

[178] This recommendation has since been overruled by the HTA framework: see 1.4.

[179] Keown (n 159) 118; Polkinghorne Report and Code of Practice (n 74).

[180] See for example James Tunstead Burtchaell, 'University Policy on Experimental Use of Aborted Fetal Tissue' (1988) 10(4) IRB: Ethics & Human Research 7.

researchers should not be legally prevented from approaching parents about tissue donation during pregnancy.

The current HTA framework does not place limits on or set specific requirements regarding when consent should be sought for foetal tissue donation. Therefore, it is possible that researchers may already approach potential donors during pregnancy.[181] However, it may not always be possible for researchers to do this in practice. Research groups make arrangements with local abortion and pregnancy clinics in order to collect tissue.[182] As Pfeffer has observed, they

> [H]ave no influence on how abortion clinics are run and a change in the service offered, reorganisation of theatre lists, new staff, and so on, can result in their supply drying up.[183]

Pfeffer's research also indicates that the practical collection of foetal tissue is not standardised.[184] Therefore, the timing of consent, and other collection procedures, may be dictated by the preferences of each local clinic. It is therefore possible that some clinics will only permit consent to be sought after pregnancy loss. This raises the question of whether it is desirable for a legal framework to standardise the practice of foetal tissue collection at local clinics. This question cannot be sufficiently addressed without further research into desirable and effective consent methods, such as on the timing of consent, as well as the potential impacts on patients' abortion care if foetal tissue collection is standardised.

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[181] 'The request to donate the aborted fetus to research is usually, but not always, made during the first clinic visit': Pfeffer (n 31) 101.

[182] Ibid.

[183] Ibid 101.

[184] Ibid.

If one timepoint is considered preferable to another then we might consider whether the law should prohibit researchers from seeking consent at any other timepoint. It would be difficult to justify such a prohibition unless research demonstrated that there was an unequivocal and unanimous preference for a single timepoint, *and* that greater harm is caused when consent is sought at other timepoints. Given the variance in the views and interests of parents, as demonstrated in this and the previous chapter, it is unlikely that a unanimous preference will emerge. Furthermore, unless the practices of abortion and pregnancy clinics are standardised – which might involve substantial overhauls in local practices – not all clinical pathways will easily align with attempts to seek consent at a specific timepoint. This would place unnecessary and unjustified legal barriers on the donation of foetal tissue which would undermine public health interests in the medical use of foetal tissue. As argued in the previous chapter, public health interests should be facilitated where these do not conflict with parental or overriding interests, as is the case here.

A legal framework should tackle this variability in two ways. Firstly, best practice guidelines should be created to provide guidance about taking consent at various timepoints, including during pregnancy and after pregnancy loss. Guidance should be tailored to the challenges that may arise in each timepoint. Secondly, these guidelines should recommend that, where possible, consent should be taken at a timepoint that is deemed most appropriate. This must be determined by empirical research.

In conclusion, consent must be informed. Focus should be placed on the provision of detailed information by the researcher, but we should not scrutinise the extent to which parents engage with this information. This is because some

parents may not want to engage with it or may feel unable to do so due to distress in the aftermath of pregnancy loss. Their distress or lack of engagement should not bar them from participating in the consent process. Distress should be minimised where possible, such as through improving communication between potential donors and donees. This may involve specific staff training and changes to the language, communication, and methods of approach used by researchers.[185] Where possible, consent should be sought at a time point that causes the least distress to parents. Empirical research should be conducted to ascertain the success of such approaches in this context, and this should inform the development of best practice guidelines.

4.4 Consent and capacity

In order for a parent to provide consent for the donation of tissue, they must have the requisite legal capacity to do so. Under section 1(2) of the Mental Capacity Act (MCA) 2005, 'a person must be assumed to have capacity unless it is established that [s]he lacks capacity'. This includes pregnant people.[186] Nevertheless, this is a rebuttable presumption, and several cases have been brought to the courts regarding pregnant people who lacked (or were suspected of lacking) capacity to make decisions about the care of their pregnancy.[187] A person is considered to lack capacity

[185] See examples presented earlier in this section.

[186] See for example *Re AA (Compulsorily Detained Patient: Elective Caesarean)* [2012] EWHC 4378 (COP); *Re SB (A patient; capacity to consent to termination)* [2013] EWHC 1417 (COP).

[187] See for example ibid. For cases decided before the passing of the MCA 2005, see *Re MB* (Caesarean Section) [1997] 2 FLR 426; *St George's Healthcare NHS Trust v S* [1998] 3 WLR 936; *Rochdale Healthcare NHS Trust v C* [1997] 1 FCR 274.

> [I]n relation to a matter if at the material time [s]he is unable to make a decision for [herself] in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.[188]

Being 'unable to make a decision' is defined as being unable:

> (a) to understand the information relevant to the decision,
>
> (b) to retain that information,
>
> (c) to use or weigh that information as part of the process of making the decision, or
>
> (d) to communicate [her] decision (whether by talking, using sign language or any other means).[189]

In *Re MB (Caesarean Section)*, it was discovered that the appellant's baby was in the breech position and on advice from the clinical team she consented to have the baby delivered by caesarean section.[190] However, due to a phobia of needles she repeatedly refused to be injected with anaesthesia. The Court of Appeal found that she lacked capacity because her phobia prevented her from being able to weigh the information provided to her when making the decision to refuse treatment. Although *Re MB* was decided before the passing of the MCA 2005, the later case of *Re AA (Compulsorily Detained Patient: Elective Caesarean)* confirms that it remains good law.[191]

In *Re AA*, an NHS Trust applied for an order to perform a caesarean section upon the pregnant respondent, X, who had been detained under section 3 of the

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[188] MCA 2005 section 2(1).

[189] Ibid section 3(1)(a)-(d).

[190] *Re MB* (n 187).

[191] *Re AA* (n 186).

Mental Health Act 1983 and suffered from psychotic episodes.[192] Mostyn J held that X lacked capacity under section 2(1) of the MCA 2005 and confirmed that the case should follow the 'guidelines given in *Re MB*'.[193] Mostyn J relied on medical and psychiatric evidence in holding that having a caesarean section was in X's best interests, including noting the 'significant' 1% risk of a ruptured womb from a natural vaginal delivery.[194] He also authorised the use of 'reasonable restraint' in order to carry out the procedure 'safely and successfully.'[195] A pregnant woman was also found to lack capacity in the 1997 case of *Rochdale Healthcare NHS Trust v C*, where Johnson J held that she could not weigh up the information given to her because she was 'in the throes of labour'.[196]

Nevertheless, there are also cases where the capacity of the pregnant person has been affirmed. In *Re SB (A patient; capacity to consent to termination)* Holman J held that a pregnant woman with bipolar disorder who was detained under section 2 of the Mental Health Act 1983 had the capacity to decide to have an abortion at twenty-three weeks of gestation.[197] Furthermore, in the pre-MCA 2005 case of *St George's Healthcare NHS Trust v S* the Court of Appeal held that the pregnant woman had capacity and therefore the provision of caesarean section treatment against her refusal was unlawful.[198]

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[192] Ibid.

[193] *Re AA* (n 186) at [1]; *Re MB* (n 187).

[194] *Re AA* ibid at [4].

[195] Ibid at [8].

[196] *Rochdale* (n 187) at [275]

[197] *Re SB* (n 186).

[198] *St George's Healthcare NHS Trust v S* (n 187).

A distinction must be drawn between decisions about medical treatment and the donation of foetal tissue. The latter raises comparably little risk. There is no immediate risk to the life or health of the foetus or any parent after pregnancy loss. The only risks are to the interests of the parents and of others.[199] In the event of a parent refusing to give consent they will simply be refusing to donate tissue, a decision which carries less risk than the refusal of medical treatment in *Re MB*.[200] In *Rochdale*, and indeed many other cases about pregnancy care, the court must make an urgent decision about a high risk scenario with 'only the scantiest information upon which to assess the patient and make a decision.'[201] In contrast, there is no cause for urgency when deciding whether a parent has validly consented to donate tissue. Furthermore, pregnant people will not be 'in the throes of labour' if consent is sought either during pregnancy or after pregnancy loss.[202] Parents may be grieving or otherwise distressed, but this usually will not be enough to render them as lacking capacity. Indeed, consent for tissue donation is regularly and successfully sought from bereaved family members. As Iltis argues, 'we accept varying degrees of … capacity … depending on the nature and scope of the decision at hand.'[203]

The pregnant person's capacity may be temporarily hindered or in flux as a result of the medication given to them as part of their abortion or miscarriage treatment. For example, one woman was 'completely off my trolley on any drugs

[199] See Chapter 3.

[200] *Re MB* (n 187).

[201] *Re MB* ibid per Butler-Sloss LJ at [434]; *Rochdale* (n 187).

[202] *Rochdale* ibid at [275].

[203] Iltis (n 127) 370-371.

that they could give me' when undergoing induced labour for a termination at thirteen weeks.[204] They may also be temporarily unconscious if they have had anaesthesia. The capacity of the pregnant person and other parents may also be impaired or in flux for other reasons. They should be given sufficient time to regain their capacity (whether permanently or temporarily if it is in flux) before being approached about giving consent. This recommendation is echoed by the HTA Code of Practice on Consent:

> Individuals may sometimes temporarily be unable to make a decision, for example, if they are affected by trauma, illness or shock. It may therefore not be appropriate to seek consent at that time and, in some cases, it may be necessary to delay the decision until the person regains the capacity to make it.[205]

If they do not regain capacity, but they have created an advance directive expressing their wishes regarding foetal tissue use before death or incapacity, then these wishes should be respected just as they would in other cases of medical decision-making.[206] Otherwise, the law requires that a decision is made in their best interests.[207]

The best interests assessment has limited application in cases of tissue donation. It may be relevant if the suggestion of donation would cause great distress to the parent, or if the tissue could be used for the parent's personal medical treatment.[208] Outside of this, it appears to be of little assistance. In most cases,

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[204] Fuller and others (n 43) 8.

[205] HT Authority, *Code of Practice A* (2023) (n 4) 25 at [122].

[206] MCA 2005 sections 24 – 26.

[207] Ibid section 4.

[208] For example, tissue could be used in transplantation treatment to treat a disease they have: see for example Jeffrey H Kordower and others, 'Neuropathological Evidence of Graft Survival and Striatal Reinnervation after the Transplantation of Fetal Mesencephalic Tissue in a Patient with Parkinson's Disease' (1995) 332 N Engl J Med 1118; see 1.3.

tissue donation will not affect them physically and will only affect their interests. A best interests exercise will therefore rest largely on an assessment of their interests, rather than considering other aspects of their health and wellbeing. Because of the lack of public knowledge and social scripts about foetal tissue donation, it is likely that others may not know what the parent's interests are regarding this decision. They may have never discussed this topic. For the same reason, it is unlikely that others will be able to predict how a parent would respond to the provision of detailed information about donation: whether they would be in favour of donation or against it. If their interests are unknown, it will be near impossible to ascertain whether donation would be in their best interests or not. As argued in the previous chapter, the donation of tissue for non-natural uses could cause more harm than denying another parent the chance to donate.[209] Therefore, if best interests cannot be ascertained, consent cannot be given on their behalf, and the default position must be that foetal tissue cannot be donated.

4.4.1 What if a parent is deceased?

After their death, a parent can no longer give consent. Should their former interests be legally protected in another way? When deciding what to do with the body or tissue of a deceased person, Dorothy Nelkin, Lori Andrews, McGuinness, and Brazier argue that the wishes of the former person should be respected and upheld over other interests.[210] The crucial difference here is that foetal tissue is not the

[209] See 3.3.

[210] Dorothy Nelkin and Lori Andrews, 'Do the Dead Have Interests - Policy Issues for Research after Life' (1998) 24 Am JL & Med 261; Sheelagh McGuinness and Margaret Brazier, 'Respecting the Living Means Respecting the Dead too' (2008) 28(2) OJLS 297.

personal tissue of the parents. It is the tissue of another. Furthermore, after death a parent cannot be harmed in the ways described in the previous chapter. They cannot be distressed or suffer psychiatric harm if foetal tissue is used against their interests. There is no longer a need to protect their interests from potential harm after death if the possibility of harm no longer exists. For the donation of tissue from a deceased person, consent must be obtained from a *living* family member or person in a qualifying relationship under the HTA 2004.[211] We would not suggest that the wishes of another deceased family member should be consulted in this decision. They will not suffer the 'life-destroying' pain described by Brazier.[212] Therefore, no other legal requirements should be introduced to protect the interests that deceased parents will have had in life.

4.5 The scope of consent

4.5.1 Modification and withdrawal of consent

The provision of consent should not be viewed as a one-off event that cannot be undone. The views and feelings of parents towards foetal tissue are not set in stone. They are varied and variable.[213] The law should therefore not treat them as fixed. Parents should be permitted to modify or withdraw their consent, to allow their interests to be upheld over others (such as public health interests) if these change after donation. Laurie and Postan present a similar view, albeit in the context of consent to medical research more generally, arguing that to treat 'the consent

[211] HTA 2004 sections 27(4)(a)-(h).

[212] Brazier (n 126) 560.

[213] See Chapter 3.

process as a one-off, up-front event is a distraction from the fundamental importance of fostering trust and respecting the underlying interests.'[214] They also suggest that seeing consent as a 'continuing relational process' would also best serve other interests, including the interests of 'ethical research governance'.[215]

This position is already reflected in existing legal consent requirements for the donation of embryos and other human tissue. The respective governing frameworks permit consent to be varied, withdrawn, or time-limited in line with the wishes of the donor.[216] The law has an even *greater* imperative to permit the modification of consent for foetal tissue donation due to the challenges of obtaining informed consent following pregnancy loss. This is illustrated in the following example:

> Person A is approached about donating foetal tissue to a medical research study after their abortion. They do not wish to read the information provided to them at the time, but they are happy to give consent based on their pre-existing views. A few weeks later they become curious about the research and read the information given to them by the researcher. They then regret their decision to donate foetal tissue to that research study.

Parents may not be willing or able to engage with information when approached about donation.[217] Yet it also the case that being provided with information may substantially change their views, due to a lack of public knowledge about foetal tissue use.[218] Some women reported becoming curious to learn more about foetal

[214] Laurie and Postan (n 173) 411.

[215] Ibid 413.

[216] HFEA 1990 Schedule 3 at [4(1)]; HT Authority, *Code of Practice A* (2023) (n 4) 13 [49]-[52].

[217] See 4.3.

[218] See 4.2.1 and 4.2.2.

tissue use long after their abortion or miscarriage.[219] It is therefore very possible that they may change their views about donation if they engage with the information provided to them at a later date. To accommodate these changing interests, the law should therefore enshrine an entitlement for foetal tissue donors to later modify or withdraw their consent.

However, practical limitations must be recognised. The HFEA 1990 places a legal limit on the variation of consent once an embryo has been used in research.[220] A similar limitation exists for human tissue.[221] It is justifiable for the law to place such limitations when necessary.[222] Such necessity arises here: material cannot be unused; research cannot be undone. Furthermore, if foetal tissue or data drawn from it is completely anonymised, then this too cannot be undone. Researchers will not be able to identify which foetal tissue samples or data are connected to the consent that is withdrawn, so it will be impossible to destroy them after complete anonymisation has taken place.[223] Similar limitations will therefore be needed for foetal tissue governance.

Another necessary limitation is one of communication. Consent can only be modified when this is communicated. It is possible for researchers to lose contact with donors if the contact details and addresses of the latter change.[224]

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[219] Myers, Lohr, and Pfeffer (n 56) 87; Pfeffer (n 39) 2551.

[220] HFEA 1990 Schedule 3 [4(2)].

[221] HT Authority, *Code of Practice A* (2023) (n 4) 13 at [51].

[222] See 3.2.2.

[223] This is only true for complete anonymisation. If samples and data are only pseudonymised, this can be undone.

[224] See for example Nikki Lee Stephenson and others, 'Mitigation of Participant Loss to Follow-Up Using Facebook: All Our Families Longitudinal Pregnancy Cohort' (2019) 21(2) J Med Internet

Donors should be provided with the contact details of the researchers as part of the information provided in the consent process, but these may also change if staff or the institution sponsoring the research changes. Human material is also sometimes transferred to other institutions for specific tests or further research.[225] Whilst researchers should make every effort to communicate changes in their own contact details to donors, this may be challenging if the contact details of the latter have changed. Any foetal tissue stored by the researchers will have been obtained with valid consent, in line with the parents' interests, so there should not be any assumption that consent would be withdrawn simply because contact is lost.

In some cases, these practical limitations cannot be avoided entirely. Donors should therefore be warned about these possibilities in the information that is provided to them. The consent rights of donors should not, however, be limited simply because an action is impractical for the research team. Moreno and Joly note that many biobanks consider it 'impractical that participants withdraw their data once those have been coded, de-identified, and placed in the bio-bank.'[226] Impracticality is not a sufficient excuse to deny donors the ability to modify or withdraw consent. Mette Hartlev notes that 'the right of research participants to withdraw samples from research biobanks is more restricted' in Denmark because 'the interest in securing valid research results' is prioritised.[227] Both of these

Res 1; Karen S Lyons and others, 'Locating and Retaining Research Participants for Follow-up Studies' (2004) 27(1) Res Nurs Health 63.

[225] This can be done via a Material Transfer Agreement: Integrated Research Application System, 'Model Material Transfer Agreement (mMTA)' (updated 12 June 2025) <https://www.myresearchproject.org.uk/help/hlptemplatesfor.aspx#mMTA> accessed 24 July 2025.

[226] Moreno and Joly (n 11) 238.

[227] Mette Hartlev, 'Genomic databases and biobanks in Denmark' (2015) 43(4) JL Med & Ethics 743, 749.

positions favour public health interests and permit them to override parental interests, which the law should not allow.[228] Nevertheless, if it may become genuinely impossible for consent to be modified – perhaps because tissue or data stored will become fully anonymised – then this must be communicated as part of the consent process.

4.5.2 Biobanks and consent to future uses

Foetal or other human tissue that is donated for medical use is either used in a specific research study or added to a biobank collection.[229] If stored in a biobank, material may be used in one or several research projects. At the point of collection, it is unlikely that researchers will know what specific projects the tissue will be used in. Because of this, Rebecca Hewer suggests that 'it is not possible to secure truly *informed* consent at the time of donation.'[230] A researcher cannot provide information that they do not have. Therefore, generic consent is often presented as an acceptable solution for materials donated to biobanks.[231]

The question here is therefore whether generic consent should be legally accepted as a necessary alternative to informed consent for biobank donation.[232] The answer must be no when alternative methods of providing detailed information exist. If detailed information cannot be provided at the point of

[228] See 3.2.1-3.2.2.

[229] It will be specified as part of the consent process whether the tissue will be donated to a specific research project or a biobank.

[230] Hewer (n 11) 291.

[231] Moreno and Joly (n 11).

[232] The law can justifiably place limits on interests when it is necessary: see 3.2.2.

consent, it could be provided at a later stage when a specific research project requests the use of the tissue. This is known as dynamic consent.[233] Researchers can provide this information – as part of the ongoing relationship of trust and communication between researchers and donors – and check whether donors wish to modify or withdraw their consent in light of the new information. Hewer points out that this approach 'has been framed as expensive, administratively fraught, and prohibitive' and so generic consent which avoids the expectation of iterative consent is preferred.[234]

These are not justifiable reasons for rejecting dynamic informed consent for foetal tissue donation. The interests of researchers in avoiding impractical requirements should not supersede those of parents.[235] If iterative or dynamic consent comes at a high resource cost, this does not make it impossible to carry out. Focus should instead be placed on making this process less resource intensive. Furthermore, different types of research may require different formulations of consent.[236] This is because the use of different human tissues, or particular research uses of these materials, raise different ethical issues. The way that material is stored – such as in a biobank – does not alter or eradicate these ethical issues. Choices about storage arrangements thus do not provide sufficient justification to lower consent requirements.

When parents are asked to donate foetal tissue to a specific research study, they may also be asked to consent to the use of the material in unspecified future

[233] See for example Kaye and others (n 11) 101; Moreno and Joly (n 11) 224.

[234] Hewer (n 11) 291.

[235] See Chapter 3.

[236] See 4.1.

research. This may include its use in other studies or in new research applications that are discovered in the course of current research. For the same reasons given regarding biobank donation above, parents should be permitted to consent to unspecified future uses of foetal tissue on the basis of dynamic consent. Every effort must be made to maintain a dialogue with them and provide them with further information when it becomes available.

Two significant exceptions to dynamic consent must be noted. Firstly, when informed consent is obtained, parents should exercise control over the extent of the information they engage with. This too should apply to dynamic consent. Information may be provided but it is the purview of the parents to decide whether to accept this or engage with it. Secondly, dynamic consent is desirable because it will satisfy the interests of parents who want information about foetal tissue use. It will not, however, meet the interests of those who want to donate foetal tissue and have nothing to do with it afterwards.[237] Anonymised donation may prove a more attractive option for these individuals. The Human Developmental Biology Resource fully anonymises foetal tissue after it is collected.[238] Donors can withdraw their consent up until the point of collection but cannot do so afterwards because all of the information linking them to the tissue is destroyed. Dynamic consent is no longer possible with complete anonymisation, and the latter would be outlawed if there was a legal requirement for the former in all cases. To do so

[237] Some 'may prefer not to be reminded of the events that led to the existence of the tissue': Department of Health (n 47) 138 at [15.15]; 'Less than half the women in each group would wish to know the exact details of the research' (38 per cent): Anderson (n 76) 38; 'Some women agree to donate the aborted fetus without asking any questions about what the research involves': Pfeffer (n 31) 102.

[238] Human Developmental Biology Resource (HDBR) <https://www.hdbr.org/> accessed 24 July 2025; see for example Nils O Lindström and others, 'Conserved and Divergent Features of Human and Mouse Kidney Organogenesis' (2018) 29(3) J Am Soc Nephrol 785.

would remove the possibility of donating anonymously, and this would not satisfy the interests of parents who would prefer this form of donation. Both of these donation options – dynamic consent and consent followed by complete anonymisation – should be facilitated to satisfy these interests.[239] Note that this exception only applies to *complete* anonymisation. If information linking a parent to the foetal tissue is only pseudonymised (or de-identified), then it will still be possible to identify them.[240] Their interests in cutting all ties with the donated tissue will not be met. In this latter case, dynamic consent remains possible and should be required.

Another consideration is whether the law should place time limits on how long foetal tissue can be stored. Embryos stored for research use can only be kept for a maximum of 10 years.[241] However, the ethical concerns that underly such limits are not relevant to deceased foetal tissue. Embryos are living human organisms which, if implanted into a womb, have the potential to grow into a human being. We may not wish to store these organisms indefinitely because of this potential.[242] In contrast, foetal tissue is deceased and does not possess potential life. Other areas of research, which do not raise these ethical concerns, do not have

[239] Researchers must communicate whether foetal tissue will be anonymised as part of the informed consent process.

[240] For an explanation of the difference between anonymised and pseudonymised data in medical research, see HRA, 'Step 1: Scoping - What are the data requirements for your project?' (updated 5 December 2022) <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/how-were-supporting-data-driven-technology/accessing-health-and-care-data-research-data-driven-technology-step-step-guide-and-glossary/step-1-scoping-what-are-data-requirements-your-project/> accessed 25 July 2025.

[241] HFEA 1990 sections 14(3)(c)-(d).

[242] See Chapter 2 for arguments about the moral value of potential: see 2.2 – 2.4.

time limits on tissue storage.[243] Currently, there appear to be no compelling reasons for the law to place time limits on the storage and use of foetal tissue.

4.5.3 Should we permit consent to be given for any use of foetal tissue?

It is outside the scope of this thesis to consider whether legal or regulatory controls should be placed on specific uses of foetal tissue.[244] This is a question which requires attention and lacks sufficient examination. Nonetheless, if such controls are created, then consent options must be limited to legally permitted uses.[245]

4.6 Conclusion

Currently, explicit informed consent is the most suitable legal mechanism for protecting parental interests. Whilst deemed consent may be more desirable in theory, because it places less of a burden on parents who may be distressed following pregnancy loss, the introduction of such a model is unjustified due to the lack of public knowledge and social scripts about foetal tissue use and experiences of pregnancy loss. A deemed consent model, which enshrines a parent's right to veto tissue donation, should be worked towards. For now, parental interests must be protected by a legal requirement to provide them with information and obtain their explicit consent. We should not, however, expect ideal informed consent to be obtained, and the law should not scrutinise the extent to which parents engage

[243] See for example HTA 2004; Moreno and Joly (n 11) 238-239.

[244] See the Introduction for an explanation of the scope of this thesis.

[245] The law can justifiably place limits on interests when it is necessary: see 3.2.2.

with or understand the information provided to them. The law's focus should be on the provision of detailed information by the researcher, not the receipt of it.

The distress caused by asking parents for informed consent can be minimised by certain practices including how researchers approach and speak to them about donation. Consent does not necessarily need to be sought within the challenging context following pregnancy loss. Where possible, consent should be sought at different timepoints which present fewer challenges. More research is needed to identify suitable timepoints for consent. Nonetheless, it may not always be possible to approach a potential donor for consent at an ideal timepoint. The legal framework governing foetal tissue collection should include best practice guidance about obtaining consent at various timepoints and specifically include guidance and training about the challenges that researchers will face. The legal framework must also produce guidance and training on sensitive language and methods that should be used for obtaining consent in the context of miscarriage and abortion. This should be informed by empirical research on what approaches can effectively respond to the challenges within this context.

If a parent lacks capacity, any decision to donate tissue must be made in their best interests. This may largely depend upon what is known about their interests about donation. If this is unknown, consent cannot be given on their behalf. Furthermore, the law no longer needs to protect the interests of a parent after their death.

The provision of information and consent should not be seen as a one-off event. Both parties should be encouraged to view consent as a continuing dialogue. This may involve further information being provided and additional consent being

given for future research purposes. This will permit the pregnant person more time to consider the information provided to them and allow them to donate foetal tissue to future unspecified research uses such as in biobank collections. Although the primary purpose of the law should be to protect the interests of parents (or other overriding interests), this collaborative dialogue between donors and researchers may also serve the interests of the latter and of advancing public health research.

It must also be permissible for consent to be modified or withdrawn, to reflect that the interests of the pregnant person may change over time. These options should be facilitated by researchers as far as possible, but they can justifiably be overridden by practical limitations. These include the loss of contact between donor and researcher, the complete anonymisation of material and data, or the use of the material. The possibility of these events and their interference with the donor's ability to modify their consent should be included in the information provided as part of the consent process.

Nevertheless, a requirement for informed consent alone is not enough to protect the interests of pregnant people. It must be embedded within a broader legal framework which contains other protective mechanisms. The format, scope, and context of this framework will be considered in the next and final chapter.

Chapter 5: A Legal Framework for Foetal Tissue

5.1 Introduction

A legal framework is needed to enshrine the requirement for explicit informed consent and to provide further protections for parental interests. The question of what framework should be used to govern foetal tissue use has received insufficient attention in the literature.[1] Whilst far more consideration has been given to questions about what framework should govern other human tissue, there is little consensus about this. The current Human Tissue Act (HTA) 2004 framework is centred around consent. Frameworks based on property rights or privacy rights have received critical attention as alternative proposals for governing human tissue.[2] Hybrid approaches, combining rules from both areas of law and others, have also been proposed.[3] The lack of accord is perhaps unsurprising, as there are many complex ethical issues and variables involved in the governance of tissue.[4]

[1] Primary consideration of this comes from Heather Meeker and Noah Gimbel, both writing in the US context: Heather J Meeker, 'Issues of property, ethics and consent in the transplantation of fetal reproductive tissue' (1994) 9(2) High Tech LJ 185; V Noah Gimbel, 'Fetal Tissue Research & Abortion: Conscription, Commodification, and the Future of Choice' (2017) 40 Harv J L & Gend 229.

[2] See for example Simon Douglas and Imogen Goold, 'Property in Human Biomaterials: A New Methodology' (2016) 75(3) CLJ 478; J Kenyon Mason and Graeme T Laurie, 'Consent or Property? Dealing with the Body and Its Parts in the Shadow of Bristol and Alder Hey' (2001) 64(5) MLR 710; Radhika Rao, 'Property, Privacy, and the Human Body' (2000) 80 BUL Rev 359.

[3] The debate is not simply a binary choice between property and no property: see Imogen Goold, 'Property or Not Property? The Spectrum of Approaches to Regulating the Use of Human Bodily Material' (2013) 21 JLM 299, 299; see for example Loane Skene, 'Proprietary rights in human bodies, body parts and tissue: regulatory contexts and proposals for new laws' (2002) 22(1) LS 102.

[4] See for example Caroline Banwell, 'Should I have property in my body?' (1994) 1 UCL Juris Rev 1; Joan M Gilmour, '"Our" Bodies: Property Rights in Human Tissue' (1993) 8(2) Can JL & Society 113.

As Imogen Goold explains, navigating these issues is difficult and the law is unable to govern tissue use in a way that would satisfy *all* interests and resolve *all* issues:

> Much of the complexity in determining which approach to adopt in regulating the use of bodily material arises from the variety of both uses and users of that material, and the contexts and reasons for its use. These may lead to conflicts between the person from whom the material was taken, the person who uses it or transfers it, and subsequent users. Add to this the need to promote more general goals such as supporting medical research, enabling effective health protection and promotion, encouraging investment in drug production while still avoiding an approach that produces absurd consequences, and the task of choosing an approach is understandably a vexed one. The law cannot make everyone happy all of the time.[5]

This chapter will examine why a governing framework is required for foetal tissue and what form this should take. This thesis has identified the ways in which the legislative response to foetal tissue must be different to that for other human tissue. To realise this, it has proposed two foundational principles that a legal framework must be shaped around. It must prevent deceased foetal tissue from being used in a way that undermines its special liminal moral status, and it must protect and prioritise the interests of parents (except where it is necessary to override these).[6] To meet these requirements, an argument will be presented for the adoption of a property law framework. The remainder of the chapter will consider what remedies and sanctions should be included in a governing framework and whether oversight from a regulatory authority should continue under the Human Tissue Authority (HT Authority) for the storage and use of foetal tissue.

[5] Goold (n 3) 302.

[6] For the discussion underpinning the first principle, see Chapter 2; for the second, see Chapter 3.

5.2 Why consent is not enough

A legal requirement for explicit informed consent is necessary to protect the interests of parents. However, as Jane Kaye and others point out, consent will 'rarely suffice to fully protect those interests alone.'[7] This was clearly demonstrated during the Organ Retention Scandal, which uncovered many breaches of the consent provisions for foetal tissue donation under the Polkinghorne Code of Practice.[8] The Code imposed no sanctions for breaches and offered no redress for the parents who felt that 'their trust [had] been betrayed, they [had] been deceived and their child desecrated'.[9] To borrow Margaret Brazier's famous critique of the Human Tissue Act 1961 – the provisions of which were also contravened during the scandal – the Code can be described as 'a toothless tiger imposing fuzzy rules with no provision for sanctions or redress.'[10] Given this historical context, it would be naïve to expect a standalone legal requirement for consent to sufficiently protect parental interests.

A key issue that cannot be resolved by consent requirements alone is the interference of third parties. Even if all donors and donees act in accordance with the provisions a consent form, the tissue may still be used in other ways if a third

[7] Jane Kaye and others, 'Biobank Report: United Kingdom' (2016) 44 JL Med & Ethics 96, 101.

[8] For an explanation of the Organ Retention Scandal and the breaches of the Polkinghorne Code of Practice, see 1.2 and 1.4; John Polkinghorne, *Review of the Guidance on the Research Use of Fetuses and Fetal Material* (Cm 762, 1989) (hereafter Polkinghorne Report and Code of Practice). Even though the recommendations of the Polkinghorne Code of Practice were 'ignored' and breached during the Organ Retention Scandal, the foetus and 'the mother had no rights in law' for redress: Michael Redfern, *The Royal Liverpool Children's Inquiry Report* (HC 2001, HC12-II, London: The Stationery Office 2001) (hereafter Redfern Report) 102 at [11.1]-[11.2].

[9] This quote is taken from the parents of Alexandra, their stillborn baby, whose organs were retained at Alder Hey: Redfern Report ibid 407.

[10] Margaret Brazier, 'Organ retention and return: problems of consent' (2003) 29 J Med Ethics 30, 31.

party interferes with it. Third parties are not bound by the consent process – it only binds the donors and donees. A consent requirement therefore cannot prevent or deter third parties from interfering with tissue nor provide a remedy if this occurs. As Goold explains:

> [T]he consent approach, without more, cannot adequately resolve situations in which a third party deals with bodily material, as the consent relationship establishes only rights in personam, which are not enforceable against someone outside that relationship who deals with the tissue.[11]

Therefore, for foetal tissue donation, the interests of the parents as donors cannot be prioritised through the mechanism of consent alone. Muireann Quigley also recognises that, without more, consent is not enough to 'give effective protection to source interests'.[12]

The HTA 2004 has been criticised for failing to provide adequate protections against the misuse or misappropriation of tissue by third parties.[13] It does not provide a sufficient answer to questions about whether tissue can be stolen, harmed, or otherwise used by third parties. Whilst it does impose criminal sanctions for non-consensual use of tissue, Goold and Quigley argue that this does not do enough to protect the expectations of donors and donees:

> [I]t is notable that few remedies are available to the person whose biomaterials are misused or misappropriated beyond the initial consent stage. While non-consensual use per se is captured by the 2004 Act, it is silent on who has the right to possess samples, who can control their uses and to what extent, and what ought to happen downstream if transfers are undertaken (for example, to other

[11] Goold (n 3) 304.

[12] Muireann Quigley, *Self-ownership, property rights and the human body* (CUP 2018) 27; see also Goold ibid 304.

[13] Imogen Goold and Muireann Quigley, 'Human biomaterials: The Case for a Property Approach' in Imogen Goold and others (eds), *Persons, Parts and Property: How Should We Regulate Human Tissue in the 21st Century?* (Hart 2014) 231, 246; see also Quigley ibid 45-46; Simon Douglas, 'Property Rights in Human Biological Material' in Goold and others (eds) ibid 89, 89-100.

> institutions). There are also no clear protections for researchers whose research samples are damaged or taken, or for holders of biomaterials outside the research or certain therapeutic areas.[14]

This concern has also been raised by J Kenyon Mason and Graeme Laurie regarding the legal reforms that were proposed following the Organ Retention Scandal.[15] They argue that 'Reform through the consent model on its own is … deficient' because it provides no 'remedy in law for the families who have suffered as a result of these practices'.[16]

This is perhaps unsurprising. The HTA 2004 appears to be a privacy framework, because it focuses on protecting individuals against unwanted interferences with their bodies. Jonathan Herring and P-L Chau argue that privacy rights alone cannot guard against interferences by third parties:

> [P]rivacy rights are negative and focus on preventing people doing things to your body. While, therefore, privacy rights may be useful to prevent the non-consensual removal of bodily material, they would not provide a means to claim back the material. The problems arise particularly where the material has been passed on to a third party. While a property claim may succeed against a third party, the claims of a right of privacy or bodily integrity may only be effective against the remover.[17]

It is evident that, without more, the HTA 2004 (or any other privacy or consent-based framework) cannot adequately respond to the identified issues. This leaves a lacuna and vulnerability in the law, where foetal tissue could be interfered with by third parties – against the interests of parents – without due recourse. For example, if foetal tissue is misappropriated by a third party, there is no legal redress

[14] Goold and Quigley ibid 246.

[15] Mason and Laurie (n 2).

[16] Ibid 727.

[17] Jonathan Herring and P-L Chau, 'My Body, Your Body, Our Bodies' (2007) 15 Med L Rev 34, 44.

under the HTA 2004 which would permit the recovery of the tissue, either by the donor or the donee. This lacuna is highlighted by Simon Douglas, who relies on the notion of the 'instability of possession' and extends it to human tissue.[18] Douglas argues that there is a real danger that scarce resources – including human tissue – will be dispossessed by others.[19] This argument can capture foetal tissue as it is an especially scarce resource.[20] Without a sufficient legislative response, 'there would be nothing to stop someone, such as a rival researcher, from taking the tissue samples from the defendants with complete impunity.'[21]

The real danger of dispossession is exemplified by the events of the Organ Retention Scandal – during which over a thousand foetal bodies and thousands of other human tissue samples were taken – and the case of *R v Kelly*.[22] In the latter, several body parts including human heads were removed from the Royal College of Surgeons. They were subsequently given to and used by an artist in his work. The Court of Appeal, in upholding the convictions against the defendants, recognised property rights could be held in the body parts. In making this determination, the court accepted the rule that property rights can accrue when a body or its parts have been altered following an application of work and skill.[23] The work and skill rule may go some way in protecting the interests of any researchers

[18] Douglas (n 13) 100.

[19] Ibid 100.

[20] See 1.3. Foetal tissue is a 'scarce resource' and 'often described as "precious"': Simon Woods and Kenneth Taylor, 'Ethical and governance challenges in human fetal tissue research' (2008) 3 Clinical Ethics 14, 15.

[21] Douglas (n 13) 102.

[22] Redfern Report (n 8) 100-120; *R v Kelly* [1999] QB 621.

[23] This rule originated from the Australian case of *Doodeward v Spence* (1908) 6 CLR 406; see 1.4 for further discussion of this case. Note that *R v Kelly* preceded the HTA 2004: ibid.

or users in possession of foetal tissue. However, it should be noted that if the facts of the case had been slightly different, so as to prevent the work and skill rule from applying, there would have been no clear remedy open to the court.[24] Furthermore, the work and skill rule cannot sufficiently protect the interests of parents because they themselves are unlikely to alter the tissue in a way that fulfils the legal standard for this rule to apply. It is their interests, not those of researchers or other users, which must be protected.

In the event of dispossession or interference with foetal tissue, the interests of parents are clearly overridden by the interests of a third party. Furthermore, foetal tissue is vulnerable to being used in ways which undermine its special moral status. The law should not permit either of these outcomes. A legal framework must therefore be able to provide sufficient protection against the actions of third parties.

It must also protect against certain uses of tissue by the donee. When consent is breached by the donee, or taken improperly, the HTA 2004 framework responds by imposing sanctions for non-consensual use of tissue.[25] This would appear to cover all scenarios involving the misuse of tissue. Again, however, it would not permit tissue to be recovered. The case of *Yearworth v North Bristol NHS Trust* illustrates that the existing HTA framework does not provide an adequate response to all possible acts or omissions by the donee that subvert the interests of

[24] The court could of course still find remedies in property law rules, as the court in *Yearworth* did, but there was no clear precedent for doing so at the time: *Yearworth v North Bristol NHS Trust* [2009] EWCA Civ 37, [2010] QB 1. It is also very unlikely that the court in *R v Kelly* would take the same approach because it felt it was bound by the entrenched rule that there could be no property in a corpse: *R v Kelly* ibid.

[25] HTA 2004 section 5(7).

donors.[26] In this case, sperm from six claimants, who were undergoing chemotherapy treatment, were stored by the defendant NHS Trust. The sperm were damaged following the careless storage of the samples. The sperm fell under the Human Fertilisation and Embryology Act (HFEA) 1990 which provided no suitable remedy for the claimants. Like the HTA 2004, the HFEA 1990 imposes criminal sanctions on the non-consensual use of sperm and other reproductive material, but these do not apply when samples are damaged by negligent storage.[27] Neither Act contains personal remedies and so they could provide no assistance to the claimants in *Yearworth*. It therefore fell to the court to consider whether this gap in the law should be filled by the common law. The court believed it should. They allowed a claim which recognised that the claimants held property rights in the sperm. The court held that their property rights were retained when the possession of the sperm was transferred to the defendant for the purposes of storage because the sperm were held on bailment. As bailors, the claimants retained a right to possession of the sperm and so were entitled to a remedy under the tort of negligence.

There is a debate over whether the court in *Yearworth* truly intended to create a property right – which is a right enforceable against the world – or only a personal right between the parties of the case.[28] If they did intend to recognise property rights, the approach taken by the court is criticised by Douglas and Goold

[26] *Yearworth* (n 24).

[27] Human Fertilisation and Embryology Act (HFEA) 1990 section 41.

[28] See for example Quigley (n 12) 108-109 and 176-180; Douglas and Goold (n 2) 482-483.

for overlooking the question of how these property rights should be acquired.[29] They argue that:

> The court did not consider the standard rules of acquisition. Instead … the court focused on the question of whether sperm could form the subject matter of a property right. Having answered that question in the affirmative, the court simply presumed that the right was allocated to the men. In taking this approach, the court conflated the question of the property status of the sperm with the question of in whom rights to that sperm would vest, and consequently side-stepped the established rules of acquisition of property rights.[30]

This calls into question the court's conclusion that the property rights in the sperm vested in the claimants.[31] Quigley suggests that we should not be hasty to read the case narrowly because the court was bound to answer the question before it rather than undergo a full examination of how property law should apply to human tissue.[32] We should therefore read the case as recognising property rights and not personal rights. Many of those who disagree with the court's application in *Yearworth* still agree with the outcome – namely the recognition of property rights in the sperm and that these vested in the claimants.[33]

Similar to the HFEA 1990, the HTA 2004 does not contain any remedies that would assist the claimants in *Yearworth*. Although the case was about sperm and so fell under the remit of the HFEA 1990, we might envisage a similar scenario occurring with separated human tissue that falls under the HTA 2004. One

[29] Douglas and Goold ibid.

[30] Ibid 482.

[31] Douglas and Goold argue that *Yearworth* 'set a precedent for (wrongly) presuming that the question of in whom property rights vest is answered by determining only whether they will vest at all': ibid 484; *Yearworth* (n 24).

[32] Quigley (n 12) 177.

[33] See for example Douglas and Goold (n 2); Shawn HE Harmon and Graeme T Laurie, 'Yearworth v North Bristol NHS Trust: Property, Principles, Precedents and Paradigms' (2010) 69(3) CLJ 476.

example is private cord blood banking. Umbilical cord blood may be stored for use in future personal medical treatment. Although it is different to sperm – for one, it cannot be used for reproductive purposes – it is an example of personal tissue which is stored as a service with the expectation of it being used for the person's benefit in future medical treatment. If cord blood was damaged from negligent storage, and the case was brought to the courts, it is likely that the precedent in *Yearworth* would be followed, and property rights would be recognised in the tissue. The donor of the tissue would be recognised as a bailor retaining a right to possession over the cord blood. The HTA 2004 would not prevent such a finding, nor would it provide alternative recourse for the claimant, because it contains the same lacuna as the HFEA 1990 that was identified in *Yearworth*.

Yearworth demonstrates that a legal framework must be able to provide sufficient protection against all acts or omissions of the donee in relation to foetal tissue that could override parental interests or undermine the status of foetal tissue. This is in addition to the obligation identified earlier in this section: that a framework must provide sufficient protection against the actions of third parties. The HTA framework does not provide an adequate response to these issues. While *Yearworth* appears to have filled this lacuna, by recognising property rights and allowing claimants to access property-based remedies, we should not continue to rely on this approach. For one, the court's application of property law rules was less than satisfactory.[34] A comprehensive legislative approach is needed to respond to these issues.

[34] Ibid; (n 31).

One way that the law could respond would be to create bespoke provisions to tackle these issues. For example, the law could specify that if tissue is donated with consent, a third party cannot interfere with this. If it does, the tissue can be reclaimed by the former possessor, or perhaps the donors, and sanctions will be imposed on the offender. The law could create provisions to this effect which address specific scenarios. Such provisions could theoretically come under a variety of approaches including those based on consent, property rights, or privacy rights. We have seen that the HTA 2004 – and HFEA 1990 – frameworks have failed to develop sufficient bespoke provisions in this regard. At the time of its passing, the HTA 2004 was considered to be a comprehensive response to the issues that arose during the Organ Retention Scandal.[35] Yet now, with the benefit of hindsight, we can appreciate that there are gaps in the law that the HTA 2004 does not cover. It is possible that lawmakers had not envisaged these issues at the time and were understandably focused on tackling the issues arising from the Organ Retention Scandal. However, such issues should have been addressed by legislative amendments when they were identified, such as in 2009 when *Yearworth* was decided.[36] This has not happened.

Even though we have identified some outstanding issues, we do not have a complete understanding of their scope. Nor can it be said with any certainty that we have identified all issues that may arise and are not adequately addressed by the HTA 2004. The scope of the issues identified remain unclear and untested, and

[35] See Chapter 1. In contrast, we cannot consider it a comprehensive or even adequate response to the challenges raised by the use of foetal tissue, but this was not given much consideration at the time due to the general avoidance of the topic: see 1.3 – 1.5.

[36] *Yearworth* (n 24).

further issues may arise later. Very few cases concerning human tissue and reproductive material have reached the English courts after the passing of the HTA 2004, and none have concerned foetal tissue.[37] Scenarios involving third party interferences have also only been the subject of litigation in other jurisdictions, such as the US, and these do not tell us how English law would respond if a similar case arose here.[38] There is therefore little knowledge of what interferences the law should expect and guard against, and how it might do so effectively. This is further compounded by the lack of public knowledge about foetal tissue use in England and Wales generally.[39] Therefore, a bespoke approach would face several challenges. First, as Goold points out, of 'developing rules to cover all potentially problematic interferences.'[40] Second, as noted by Herring and Chau, this would require breaking new ground, because creating such rules for an integrity or privacy-based model 'would not be directly analogous to privacy rights as recognised in the law to date.'[41] A third challenge would be to meet these aforementioned challenges (and potentially others) without creating further problems or an overly complex framework. Bespoke rules may lose their appeal if they are seen as unduly complex and arduous to comply with.

Given this, it is unlikely that lawmakers will be able to identify the scope of all possible issues and effectively respond to them through the creation of (likely

[37] The primary example is *Yearworth*: ibid. The events in the case of *AB v Leeds Teaching Hospitals NHS Trust*, which involved a claim regarding the body of a stillborn foetus, took place before the passing of the Act: *AB v Leeds Teaching Hospitals NHS Trust* [2004] EWHC 644 (QB), [2005] QB 506.

[38] See for example *Washington University v Catalona* 490 F 3d 667 (2007); *Moore v Regents of University of California* 51 Cal 3d 120 (1990).

[39] See 1.3.1 and 4.2.1.

[40] Goold (n 3) 304.

[41] Herring and Chau (n 17) 42, see also 41-42.

untested) bespoke provisions. We could of course make a reasonable effort to achieve this and amend the law in future if further issues arise. However, there is a long history of reluctance to discuss reform of foetal tissue governance in England and Wales, so we should not assume that this approach would be successfully followed in future.[42]

A bespoke private law approach seems to be a poor choice when a better approach exists: adopting a property law framework. Recognising property rights in foetal tissue would allow a rights holder to exclude any other person from interfering with this material. Under property law, obligations of non-interference imposed on others do not depend on the existence of *in personam* (personal) rights, such as those arising from a consent process between two parties. Rather, they apply to anyone, regardless of whether that person is aware of who holds the requisite property rights.[43] As Michael Bridge puts it, they 'bind those who are not parties to the transactions that create them.'[44] Douglas explains this further:

> [I]f A owns a house, which is to say that he has a freehold title in land, then his right would be enforceable not just against B, but against all other third parties (C, D, E, etc): if B, C, D or E walk across A's land without A's consent, A will have a claim against each individual. Because all persons (B, C, D, etc) owe A a legal duty to stay off the land, we can say that A's property right in his land is 'exigible' against all persons. Property rights, as distinguished from personal rights, are rights that are exigible against all persons (sometimes expressed as being 'exigible against the world').[45]

[42] See 1.3.1 and 4.2.1.

[43] In *theory* they would apply against anyone, with the rights holder having the strongest claim in property law. In practice, if an object of property is obtained by a subsequent innocent purchaser, then the law may choose to protect the rights of the latter over the original owner, depending on the circumstances. For an explanation of this, see exceptions to the *nemo dat quod non habet* rule in Michael Bridge, *Personal Property Law* (4th edn, OUP 2015) 198 onwards.

[44] Bridge ibid 41.

[45] Douglas (n 13) 90.

The concept of property rights is not settled. There are two popular positions.[46] The first posits that property rights are exclusionary rights, in the manner described above. They grant the holder the right to exclude all others from interfering with the subject of the right. The second theory conceptualises property rights as a bundle of rights. As Douglas explains, this theory 'holds that "ownership" does not consist of a single right, the "right to exclude", but of other rights as well, such as the "right to use" and "right to control" the thing.'[47] This debate will be revisited later in this chapter.[48] For now, it is merely necessary to note that most property theories recognise a right to exclude others from interfering with the object, which is the relevant consideration at this juncture.

If parents held property rights in foetal tissue, then they could prevent others – including donees and third parties – from using it in ways that interfere with their interests.[49] If tissue is donated and the donee holds property rights in the material, then they could bring an action to recover it against anyone who dispossesses it, such as the artist in *R v Kelly*.[50] The existence of this right may also act as an effective deterrent to dispossession in the first place. For example, if the parents donate foetal tissue to a research organisation, and a third party dispossesses it, any property rights vested in the research organisation would allow the latter to bring

[46] See Quigley (n 12) 138; Michelle Bourianoff Bray, 'Personalizing Personalty: Toward a Property Right in Human Bodies' (1990) 69 Tex L Rev 209, 211.

[47] Douglas (n 13) 92; for a demonstration of the bundle of rights argument, see Barbro Björkman and Sven Ove Hansson, 'Bodily rights and property rights' (2006) 32 J Med Ethics 209.

[48] See 5.3.2.

[49] This can be achieved through the mechanism of bailment, which is discussed in 5.3.5.

[50] *R v Kelly* (n 22).

an action to recover the foetal tissue in trespass.[51] This would bring the foetal tissue back to the research organisation who could continue to use it in line with the donors' interests. Alternatively, property rights vesting in the parents would allow them to bring an action for recovery. It would also permit them to bring an action against the donee if their use of the foetal tissue failed to align with the parents' interests.[52]

The force of such claims would depend on which individual or individuals held property rights in the tissue. Property rights can vest in just the donors, or just the donee, or in both through the legal mechanism of bailment.[53] Property law may also avoid some of the pitfalls of a bespoke approach insofar as it contains pre-established legal rules. As Quigley explains:

> Property law gives us a pragmatic and established framework for dealing with things. It already has a comprehensive set of doctrines and rules for dealing with the transfer of chattels. Via its system of rules we can manage many of the varied problems which may arise regarding biomaterials; from unconsented interferences such as theft to illegitimate transfers to negligent damage. Property law can thus provide a means to protect source interests in biomaterials, not just those of third parties who might acquire them. If human biomaterials are obtained illegitimately (that is, non-consensually or without proper disclosures being made) then property law provides a framework for redress. Transfers may be voidable and remedies available which can deal with a variety of misappropriations or misuses of these materials, something which is not available within the framework of the free-floating consent-based regimes inherent in the current legislation.[54]

Property law has established rules and remedies for a variety of situations which have been tested and developed over time. This is what a bespoke approach lacks.

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[51] Torts (Interference with Goods) Act 1977 section 1. For a discussion of trespass and other property-based remedies see 5.4.

[52] This can be achieved through the mechanism of bailment, which is discussed in 5.3.5.

[53] Bailment will be discussed in further detail in 5.3.5.

[54] Quigley (n 12) 303.

The application of property law has slowly crept into the governance of human tissue. This was clearly illustrated in *Yearworth*, where the court recognised property rights in the claimants' sperm.[55] It is unclear to what extent this case has moved the law away from the previous entrenched rule that there can be no property rights in a corpse.[56] The court in *R v Kelly* noted that while the principle had 'questionable … historical origins', it believed that the no property rule was so embedded in law that it could only be changed by Parliament.[57] *Yearworth* has cast doubt on the continued force of this rule, but it is not considered to be overruled as yet.[58] Furthermore, some tissues are already treated as property.[59] Stem cells are regularly bought and sold for scientific purposes, as are other human materials which do not fall under the HTA 2004 or do not fall under its prohibition on the sale of human organs for transplantation.[60] Shawn Harmon and Laurie explain that this piecemeal adoption of property rules has left a 'lingering uneasiness' in the law: 'while this history does represent an evolution toward the property paradigm (with "property" featuring to different degrees in the decisions), it is not

[55] *Yearworth* (n 24).

[56] *R v Kelly* (n 22); see also Samuel Walpole, 'Property in human bodily products' (2019) 135 LQR 31, 32.

[57] *R v Kelly* ibid at [749].

[58] '[A]lthough we might not yet deem the rule to be entirely dead, its death knell has been tolled': Quigley (n 12) 55.

[59] See Quigley ibid 18.

[60] HTA 2004 section 32. Materials, such as stem cells, are not considered 'relevant material' under the HTA 2004 if they have 'divided or been created outside the human body' or have been rendered 'acellular': Human Tissue Authority (HT Authority), 'Relevant material under the Human Tissue Act 2004' <https://www.hta.gov.uk/guidance-professionals/hta-legislation/relevant-material-under-human-tissue-act-2004> accessed 18 July 2025. For an example of the sale of stem cells, see Merck, 'Stem Cells' <https://www.sigmaaldrich.com/GB/en/products/cell-culture-and-analysis/cell-lines-and-specialty-cell-culture/stem-cells> accessed 18 July 2025. Joan Gilmour notes that 'the biotechnology industry already operates on the premise that such material can be owned', and this 'may have irretrievably and irreversibly shaped the discourse in this area': Gilmour (n 4) 113 and 134.

a conscious and principled development of the property paradigm'. [61] An intentional and comprehensive adoption of property law would resolve the issues that have been created by the piecemeal adoption of select property rules without a coherent unifying basis.

5.3 An argument for a property law framework

Much attention has been given to the question of whether other human tissue should be governed by property law.[62] However, Douglas and Goold warn that in some existing discussions – and in the case of *Yearworth* – 'the rules governing the operation of property rights have often been ignored, misunderstood or misapplied.'[63] This is also highlighted by the unprincipled piecemeal adoption of property rules for human tissue use. To avoid such pitfalls, the following discussion will follow the methodology provided by Douglas and Goold.[64] They suggest that the suitability of adopting a property framework can be ascertained by considering the following questions:

(1) Can the biomaterial form the subject matter of a property right?

(2) Should the biomaterial form the subject matter of a property right?

(3) To whom would the property right be allocated?

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[61] Harmon and Laurie (n 33) 484.

[62] See for example Douglas and Goold (n 2); Quigley (n 12); Mason and Laurie (n 2); Bray (n 46); Skene (n 3); Banwell (n 4); Meeker (n 1); Sonia M Suter, 'Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy' (2004) 72 Geo Wash L Rev 737.

[63] Douglas and Goold ibid 480; *Yearworth* (n 24).

[64] Douglas and Goold ibid.

(4) Would there be any defences to the property right?[65]

To apply these questions to the context of foetal tissue, we must ask:

(1) Can foetal tissue form the subject matter of a property right?

(2) Should foetal tissue form the subject matter of a property right?

(3) To whom would a property right in foetal tissue be allocated?

(4) Would there be any defences to the property right?

5.3.1 Can foetal tissue form the subject matter of a property right?

There is legal precedent for recognising human tissue as the subject of property rights in England and Wales following *Yearworth*.[66] This thesis has argued that, on a conceptual level, foetal tissue is distinct from other human tissue.[67] Nevertheless, these distinctions are not strictly relevant here. As Douglas explains, the answer to the question of whether human tissue can form the subject matter of a property right is a doctrinal one.[68] Douglas and Goold state that the metric for determining this is simple: 'the material must have a physical existence and be separate from the potential right holder.'[69] So to answer the overarching question, we only need to show that foetal tissue meets these two criterions. As with other human tissue, foetal tissue plainly has a physical existence. Once removed from the body of the

[65] Ibid 493.

[66] *Yearworth* (n 24).

[67] See Chapters 1 and 2.

[68] Douglas (n 13) 89.

[69] Douglas and Goold (n 2) 494. There is disagreement over whether property rights can only be held in tangible objects, or whether they can also apply to intangible items such as shares and debts. For example, Simon Douglas argues that property rights can only be recognised in tangible items: Douglas ibid 90-94. Bridge recognises that intangibles can also be subject to property rights: Bridge (n 43). This debate is not relevant here because foetal tissue and other biomaterials are clearly tangible objects.

pregnant person, it is separate from the body of any potential right holder – whether that is a parent, a researcher, or any other person. On these criteria alone, the conceptual differences between human and foetal tissue are irrelevant. Both questions can be answered in the affirmative and so we have a clear answer to the overarching question. Foetal tissue can form the subject matter of a property right. This logically aligns with the words of Master Sanderson in the Australian case of *Roche v Douglas*:

> Such samples have a real physical presence. They exist and will continue to exist until some step is taken to effect destruction. There is no purpose to be served in ignoring physical reality. To deny that the tissue samples are property, in contrast to the paraffin in which the samples are kept or the jar in which both the paraffin and the samples are stored, would be … a legal fiction.[70]

5.3.2 Should foetal tissue form the subject matter of a property right?

This question speaks to the ethical and policy implications of determining that foetal tissue should or should not form the subject matter of a property right. Returning to a point made earlier in this chapter, if foetal tissue is not recognised as such, then it can be taken by a third party with impunity. Outside of property, other rights and rules cannot sufficiently protect foetal tissue from the vulnerability of dispossession or interference. This in turn prevents the law from upholding the two foundational principles that I have argued should guide foetal tissue governance. Property law can guard against this vulnerability because one of its primary aims is to protect peaceful possession against interference by third

[70] *Roche v Douglas* [2000] WASC 146 at [24].

parties.[71] This compels us to recognise that foetal tissue should form the subject matter of a property right.

However, as we will see, answering in the affirmative raises some ethical concerns. These include concerns about the commodification and commercialisation of tissue. Allowing human tissue and body parts to be bought and sold within a commercial property framework – and otherwise treated as fully alienable products subject to market forces and commodification – may, as Herring and Chau argue, be viewed as 'demeaning and degrading to the body.'[72] This raises the question of whether the application of property law would be degrading insofar as to undermine the special status of the deceased foetus. Michelle Bourianoff Bray argues that:

> Complete alienability over one's body … may negatively affect personhood. An individual's integrity is affected negatively by being discussed in market rhetoric as a fungible commodity, because such terminology ignores the unique qualities and differences between individuals … Similarly, recognizing body parts as fully alienable property would encourage the perception of body parts as interchangeable commodities and undermine the recognition of the human body as the physical embodiment of the personality.[73]

This argument could also be read as proposing that complete alienability over one's body may negatively affect *the status of that body*. If we then extend this to encompass the deceased foetus, we might conclude that to treat it as an alienable good and commodity would negatively affect its special status.[74] Placing market

[71] Douglas (n 13) 99-101.

[72] Herring and Chau (n 17) 42; see also Suter (n 62) 742-743; Banwell (n 4) 1. For further discussion of commodification, see 2.3.

[73] Bray (n 46) 241; for an application of this argument outside of the context of human tissue, see Margaret Jane Radin, 'Market-Inalienability' (1987) 100 Harv L Rev 1849, 1925-1928.

[74] As argued in 2.3.

value on foetal tissue may also undermine its liminal nature.[75] Such rules should therefore not be present in a legal framework governing foetal tissue. If the alienation and commodification of tissue and other goods are fundamental and inseparable features of a property law model, then we must reject it. But this is not the case.

Douglas and Goold argue that the commercialisation and commodification of tissue are independent from property and may even occur without it.[76] It is, nonetheless, still possible for commodification to occur within a property model. To combat this, property law facilitates the creation of controls and limitations which can be used to avoid the risk of undermining the status of foetal tissue. Margaret Radin argues that personal property – items of special value that, if lost, may cause personal harm and could not be replaced by goods of equivalent market value – should not be subject to market forces.[77] They should be made market-inalienable – 'things that may be given away but not sold' – to protect individuals from the risks of degradation via commodification.[78] Radin's application of this theory to body parts is unsettled, but Bray argues that it should apply to them because they are 'a part of an individual's personality and identity'.[79] This could be

[75] See 2.2-2.4.

[76] Douglas and Goold (n 2) 492; see also Mason and Laurie (n 2) 727.

[77] Fungible items are 'capable of being reduced to money without changing in value, and completely interchangeable with each and every other commodity in terms of exchange value': Radin (n 73) 1859-1860, see also 1880-1881.

[78] Ibid 1849.

[79] Radin suggests that there is no single view that can encapsulate body parts. Some body parts could be personal property whilst others such as blood, hair, and organs might simply be fungible property, and others 'may be too "personal" to be property at all': Margaret Jane Radin, 'Property and Personhood' (1982) 34(5) Stanford Law Rev 957, 966; Bray (n 46) 214.

extended to cover the deceased foetus. As argued in Chapter 2, the body of the foetus represents a significant part of its biography.[80]

Ela Leshern identifies other liminal entities that are adequately governed by property law including 'animals … plants, and AI models'.[81] Leshern argues that when property rights are limited – that is, when a proprietary interest includes only 'rights to possess, exclude, and dispose' of something – the law successfully treats deceased bodies 'in accordance with their liminal moral status: namely as distinct from and better than property.'[82] Leshern suggests that US law does this in several ways by treating deceased bodies in ways which situate it 'on a spectrum between things and persons.'[83] As will be outlined later in this section, this thesis proposes that foetal tissue should be governed by a property model that is understood as granting only exclusionary rights, and not any further rights such as a right to use the tissue. This is an even more limited conceptualisation of property than the one proposed by Leshern for governing the use of deceased bodies and is also capable of respecting the liminal status of deceased foetal tissue.

This theory is not limited to tissue that is from *our own* bodies but rather focuses on personal property that is important to us. It could therefore capture the feelings that parents have towards the deceased foetus and their interests in its disposition. It could also reflect the duty of care that they may feel they owe

[80] See 2.3.

[81] Ela A Leshern, 'Dead Bodies as Quasi-Persons' (2024) 77(4) Vand L Rev 999, 1108.

[82] Leshern refers to this limited conceptualisation of property as 'quasi-property': Ibid 1009.

[83] Ibid.

towards the foetus.[84] Concerns about commodification, and other aspects of property that could undermine foetal status, could also be resolved by placing limits on property controls. Such limits have been considered by Goold, Douglas, Mason, Laurie, and Lyria Bennett Moses.[85] It appears that a property approach does not need to involve it and can impose rules to prevent its occurrence. Moreover, outside of commodification, recognising property rights in foetal tissue would not undermine its special liminal status. In relation to embryos created as part of in vitro fertilisation (IVF), Heather Meeker argues that 'The mere status of the embryo as property says little about its nature, and everything about who possesses the right of control.'[86] We therefore should not reject property on this basis.

There are also concerns that recognising property rights would give individuals too much control over tissue. Herring and Chau argue as much, stating that to do so would not reflect the relational nature of bodies, and that tissue should instead be treated as a community resource.[87] However, it is not a foregone conclusion that extensive control would be granted to a single individual under a property framework. Firstly, property rights can be held by multiple people. One example is that of bailment, where the bailor transfers the possession of a chattel

[84] See 3.2.1 for a discussion of the duty of care that some women feel towards the deceased foetus: Naomi Pfeffer, 'What British women say matters to them about donating an aborted fetus to stem cell research: A focus group study' (2008) 66 Soc Sci Med 2544, 2551 and 2553.

[85] Goold (n 3) 302; Simon Douglas, 'The Argument for Property Rights in Body Parts: Scarcity of Resources' (2014) 40 J Med Ethics 23, 26; Douglas and Goold (n 2) 489-492; Mason and Laurie (n 2) 727; Lyria Bennett Moses, 'The Applicability of Property Law in New Contexts: From Cells to Cyberspace' (2008) 30(4) Syd LR 639, 660-661.

[86] Meeker (n 1) 203.

[87] Herring and Chau (n 17) 54-55.

to a bailee. Both bailor and bailee hold property rights in the chattel.[88] Limits may also be placed on property rights. Douglas and Goold note that 'Imposing such restrictions is a fairly common practice with certain types of property rights.'[89] Furthermore, earlier in this chapter it was noted that there is no settled answer to the question of what form property rights take. The two main theories posit that they can be understood as either exclusionary rights or as a bundle of rights.[90] An examination of this debate will explain why we should not view property rights as granting any holder unfettered control over tissue.

Both Douglas and Quigley argue that we should understand property rights as granting exclusionary rights rather than as a bundle of rights.[91] In their view, the bundle of rights view suggests that property confers rights that are more extensive than what are conferred in practice. To demonstrate this, Douglas gives the example of the *right to use* a chattel, which is often included in bundles of rights theories.[92] He points out that when the law prevents owners from using a chattel in a particular way, this does not have the effect of depriving the owner of their property rights.[93] Douglas uses the case of *D Pride & Partners (A Firm) v Institute for Animal Health* to illustrate that whilst the law imposes a duty on others to not interfere with the owner's land (which was not breached in this case), it does not

[88] See 5.3.5 for further discussion of this.

[89] Douglas and Goold (n 2) 491.

[90] See 5.2.1; Douglas (n 13) 92; Björkman and Hansson (n 47).

[91] Douglas ibid; Quigley (n 12).

[92] Douglas ibid 105.

[93] Ibid 106-107.

impose a 'duty to refrain from impairing the claimant's ability to use his land.'[94] Therefore, the so-called *right to use* is not a right at all and would be better understood as a 'liberty to use'.[95] Goold illustrates the same point using the example of a knife: 'I am still guilty of grievous bodily harm for stabbing someone if I use a knife of which I am the owner.'[96] Douglas, Goold, and Quigley persuasively argue that property rights are instead better understood as only conferring on the holder a right to exclude others from interfering with the chattel.[97] On this view, we cannot conclude that property rights would grant extensive control over tissue to one or more individuals. They would simply allow the rights holder to exclude others from interfering with it.

As such, we can conclude that property law should not be rejected on the basis of these concerns. We can also answer the first two questions in the affirmative. Yes, foetal tissue *can* form the subject matter of a property right and yes, foetal tissue *should* form the subject matter of a property right.

5.3.3 To whom would a property right in foetal tissue be allocated?

The law does not currently provide a satisfactory answer about how property rights in human tissue should be allocated.[98] Several accounts have been proffered about

[94] Ibid 105-107; *D Pride & Partners (A Firm) v Institute for Animal Health* [2009] EWHC 685 (QB).

[95] Douglas ibid 106.

[96] Imogen Goold, 'Abandonment and Human Tissue' in Goold and others (eds) (n 13) 125, 150.

[97] Douglas (n 13); Goold ibid; Quigley (n 12).

[98] Quigley ibid 233.

how the law should do this.[99] We must consider this anew in the context of foetal tissue. The starting point is to determine the initial status of foetal tissue. Chattels and things can either be described as *res* (a thing which may be subject to property rights) or *res nullius* (a thing belonging to no one). A wild animal is a common example of something that is *res nullius* but may become *res* and owned by any person who captures or kills it.[100] If we can answer yes to the first two questions in our enquiry – whether foetal tissue could and should form the subject of a property right – this tells us that foetal tissue is capable of being or becoming *res* at some point. This does not, however, tell us much about its initial status. We can presuppose that its initial status will be one or the other. Foetal tissue may be *res nullius* until any person takes possession of it, making it *res*. Alternatively, it may become *res* at a particular point in time, with property rights being allocated to a specific person. The purpose of the following discussion is to determine which of these should be the case. Once we have ascertained the initial status of foetal tissue, this allows us to then determine how property rights in it might be obtained and who might obtain them. If foetal tissue is *res nullius*, then potentially anyone can obtain rights in the tissue by taking possession of it. If foetal tissue is *res*, then property rights will first vest in a specific person.

It is often said that living human bodies are *res nullius* and so cannot be the subject of property rights. On this view, property rights could only be recognised

[99] For example, Quigley argues that property rights should be allocated to the source on the basis of self-ownership: ibid 194-230.

[100] Douglas and Goold (n 2) 480; Banwell (n 4) 3-4.

in separated human tissue and corpses.[101] If true, this would also apply to the foetus in life, and so would need to be taken into account in asking when and how it becomes *res*. However, the position that living bodies are *res nullius* is contested. The theory of self-ownership contends that individuals are the owners of their bodies in life. This theory is defended by Quigley as a justified basis for recognising that property rights in separated human tissue should vest in the source (the individual from whom the tissue is taken).[102] In Quigley's view, each person has property rights in both their living body and such rights are retained in any human tissue that is separated from their body.[103] However, Quigley also argues that self-ownership does not include children, because they have not 'developed the requisite capacities' and their 'interests do not (yet) amount to self-ownership'.[104] This conceptualisation of self-ownership clearly would also not capture the foetus, who certainly has not developed capacities or interests to the extent that adults or even children have before death.[105] This suggests that we should accept the position that the living foetal body is *res nullius*.

The next step is to ascertain at what point the foetus could become *res*. The possibilities to consider are whether this should happen at a particular point, whether rights should be first assigned to a specific person, or whether rights only accrue when any person takes possession of it. Physical separation is one of the

[101] Although of course some also reject the idea of recognising property rights in human tissue and corpses. The point is that recognising such rights in separated tissue is not incompatible with the view that living human bodies are *res nullius*.

[102] Quigley (n 12). For criticism of this theory, see Douglas (n 13).

[103] Quigley argues that 'no moral magic occurs upon separation. Persons' normative authority over their biomaterials thus remains fundamentally unchanged': Quigley ibid 20.

[104] Ibid 223-224.

[105] See Chapter 2.

basic requirements for establishing whether something can form the subject matter of a property right.[106] This indicates that when the foetus dies *in utero*, before it has a separate existence from the pregnant person, it cannot immediately become *res*. The earliest this can occur will be once it is physically separated from their body.

We should recognise property rights in foetal tissue as vesting in the parents after physical separation. This is the only way for the law to allow their interests to be prioritised over others. If deceased foetal tissue is considered to be *res nullius* after separation, then property rights can be allocated to any person who takes first possession. This could be just one of the parents or another person altogether. If the pregnant person experiences abortion or miscarriage at a hospital, the member of the clinical care team who extracts the tissue may be seen as taking possession. If pregnancy loss occurs in a different setting, such as at home, then another family member or partner may take possession. Whilst it is possible for one or more of the parents to take possession in these scenarios, it is not a given. If property rights vest in another person, then the law will uphold the rights and interests of that person in determining the disposition of the tissue. The interests of all of the parents cannot in this instance be protected by the law. They can, however, if we recognise that property rights first vest in them. As Quigley notes, 'It is only by recognising persons as the holders of legal property rights in their separated biomaterials that we can adequately protect their interests in these.'[107] Although we should not recognise foetal tissue as the personal tissue of the parents, the rest of this statement

[106] Douglas and Goold posit that the criteria for ascertaining whether something can form the subject matter of a property right is that 'the material must have a physical existence and be separate from the potential right holder': Douglas and Goold (n 2) 494; see 5.3.1.

[107] Quigley (n 12) 23.

still rings true.[108] This is the only way to prioritise parents' interests in a property law model.

Vesting interests in this way is also necessary to ensure that this legislative framework is compatible with the parents' human rights. As argued in Chapter 3, the use of foetal tissue engages parents' right to respect for private and family life under Article 8.[109] This was confirmed by the European Court of Human Rights in *Hadri-Vionnet v Switzerland*.[110] Section 3(1) of the Human Rights Act 1998 provides that:

> Interpretation of legislation
>
> (1) So far as it is possible to do so, primary legislation and subordinate legislation must be read and given effect in a way which is compatible with the Convention rights.

Parents' Article 8 rights cannot be respected if property rights vest in another person, because that person would then be permitted to use the tissue in ways that could interfere with the parents' interests in the management of their private and family life.

If we allocate property rights to parents when foetal tissue is extracted, this could protect the interests of those who would want to have control over the use of the tissue. It may also align with feelings of 'ownership' and owing a 'duty of care' to the deceased foetus that some parents have expressed.[111] Naomi Pfeffer has observed that 'an invitation to donate an aborted fetus to medical research …

[108] See Chapter 2.

[109] See 3.3.

[110] *Hadri-Vionnet v Switzerland* App no 55525/00 (ECtHR, 14 February 2008).

[111] Pfeffer (n 84) 2548-2549; see Chapter 3 for more on this.

places a woman at the juncture of a host of concerns over which she has no authority.'[112] Participants in this research expressed concerns over having a 'lack of control' over something they felt 'ethical responsibility' for.[113] Granting them property rights in foetal tissue would remedy this.

However, this may not be desirable for all parents. Someone who wants nothing to do with foetal tissue after pregnancy loss may not want to be considered as having property rights in and control over it. This position could only be fully avoided if we reject a property approach. Even if we do not first allocate property rights to the parents, they may still acquire them if they take possession of the tissue. Yet it is important to recognise that parents who want nothing to do with the resulting foetal tissue after pregnancy loss may also not want anyone else to use it. Several women in Pfeffer's research expressed concerns that the use of foetal tissue may 'reinstate and even develop the fetus's physical existence and social biography beyond abortion'.[114] They might feel that the foetus was 'haunting' them.[115] If they hold property rights in foetal tissue, they will be able to exclude others from using it against their interests. If rights vest in another, they cannot do so. They may also be unable to protect against third party interferences under a non-property

[112] Pfeffer ibid 2552.

[113] Ibid.

[114] Ibid 2553.

[115] Ibid 2550. As another participant said: 'You'd want to know whether it was dead as well. I mean you'd want to know what they tell you when they'd killed it. You wouldn't want for it to be living for ages not knowing if this thing that you produced is still alive or not, would you? I'd be really horrified': ibid 2551.

model.[116] Therefore, the interests of parents – whatever these may be – will be better served if they are allocated property rights.

Those who really do not want to hold such rights could potentially discard them via the law of abandonment, which allows someone to give up 'ownership or possession of the thing entirely and irrevocably.' [117] The abandoner would surrender all property rights in the thing. A parent who does not want to retain property rights in foetal tissue could choose to abandon it. In theory, this may seem a straightforward solution. However, there are a few issues with the law of abandonment that must be addressed. Abandonment is an unsettled and dubious concept in English law. As Goold explains, 'There has been, in fact, considerable doubt as to whether divesting abandonment is possible under English law, although the preferred view is now in favour of its existence.'[118] On the basis that it might exist, it is worth considering its application to foetal tissue.[119] Goold goes on to identify the requirements that are necessary for abandonment:

> Three requirements emerge from the foregoing explanation of the case law: an original owner of the tissue, a physical relinquishment of the tissue, and a clear, unequivocal intention on the part of the owner to divest herself of all rights in relation to the tissue.[120]

The first of these involves identifying the original owner or owners of the foetal tissue. It would not be possible to satisfy this requirement if the tissue remained *res nullius* after separation from the pregnant person's body. If no one took possession

[116] See 5.2.

[117] Goold (n 96) 126.

[118] Ibid 129.

[119] Some (albeit limited) support for the existence of abandonment in English law is considered by Goold ibid; see also *Vandervell v Inland Revenue Commissioners* [1966] Ch 261.

[120] Goold ibid 149.

of it, there would be no owner who could abandon it. This supports the view that property rights should initially vest in someone. Furthermore, parents can only choose to abandon foetal tissue if such rights are first allocated to them.

If multiple parents are identified, and only one parent seeks to divest their property right in the tissue, then it would remain subject to the property rights of the other parents. The abandoner would lose any right to prevent another parent or anyone else from using the tissue. If all parents were to abandon their rights, a key concern that then arises is that they would not be able to prevent another from subsequently possessing the foetal tissue and acquiring property rights in it. When someone abandons their property rights, they can only alter the rights they hold in relationship to the tissue. They do not change the nature of the tissue as a thing that can be subject to property rights. Once rights are divested, another person can subsequently acquire such rights in the tissue. This would not be a cause for concern for someone who does not care what happens to the foetal tissue and does not want anything to do with it. As we have seen, there may be others who would mind if foetal tissue was subsequently used by another.

The third requirement of abandonment provides a safety net in this regard. The law sets the bar very high for meeting the third requirement of the intention to abandon.[121] Physical relinquishment – the second requirement – does not alone demonstrate intention. In the words of Plowman J, 'a man does not cease to own property simply by saying "I don't want it". If he tries to give it away the question

[121] '[T]he informational content of almost all human tissue, and the subjective value of some of it, coupled with the English law's reluctance to find property has been abandoned suggest it is unlikely that human tissue will be found abandoned in any but the clearest circumstances': ibid 155.

must always be, has he succeeded in doing so or not?'[122] The absence of an interest in something – such as not caring what happens to the foetal tissue – is also unlikely to be sufficient to establish intention.[123] Something more is required to demonstrate a clear, unquestionable intention to abandon the tissue. Having the bar set so high protects individuals from accidently abandoning their rights or doing so flippantly and later regretting it. As discussed in the previous two chapters, the experience of pregnancy loss can be highly distressing and there is a lack of public information about how foetal tissue is used. Within this context, it becomes more likely that someone may believe that they want nothing to do with the foetal tissue but later change their mind, especially after they have had a chance to engage with information about tissue use.[124] Research by Pfeffer

> [O]bserved a clear pattern where participants changed their position on the core question of the rights and wrongs of donating a fetus for stem cell research as they gained information and thought more carefully about the implications of such a decision.[125]

The high legal standard of this third requirement prevents the law from accepting superficial or fleeting expressions of wanting to abandon property rights, whilst still allowing those with the incontestable intention to abandon to do so. As Goold points out, we would not want to lower this bar because 'presuming abandonment too lightly might lead us back to the practices that led to the organ retention scandals of the early 2000s.'[126] It appears that the application of abandonment – if

[122] *Vandervell* (n 119) 275; taken from Bridge (n 43) 188.

[123] Goold (n 96) 144.

[124] See 4.2.1.

[125] Pfeffer (n 84) 2553.

[126] Goold (n 96) 151.

it does exist in English law – may meet the needs of some parents. It also underscores the need for property rights in foetal tissue to first be allocated to them.

Concerns have been voiced about assigning property rights to anyone other than a medical researcher. It is suggested that giving anyone else the primary control of tissue will have a negative impact on medical research. In the case of *Moore v Regents of University of California*, the Supreme Court of California refused to recognise that the claimant could have property rights in his separated tissue.[127] They believed that to do so 'threatens to destroy the economic incentive to conduct important medical research'.[128] Similarly, the United States District Court for the Southern District of Florida in *Greenberg v Miami Children's Hospital Research Institute* believed granting property rights to research subjects would 'chill medical research' by allowing them to 'dictate how medical research progresses'.[129] While these concerns are worth considering, they are, as Sonia Suter argues, 'empirically untested'.[130] Suter also warns that we should be 'hesitant' to accept concerns from researchers who have a 'tremendous financial stake' in the matter of how human tissue is controlled.[131] Empirical research is needed to prove such claims before we should strongly consider rejecting property rules on this basis. Even so, it is doubtful that this would be enough for us to reach this conclusion. Although the promotion of medical research is a worthy cause for the law, insofar that it

[127] *Moore* (n 38).

[128] Ibid 146.

[129] *Greenberg v Miami Children's Hospital Research Institute* 264 F Supp 2d 1064 (2003); see also Quigley (n 12) 70.

[130] Suter (n 62) 762.

[131] Ibid 761.

advances public health interests, it should not be prioritised to the detriment of overriding parental interests or foetal status.

Evidence has not been given to show that parents would be less likely to donate foetal tissue if they obtained property rights in the material. In the absence of such evidence, we should not be persuaded that this would be a likely consequence. If anything, it is likely that they might feel more comfortable to donate foetal tissue if they were reassured that their interests would be clearly respected and upheld and not overridden by those of others.

Furthermore, allocating property rights to the parents may directly alleviate some of the concerns raised by researchers. As Suter explains, researchers fear that a huge burden will be placed on them if they are required to identify who has the legal title of each sample, to ensure that they are permitted to use it.[132] This might be a real issue if there was no consistency in the initial allocation of property rights in foetal tissue. If tissue is *res nullius* it could be subsequently possessed by any person, making it difficult for researchers to ascertain who had acquired the property right. However, if the law consistently allocated property rights to the parents, this would give researchers clarity on this and remove this burden.

5.3.4 Would there be any defences to the property right?

The final question that Douglas and Goold ask us to consider pertains to defences. If only A has a property right in foetal tissue, and B uses the tissue, A could bring

[132] Suter (n 62) 758.

a claim against B for wrongful interference.[133] Would B then have any defences to this? The previous section has already addressed the law on abandonment. If we can say that A successfully abandoned their property right, and B subsequently gained a property right in the foetal tissue through possession, then B would have a defence against this claim. Another possible defence could be found if A gives consent for B to use the tissue in research, as B's actions would not amount to a legal wrong.[134] Douglas and Goold also rightly point out that the law could create bespoke defences. They argue that, 'Given the interest in scientific research, and the importance of human biomaterials to this activity, there may be good policy reasons to develop such a defence for research institutions acting in good faith.'[135] Additional defences may be identified once we determine which property mechanisms should govern the relationship between donors and donees, in the event that parents decide to donate foetal tissue.

5.3.5 Mechanisms of property law

Foetal tissue must be donated with the explicit informed consent of the parents.[136] As part of this process, the parents will consent to the transfer of possession of the foetal tissue to a donee, such as a researcher or research organisation. The question for this section is what property rules should govern this transfer of possession. The

[133] Torts (Interference with Goods) Act 1977 section 1; see 5.4; see also Douglas and Goold (n 2) 502-504.

[134] Douglas and Goold ibid 503.

[135] Ibid 503-504.

[136] See Chapter 4 for a discussion of this.

processes of consent and transfer inevitably alter the property rights of the respective parties. As Quigley explains:

> In this sense consent is transformative with respect to the relative normative positions of the parties. Specifically, a person's consent alters the rights relations that they have with other persons. When we consent to some third party or other using our biomaterials we are, in effect, consenting to an alteration in our rights with respect to the samples.[137]

After donation, the donee gains possession of the foetal tissue. Possession is an important signifier of property rights. Many property rules serve to protect a person's peaceful possession of a chattel. The possessor may not hold the only property right in the chattel, and they may not have the strongest right in relation to it, but they must hold some form of right. Therefore, the donee in possession – such as a researcher or research organisation – must gain a property right in the tissue. The question we must then ask is what form this should take.

Abandonment

The donation relationship cannot be governed by the rules on abandonment. Tissue cannot be abandoned *to* a specific person.[138] If tissue is abandoned, the former owner has no control over who might obtain legal title in the tissue, or if this will happen at all. If tissue is abandoned, it may ultimately be used by another in medical research, but it may also be used by another person for another reason. Abandonment rules do not permit a parent to direct foetal tissue to a particular person or for a particular use via consent.

[137] Quigley (n 12) 268-269.

[138] Goold (n 96) 144-145.

Transferring full property rights

Donation would usually involve the transfer of full property rights.[139] This would divest the parents as donors of all rights and transfer them to the donee, who would become the sole holder of property rights in the tissue. The law should not permit this. If all rights are transferred, then the person in whom they vest has full control over the tissue. They would not be bound to respect the interests of the donors and so may override these. This would not align with the foundational principle that the interests of parents must be prioritised over other interests.

Conditional transfers

Property rights can also be transferred with conditions. This could occur when tissue is considered to be given as a gift by the donor to the donee. A gift relationship reflects the gratuitous nature of the transfer, where legal consideration is not given in return for the gift of the tissue. This would still involve the transfer of property rights from the donor to the donee. The difference is that the parents as donors would be able to set conditions that the donee must adhere to. For example, they could specify that the foetal tissue must not be used to create stem cells or that it should only be used in research into the causes of miscarriage. In theory, parents could therefore express their interests in how foetal tissue should and should not be used, and the donee would be bound by them. However, it is unclear how these conditions would operate when the subject of the gift is tissue. When a conditional gift is made for real property – that is, land – the law imposes obligations on the

[139] For an exception to this, see the discussion of bailment below.

donee to comply with the conditions and provides some protection for donors if these conditions are breached.[140] There is some doubt whether a gift of a chattel – such as tissue – would attract the same legal obligations and protections. As Cameron Stewart and others explain:

> Holdsworth says that the common law never recognised that a donor of a conditional gift of goods retained a property interest in them (like a possibility of reverter). A gift of goods for a limited time (such as a life estate) was said to be a gift forever and the donee was free to do with the property as he or she pleased.[141]

The operation of a gift relationship for tissue donation is surrounded by much legal uncertainty. It is unclear whether a donee would be bound by conditions attaching to the gift of tissue, or if they are, then how strictly they would be bound, and whether the donor would retain or re-obtain any rights in the tissue following a breach.

Further issues could arise when attempting to translate personal interests into conditions. Conditions must not be impossible to fulfil, illegal, or against public policy.[142] Let us take the last two criteria. It is possible that a parent will seek to impose a condition that is illegal or contrary to public policy, regardless of whether they are aware of this or not. Considering that the law on the conditional gift of chattels is unsettled, then it is possible that the presence of this condition will not negative the transfer of property rights. Instead, the condition may simply not apply. The donee may obtain a property right in the foetal tissue without being

[140] The donor 'retains a right to resume the title if there is a breach': Cameron Stewart and others, 'The Problems of Biobanking and the Law of Gifts' in Goold and others (eds) (n 13) 25, 33 and 32-33.

[141] Ibid 34; see also William Searle Holdsworth, *A History of English Law* (4th edn, Vol 7, Methuen 1936) 470.

[142] Quigley (n 12) 281.

limited by this condition. As Quigley notes, the donee would have the 'normative authority' over the foetal tissue.[143] Without this condition, they would be free to use it in a way that may go against the interests of the donor. The same concern may arise if the donor seeks to impose a condition that is deemed impossible to fulfil. An example of this is if they say that the tissue should not be used in a degrading way. There is no settled understanding, legal or otherwise, of what would be degrading to deceased foetal tissue, so it may be considered impossible to fulfil due to a lack of certainty.[144] Again, the consequence is that the researcher may be able to use the tissue without the imposition of this condition. Without a clear determination of how conditional gifts of tissue would operate, and in the absence of the reassurance that they could prioritise the interests of parents, we should not rely on these rules.

Bailment

A clearer approach would be to use the rules of bailment. Bailment is 'a deposit of goods with an obligation to return them on request.'[145] It allows the donors to retain some property rights in the tissue after it has been transferred to the donee. The donee also gains property rights in the tissue, as it is now in their possession.[146] It permits *both* donors and donees to hold property rights in tissue. Each may

[143] Ibid 281-282.

[144] A term must be certain in order to have legal force. For an explanation of how this operates in contract law, see Edwin Peel, *Treitel: The Law of Contract* (15th edn, Sweet & Maxwell 2020) Chapter 2.

[145] Loane Skene, 'Legal Rights in Human Bodies, Body Parts and Tissue' (2007) 4 Bioethical Inquiry 129, 132.

[146] A person will gain a property right in a thing through possession.

therefore enforce a right of non-interference in the tissue against any third party. As Goold explains:

> The flexibility of property and bailment arrangements facilitates consensual donations and gifts, while allowing for greater transparency about rights retained and maintains the protection against third party interference for both donor and donee. This is a particular strength of the approach in that it can protect both source individual and the researcher to whom he or she gives bodily material, while protecting both against those whom they wish to exclude from the material for their own individual reasons.[147]

Another strength of this approach is that donors can enforce this right against donees, but donees cannot do so against donors. Furthermore, bailment would continue to protect the rights of both donors and donees even if the donated tissue was sent to another institution for testing. This is facilitated by the rules on sub-bailment.[148]

There is precedent for the application of bailment to human tissue following *Yearworth*.[149] The Court of Appeal recognised the existence of a gratuitous bailment because the claimants' sperm were provided to the defendant without any legal consideration given.[150] They found that the claimants, as bailors of the sperm, retained property rights in it. They could therefore recover damages for psychiatric injury from the defendants (the bailees) resulting from the breach of bailment conditions. The court's application of property rules in this case has been the subject of criticism.[151] Nevertheless, many still agree with the *outcome* of the case

[147] Goold (n 3) 304.

[148] See Bridge (n 43) 60.

[149] *Yearworth* (n 24).

[150] No payment was given for the provision of the sperm: *Yearworth ibid*.

[151] See 5.2; Douglas and Goold (n 2) 482.

and the decision to recognise a bailment relationship on these facts.[152] *Yearworth* has thus demonstrated the suitability of applying bailment rules to sperm, and possibly by extension, to human tissue. A few finer points must be considered before we can conclude whether these rules should apply to foetal tissue donation.

Bailment appears suitable when applied to tissue that we would want returned to us. Reproductive tissues, such as the sperm in *Yearworth* and frozen eggs and embryos, are good examples of this. These tissues are often stored with the intention of being returned to individuals for future fertility treatment. In this regard, the application of bailment appears less suitable when applied to foetal tissue. Foetal tissue is not and could not be used for reproductive treatment, as the HFEA 1990 prohibits the use of reproductive cells from an embryo or foetus for this purpose.[153] In some cases, donors may expect tissue to be returned. One example is if a deceased foetal body is used in observational research or a postmortem examination, after which the donor may expect the body to be returned later for burial or use in other rituals around death.[154] If only small pieces of foetal tissue are donated, it is unlikely that there will be an expectation for these to be returned. Samples are often used up in the course of research, and donors may not have any interest in having tissue samples returned to them. As Loane Skene points out, people generally do not expect removed tissues to be returned to them in a personal capacity – they expect them to be used, disposed of, or buried.[155]

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[152] See for example Douglas and Goold ibid; Harmon and Laurie (n 33).

[153] HFEA 1990 section 3A (as amended by the Criminal Justice and Public Order Act 1994).

[154] The claimants in *AB* had expected the organs of their children to be returned for burial or cremation after the postmortem: *AB* (n 37).

[155] There are also 'public health reasons why they should be promptly disposed of, properly preserved in a laboratory or kept hygienically until needed for transplant': Skene (n 3) 119.

In this context, the application of bailment – as it was applied in *Yearworth* - makes less sense for separated foetal tissue.

The donation of separated tissue might be better reflected by a gratuitous wasting bailment. A wasting bailment is where there is no expectation for the bailed chattel to be returned, often because it is expected that it will be used up at the end of the bailment term.[156] Bridge notes that a wasting bailment was recognised in the case of *The Span Terza (No 2)*.[157] In this case, the time charterers of a ship were responsible for supplying the bunker fuels for the ship. The charterparty ended prematurely and the possession of the bunker fuels passed to the shipowners along with the ship. The House of Lords recognised that the bunker fuels were held on bailment, with the charterers as bailors and the shipowners as bailees. In reaching this conclusion, they also recognised certain obligations were placed on the bailees due to the bailment conditions. In the previous chapter, it was argued that parents should be permitted to vary or withdraw their consent for donation if they change their mind at a later point.[158] The law should facilitate such variation by permitting the conditions of tissue bailments to be modified in line with parental interests. As for withdrawal, Bridge explains that a bailment at will grants the bailor 'the right to terminate the bailment at any time'.[159] It is evident that bailment could and should be used to facilitate the modification of consent.

[156] Bridge (n 43) 73.

[157] *The Span Terza (No 2)* [1984] 1 WLR 27; Bridge ibid 73-74.

[158] See 4.5.1.

[159] Bridge (n 43) 60.

5.3.6 Conclusion

Foetal tissue must be governed by a framework that is capable of upholding two fundamental principles. It must protect against all acts and omissions by both the donee and third parties in relation to foetal tissue that could override the interests of the parents or undermine the status of foetal tissue. Currently, these issues are not adequately protected against under the HTA 2004 or the common law. Two possible approaches have been identified to tackle these issues. One is to develop a bespoke framework. However, this is likely to raise issues of its own. The second approach is to adopt property law. It has been demonstrated that property law could apply to foetal tissue and would adequately respond to the two aforementioned issues. Following the methodology provided by Douglas and Goold, four questions have been considered and answered. Yes, foetal tissue *can* and *should* form the subject matter of a property right. Property rights should be allocated to the parents when foetal tissue is separated from the body of the pregnant person. Some defences to this right have been considered. When foetal tissue is donated, this relationship should be governed by the rules of bailment. More specifically, donation should be recognised as either a gratuitous bailment or a gratuitous wasting bailment, depending on whether there is an expectation for tissue to be returned.

5.4 Remedies and sanctions

Remedies and sanctions can play a role in protecting interests by reinforcing property rights, consent requirements, and bailment arrangements. For example, sanctions can deter parties from contravening legal requirements and remedies can provide compensation when harm occurs. The adoption of property rules opens up

the option for donors and donees to access property law remedies. The question to consider here is what role remedies and sanctions should play in a governing framework for foetal tissue.

Sanctions

The HTA 2004 framework only imposes sanctions on those who contravene its provisions. It does not contain any personal remedies. For example, if a person commits an offence under section 5 of the Act – which governs the use of tissue without consent – they could face a fine, or imprisonment for up to three years, or both.[160] Criminal sanctions can provide a strong deterrent. The sanctions under the HTA 2004 appear to have been successful in this regard – few high-profile breaches of the Act have occurred since its passing.[161] However, they have been criticised for being too heavy handed.[162] Imprisonment is a personal punishment. It cannot apply to a larger research organisation in the way that a fine can. The Act does not provide guidance on when imprisonment may be imposed, such as how severe an offence must be to invoke this. Therefore, the threat of imprisonment hangs over the heads of all medical researchers who use foetal and other human tissues in their everyday work. The same can be said for other users, such as museum curators

[160] HTA 2004 sections 5(7) (a)-(b).

[161] For breaches, see for example West Mercia Police, 'Hospital group fined £100k for illegal storage of human tissue' (23 October 2023) <https://www.westmercia.police.uk/news/west-mercia/news/2023/october/hospital-group-fined-100k-for-illegal-storage-of-human-tissue> accessed 18 July 2025; HT Authority, 'UK conviction for human trafficking organ removal offence' (23 March 2023) <https://www.hta.gov.uk/news/uk-conviction-human-trafficking-organ-removal-offence> accessed 18 July 2025.

[162] Remigius N Nwabueze, 'Regulation of bodily parts: understanding bodily parts as a duplex' (2019) 15(4) Int JLC 515, 524; JR Spencer, 'Criminal liability for the desecration of a corpse' (2004) 6 Arch News 7; Charles Erin and Suzanne Ost, 'An Ill-Suited and Inappropriate Union? Exploring the Relationship Between the Criminal Justice System and Health Care' in Charles Erin and Suzanne Ost (eds), *The Criminal Justice System and Health Care* (OUP 2007) 1.

who display human remains in their exhibits.[163] For small or accidental breaches of the Act, imprisonment would be a disproportionate and 'harsh' response.[164] As JR Spencer argues, it would be 'like using a sledgehammer to crack an egg.'[165]

It was argued in Chapter 3 that other interests in foetal tissue use should be facilitated whenever they do not conflict with parental or other overriding interests.[166] It is not necessary for imprisonment to be imposed for small breaches in order to protect these interests. Other sanctions or remedies may be sufficient for this. Therefore, when considering what sanctions should apply, we should also consider the interests of potential possessors and users of tissue. Harsh personal punishments such as prison sentences are not in their interests and cannot be justified when they are disproportionate to the wrong committed.

A prison sentence is especially disproportionate when compared with the legal consequences for personal injury and medical negligence. A medical professional who accidentally causes bodily injury during medical treatment is likely to be sued in the tort of negligence, and in many cases their hospital employer will be vicariously liable to pay compensation to the claimant.[167] It is only in rare and severe cases, such as if a surgeon intentionally causes grievous bodily harm, that they will be personally convicted under the criminal law.[168] Even Simon

[163] See for example the British Museum, 'Human remains' <https://www.britishmuseum.org/our-work/departments/human-remains> accessed 18 July 2025.

[164] Nwabueze (n 162) 524.

[165] This criticism was also levelled at the whole of the Human Tissue Bill: Spencer (n 156) 9.

[166] See 3.2.2.

[167] See for example *Cassidy v Ministry of Health* [1951] 2 KB 343.

[168] See for example Ian Paterson, who was sentenced to fifteen years' imprisonment for breaching sections 18 and 20 of the Offences Against the Person Act 1861 for deliberately misleading and conducting unnecessary surgeries on several patients: *R v Paterson* [2017] EWCA Crim 1625.

Bramhall, who branded his initials on patients' livers during transplant surgery, was only ordered to pay a £10,000 fine and complete community service.[169] He did not serve time in prison. In contrast, small misuses of human tissue could carry a multi-year prison sentence. Several pathologists highlight the fear and shock of being under the threat of personal criminal sanctions, like imprisonment, for work that they believe to be 'altruistic' and beneficial to society.[170] As one pathologist put it:

> [W]e've all been threatened with the rule that if we keep anything that we are not allowed to keep we might face a three-year prison term. I mean that's a huge thing. I'm a single parent, so the thought that anything I did might lead to me being imprisoned, well who would look after my children day-to-day?[171]

Furthermore, heavy handed sanctions run the risk of stifling research. Following the introduction of the HTA 2004 sanctions, several pathologists reported a 'sense of fear and uncertainty' surrounding their work and admitted a reluctance to take organs even when consent had been given.[172] As above, public health interests in advancing medical research should not be stifled by particular sanctions if they are not necessary for the protection of parental interests.

Outside the context of human tissue, Charles Erin, Suzanne Ost, and John Griffiths criticise the 'ill-suited and inappropriate union' between criminal law and health care.[173] As Spencer asks, 'Is it sensible to deal with the problem of "retained

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[169] Simon Bramhall pleaded guilty to common assault per the Criminal Justice Act 1988 section 39: *R (Bramhall) v GMC* [2019] EWHC 3525 (Admin) at [26]–[28].

[170] Alastair V Campbell and others, 'Human tissue legislation: listening to the professionals' (2008) 34 J Med Ethics 104, 105.

[171] Ibid 107.

[172] Ibid 105.

[173] Erin and Ost (n 162); John Griffiths, 'Criminal Law is the Problem, Not the Solution' in Erin and Ost (eds) (n 162) 119.

organs" by turning doctors and medical researchers into criminals?'[174] This issue is not limited to those using foetal tissue in medical research and treatment. Take the following example:

> C suffers a miscarriage at home. Her friend, D, cares for her during the miscarriage. C asks D to take the deceased foetus away, saying she does not want to look at it. D disposes of the foetal body in the belief that this is what C wants. On discovering this, C becomes upset and says that she did not want D to dispose of it, but only to take it out of the room while she decided what to do with it.

In this example, D has committed an offence.[175] D has used the foetal tissue in a way that goes against the interests of and the property right vested in C. To reframe the question asked by Spencer: is it sensible to deal with the problem of foetal tissue misuse by turning all users and possessors into criminals? For small offences, we should answer no. Applying harsh sanctions should be avoided in such cases for three reasons. First, they would be disproportionate to the wrong. Second, it is not necessary to do so to protect the interests of parents. Thirdly, it would act against the interests of researchers, whose work ultimately benefits public health, and other users and possessors. Nevertheless, for individuals who have committed offences on a large scale or to a great degree of severity – like the actions of Dick van Velzen during the Organ Retention Scandal – we should answer yes.[176] Strong sanctions for such actions must be included in a legislative framework because no suitable punishment would be imposed for such offences under the common law.

[174] Spencer (n 162) 9.

[175] D will not have committed an offence under the rules of the current HTA 2004 but will have done so under the property law framework proposed in this chapter.

[176] For an explanation of the Organ Retention Scandal, see Chapter 1. For details of the offences committed by or under the leadership of van Velzen, see the Redfern Report (n 8).

In many cases it would be more appropriate to apply sanctions to organisations, especially in the context of tissue used in medical research. Offences may be committed by a team of researchers rather than a sole individual. Furthermore, the actions of a researcher constituting an offence may be carried out under the order of a senior colleague. In such cases it is more appropriate and proportionate to punish the organisation. If regulatory approval has been granted for the use of tissue – such as in the form of ethical approval or the issuing of a HTA licence – this should be partially or completely revoked for a period.[177] This would prevent further offences being committed and would allow the organisation to learn from the misconduct. Fines can also act as an effective deterrent. The cost for each fine should attract careful consideration. A fine, if too low, may not prove an effective deterrent for a commercial company. If other sanctions are not imposed alongside a low fine, it may simply allow offenders to purchase the freedom of the unfettered use of tissue. If too high, fines may price academic and non-commercial researchers out of the field, which would undermine public health interests. The purpose of the fine should be threefold. To provide punishment for the offence, to deter the wrongdoer from further offences, and to financially limit their ability to commit further offences in the short term. The law should allow a court the flexibility to determine the cost of a fine on a case-by-case basis to meet these aims. A lower and upper limit for fines should be set by the legislation to avoid the imposition of fixed, disproportionate fines.

The imposition of sanctions can provide several benefits. They may promote public confidence in the research sector by serving as a reassurance that

[177] See the next section for a discussion of whether maintaining a licensing system, such as the ones under the HTA and HFEA frameworks, would be desirable for the governance of foetal tissue.

the misuse of tissue is unlikely to occur. If it does, the perpetrators will be appropriately punished, and they will be prevented from committing further offences. In acting as a deterrent, sanctions may also promote more conscientious research practice. The criminal law therefore still has an important role to play in imposing sanctions, but when these apply to individuals their application should be clear and proportionate. However, there are some ends that sanctions cannot achieve. Most crucially, they cannot facilitate the recovery of tissue that is misappropriated. Earlier in this chapter it was argued that a governing framework for foetal tissue must facilitate this. Remedies are required to achieve this.

Remedies

Property-based remedies allow the holder of a property right to claim recovery against another who wrongfully interferes with the subject of that right under the torts of trespass, conversion, and negligence.[178] In the present context, trespass applies to a direct act which interferes with tissue or takes it without authorisation.[179] Conversion involves acts that interfere with or misappropriate tissue 'in a manner which is inconsistent with the right of another to possess or be put in possession of the thing.'[180] Negligence covers negligent property damage or psychiatric injury. Trespass should be explicitly extended to apply to foetal tissue to cover a range of scenarios where this material is interfered with or misappropriated by a donee or a third party. As will become clear below,

[178] Torts (Interference with Goods) Act 1977 section 1.

[179] Bridge (n 43) 80-82.

[180] Quigley (n 12) 148.

conversion and damages for property damage under negligence may be ill-suited to a claim for foetal tissue because they would not facilitate the recovery of it. Under property law, both bailor and bailee may access property-based remedies. It is desirable for this to be maintained in the context of foetal tissue use. For example, if the parents donate foetal tissue to research and the tissue is later taken by a third party, it may be in the parents' interests for the bailee to recover the tissue and continue to use it in research as originally agreed. If this is not possible, the parents as bailors retain the right to bring an action to recover the tissue.

Remedies could also provide personal compensation. As Bridge notes, 'the primary remedy at common law for the protection of property interests is not the compulsory return of the property to the claimant but rather damages.'[181] Property-based tort remedies, as Bridge has described them, will often provide compensation *instead* of the return of the property. The tort of conversion involves the 'forced judicial sale' of the tissue to the defendant.[182] The tort of negligence provides damages for property damage. The damages provided seek to represent the commensurate value of the subject of property that has been taken from the claimant. Damages conceived in this way should not be awarded for the loss of foetal tissue, because it should be recognised as personal property and made market-inalienable.[183] Adopting this classification means that market value should not be placed on foetal tissue for any purpose. The law should therefore not allow commensurate financial compensation to be traded for the foetus. If something is made market-inalienable, it should not, as Radin argues, be treated as a fungible

[181] Bridge (n 43) 79.

[182] Bridge ibid 113, see 113-114.

[183] See 5.3.2; see also Chapter 2.

item 'capable of being reduced to money without changing in value, and completely interchangeable with each and every other commodity in terms of exchange value.'[184]

It will also not be possible to assess commensurate damages if value cannot be placed on it. Damages should not and cannot be awarded in lieu of the return of foetal tissue. Its return should always be prioritised. The torts of conversion and negligence (for compensating property damage) therefore may not offer a suitable remedy. If tissue cannot be returned, the offender may still be punished by imposing criminal sanctions.

Property remedies also include recovery under the tort of negligence, which can provide compensation for psychiatric injury flowing from damage to an interest in goods.[185] Other types of injury may be compensated if a bespoke legal remedy was created for them. The tort of negligence has, on occasion, also recognised and provided compensation for harms to autonomy.[186] The principle of autonomy is of little relevance because the foetus cannot exercise autonomy in life.[187] Furthermore, even though parents can exercise autonomy, foetal tissue is distinct from their personal tissue.[188] Therefore, if foetal tissue is misused there is no harm to autonomy for the law to recognise or seek to compensate. Nevertheless, if foetal tissue is misused or misappropriated, parents may experience great

[184] Radin (n 73) 1859-1860.

[185] Torts (Interference with Goods) Act 1977 section 1(c).

[186] See for example the case of *McFarlane,* where the claimants were awarded £15,000 for loss of autonomy: *McFarlane v Tayside Health Board* [2000] 2 AC 59.

[187] See Chapter 2; see also 4.1.

[188] Ibid.

distress.[189] We should consider whether this distress should be compensated, and if so, whether it needs to meet a particular legal standard.

Claims for psychiatric injury were brought by the claimants in the case of *AB v Leeds Teaching Hospitals NHS Trust*.[190] In this case, several parents brought claims for wrongful interference and negligence against hospitals who removed and retained organs from their children's bodies for postmortem examinations.[191] One of these concerned the retention of organs from a stillborn foetus. The court rejected the claims for wrongful interference (and contingent claims for psychiatric injury in negligence) on the basis that the claimants could not hold property rights in the deceased body of their child and had 'no right of burial and possession of organs lawfully removed at post mortem and retained.'[192] One claim for psychiatric injury was allowed, although this was on the basis of the claimant being owed a duty of care as a patient themselves rather than in relation to the interference with the body of the stillborn foetus. Nevertheless, this case tells us two things. First, that a pregnant person who experiences stillbirth can suffer from a diagnosable psychiatric injury if the foetal body is misused.[193] Second, it indicates that some parents will want to bring claims for psychiatric injury if this occurs. There seems little reason to deny the pregnant person or other parents a remedy for psychiatric injury when there is legal precedent for compensating for this harm in many other

[189] See Chapter 3 for examples of this.

[190] *AB* (n 37).

[191] The events of the case occurred during the Organ Retention Scandal: ibid.

[192] Ibid at [161].

[193] Ibid at [110].

contexts, especially when the parents will hold property rights in the foetal tissue which can form the basis for a psychiatric injury claim.

For such a claim, individuals must be suffering from a recognisable psychiatric illness.[194] We could also consider extending this remedy and allowing the parents to claim for distress arising from the misuse of tissue which does not meet the required legal threshold for a psychiatric injury claim in negligence. Extending this remedy would allow recovery for those suffering from distress which falls below this standard. This chapter does not suggest that the distress suffered by parents in this context is distinct enough from other instances of distress so as to justify making a legal exception for the former and not the latter. Instead, this remedy should only be extended if a principled basis can be given for extending such remedies for any distress falling below the current standard of diagnosable psychiatric illness. No such argument will be given here.

Providing compensation for psychiatric injury arising from the misuse of foetal tissue raises an ethical concern. If any financial compensation is given for foetal tissue misuse, does this reintroduce the concept of placing value on foetal tissue? Could we say that the financial award reflects the value of the deceased foetus? Suter recognises this risk but suggests that this is avoided when we clearly measure damages in another way: for example, not 'in terms of the market value … but in terms of its dignitary value to the individual.'[195] Just because a financial award is given does not mean that it reflects or represents the value of foetal tissue.

[194] *McLoughlin v O'Brian* [1983] 1 AC 410.

[195] Suter (n 62) 813.

We can and should conceptually separate the acts of valuing foetal tissue and valuing compensation for psychiatric injury.

In conclusion, both remedies and sanctions have a role to play in a governing framework for foetal tissue. Sanctions provide an effective deterrent against breaches and can provide suitable punishment for offenders. The level of punishment must be proportionate. Harsh measures would not satisfy the interests of tissue users and possessors and may stifle medical research. Harsh measures are not necessary to protect the interests of parents for small offences but may be justified in rare cases of severe or prolific offences. Sanctions alone cannot facilitate the recovery of misappropriated tissue, so remedies are also needed. Recovery can be sought by the parents as the rights holders, and by the bailee if tissue is donated, under the tort of trespass. Damages for psychiatric injury resulting from the misuse of tissue should also be available to the parents.

5.5 Regulatory controls

Remedies and sanctions are not the only tools that can protect interests and minimise tissue misuse. Regulatory controls and oversight may also go far in achieving these aims. The collection and use of foetal and human tissue is overseen by the HT Authority. The role that a governing authority can play in providing oversight and control of tissue use is very appealing. The HT Authority operates a licensing system and requires organisations to obtain a licence to store or use human material. [196] Further rules may be imposed by the conditions of the licence.

[196] The HT Authority oversees a licencing system for human tissue: HTA 2004 Part 2 and Schedule 3; HT Authority, 'What is a HTA licence' (updated 5 November 2024)

The HT Authority carry out inspections, collect data, and oversee what material is collected and how it is used.[197] They also issue Codes of Practice, other professional guidance, and provide clarification on legislation.[198] Similar powers are also exercised by the Human Fertilisation and Embryology Authority. These powers grant both authorities with extensive control and oversight over the use of various human materials in England and Wales. Such powers can provide safeguards to limit the misuse of tissue, and in turn protect interests in that material, as well as promptly identify and address these.[199]

Many stakeholders value the work of the HT Authority. As Matthew Limb observes, it has 'strong support from stakeholders and interest groups, from public and commercial organisations to charities'.[200] Baroness Warwick contends that its oversight has notably 'rebuilt public confidence' following the Organ Retention Scandal.[201] Oversight of foetal tissue use from a regulatory authority should be maintained to retain the benefits of these powers. The effectiveness of its operation

<https://www.hta.gov.uk/guidance-professionals/licences-inspections-and-fees/licensing/what-hta-licence> accessed 18 July 2025.

[197] HTA 2004 section 48 and Schedule 5; HT Authority, 'Licences, inspections and fees' <https://www.hta.gov.uk/guidance-professionals/licences-inspections-and-fees> accessed 18 July 2025.

[198] The HT Authority has issued several Codes of Practice on consent and other practical processes: HT Authority, 'Codes of Practice' <https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/codes-practice> accessed 23 July 2025; Bonnie Venter, 'A NHS Foundation Trust v MC [2020] EWCOP 33: Revisiting Best Interests and 'Altruistic' Incapacitous Stem Cell Donation' (2021) 29(2) Med L Rev 337; HT Authority, 'Legislation' <https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/legislation> accessed 24 July 2025.

[199] Jorgelina Trueba and Berthold Huppertz, 'A Snapshot on the Regulatory Activity of the Human Tissue Authority in the United Kingdom Research Sector' (2023) 21(1) Biopreserv Biobank 104.

[200] Matthew Limb, 'Organisations voice concerns over plans to disband Human Tissue Authority' (2012) 345 BMJ 7897, 7897.

[201] Per Baroness Warwick in Limb ibid 7897.

should, nevertheless, be significantly improved in response to the shortcomings that have been identified in this thesis.

It is desirable for governance to continue under the pre-established body of the HT Authority. The creation of a new governing authority for foetal tissue would be costly.[202] It would also be unnecessary. Whilst this thesis has argued that foetal tissue should be governed by new legal provisions – distinct from those applying to human tissue – the enforcement of these could remain under a single Authority.

A licensing system for the storage and use of foetal tissue should also remain in place under the HT Authority. This would facilitate record keeping and data collection for foetal tissue use and allow licences to be revoked or limited if misuse occurs. An outstanding issue with the HTA licencing system is that tissue can be collected and used without a HTA licence if ethical approval for the research use of the tissue is in place.[203] Under the current HTA framework, licences are therefore not used to oversee and control *all* uses of foetal or other human tissue. As Ian Ellis explains, this exception was introduced to the draft Human Tissue Bill to appease the 'serious concerns' raised by 'clinical and medical research bodies' about the strict requirements proposed by the new framework.[204] This thesis has argued that the interests of researchers and of advancing public health should not be prioritised over those of parents, so this concession is not persuasive here and should not apply.

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[202] In a different context, Duxbury indicates the relevance of cost in arguments about governance: 'the potential costs of creating regulations to facilitate the operation of the market - not to mention the risks of regulatory failure - will themselves count against arguments for commercialisation': Neil Duxbury, 'Do Markets Degrade?' (1996) 59(3) MLR 331, 339 and 338-339.

[203] HTA 2004 sections 1(8)-(9).

[204] Ian Ellis, 'Beyond organ retention: the new human tissue bill' (2004) 364 The Lancet 42, 43.

A new approach is needed to facilitate complete oversight by a regulatory authority. A single, consistent and overarching regulatory approach should cover the collection and use of all foetal tissue, ideally as part of the existing licensing scheme operated by the HT Authority. Further research is required to determine whether licences should be obtained in addition to, or instead of, ethical approval for medical research. It is not desirable to place bureaucratic burdens on the research sector by requiring them to obtain multiple sets of approvals. However, it is also not desirable to remove the ethics approval process because ethics committees play an important role in scrutinising the consent procedures of research studies collecting human material. This requires careful consideration but is outside the scope of this thesis.

5.6 Conclusion

Foetal tissue use must be governed by a legal framework that protects two foundational principles: respect for the special liminal status of the deceased foetus and the prioritisation of parental interests. Frameworks based on consent or privacy rights appear unable to completely protect against interferences with foetal tissue by donees and third parties and so cannot uphold these principles. A property law framework can protect against these interferences. By applying the methodology provided by Douglas and Goold, this chapter has demonstrated that property law can and should apply to foetal tissue.[205] Property rights in deceased foetal tissue should vest in the parents once it has been separated from the body of

[205] Douglas and Goold (n 2) 493.

the pregnant person. These rights could potentially be divested through the law of abandonment.

If foetal tissue is donated, such as to medical research, this relationship should be governed by the rules of a gratuitous bailment or a gratuitous wasting bailment. The donee will obtain a property right in the tissue and the parents as bailors will also retain rights. Both bailors and bailees should have access to the property-based remedy of trespass to recover misappropriated foetal tissue. A bailor should be permitted to vary the terms of the bailment or terminate it by modifying or withdrawing their consent, subject to practical limitations.[206] The parents should have access to damages for psychiatric injury through a claim in negligence. Sanctions may also apply to offenders who contravene the provisions under the legislation. Harsher sanctions, such as imprisonment, should apply only in cases of severe or prolific offences. For smaller offences, proportionate sanctions should apply. When sanctions are applied by a court, they should consider whether it is appropriate to apply sanctions to an individual or an organisation. The storage and use of foetal tissue should also continue to be overseen by a regulatory authority. Ideally this should remain within the purview of the HT Authority, provided that the current shortcomings in its oversight are addressed.

[206] The practical limitations of this were discussed in 4.5.1.

Conclusion

This thesis has sought to start a conversation about the governance of deceased foetal bodies and tissue. Unique ethical and legal issues are raised by its use which do not arise for other human tissues, which in turn raise questions about how these should be navigated by a governing framework. These issues have thus far been overlooked by the law and have not received sufficient attention from commentators. The avoidance of this topic is unsurprising in light of the longstanding cultural silence and controversy surrounding abortion, miscarriage, and by extension, the historical governance of foetal tissue. Although this history explains why this topic is avoided, it does not justify it. The current governance of foetal tissue under the Human Tissue Act (HTA) 2004 framework is not fit for purpose and requires reform. To determine how this material should be governed, this thesis has examined the legal and moral status of foetal tissue, conflicting interests in tissue use, and how interests can be protected through the legal mechanism of consent and a legislative framework.

The deceased foetus must be morally and legally distinguished from other human bodies and tissues. The living foetus is a developing human being. It has a unique genetic makeup with the potential to grow into a fully formed person. It occupies a liminal space which morally distinguishes it from other human bodies, including those of the parents. This liminal nature carries over from the living foetus to the deceased body after death. After this point, it is physically separated from the pregnant person and should not be considered the personal tissue of the latter or any other parent. The foetus' liminality prevents us from recognising it as

having either the status of a person during life or as a deceased person after death, in both a legal and moral sense. This nature also disrupts the legal categories that it is placed in under the HTA framework, which classify it differently based on gestational age. Because the foetus grows gradually, it is difficult to morally distinguish the foetus of twenty-four weeks of gestation from the one that existed immediately before it. It is not justified for the law to force the foetus into distinct, fixed classifications based on gestational age which deny its liminal nature. Instead, a single legal status should be adopted that encapsulates all deceased foetuses as unique beings.

The foetus also has a special moral status by virtue of being human, and its body must be treated with respect to prevent the special nature of humans from being eroded. This status must be protected by the law through provisions which prevent it from being used in ways that would undermine this. For example, at no point should it be classified as waste. Although all foetal tissue should be legally distinguished from the personal tissue of the pregnant person, sometimes conception tissue will be mixed up with and donated alongside foetal tissue. Conception tissue is derived from both the foetus and the pregnant person, and this should be acknowledged in its legal classification. It should not be classified as tissue wholly from one or the other. Foetal tissue can take several forms: whole deceased bodies, separated tissue, and tissues that cannot be easily separated from conception tissue. The law must recognise these tissues in a consistent way – within a single legal classification – to avoid undermining the special, liminal nature of the foetus.

Many groups have interests in how foetal tissue is used. For example, foetal bodies may be used in rites around death by parents and other family members

mourning their lost child or relative. This tissue is also a valuable resource utilised in medical research and treatment to further public health interests. Its use in this way produces considerable medical benefits and does not cause harm when parents and researchers are in agreement about its use. All interests should be facilitated by the law where they do not conflict with one another. However, conflicts of interest can arise between these groups over the use of foetal tissue. Under rule-utilitarianism, the law must enact clear provisions to manage these conflicts which must maximise desirable outcomes and minimise undesirable ones. Overall, parents will suffer greater harm if their interests are denied compared to other interest groups. Patients – who seek the use of tissue for personal medical treatment – will not be actively harmed if their interests are denied. Furthermore, the benefits they would obtain from such treatment is unlikely to outweigh the harm caused to parents and, crucially, the balance of these benefits and harms cannot be easily quantified in individual cases. Moreover, other family members lack the close relationship that the parents have with the foetus and so, overall, they will experience a lower level of distress if their interests are overridden. Nonetheless, it would be justifiable to override parental interests in specific circumstances where greater harm would clearly be caused to another group if *their* interests were not upheld. For example, the legal requirement to register a stillbirth should not be extended to apply to foetuses of all gestational ages, because this would infringe on the bodily autonomy rights of pregnant people and those capable of becoming pregnant and would harm wider state and public health interests. Furthermore, the moral and legal status of the foetus must take precedence over all interests. To protect this, limits should be placed on the options that the parents have when deciding how this material is used.

When *parental* interests are in conflict, the law must still uphold the interests of those who would be most harmed overall. Greater harm will be caused to a parent if the foetus is used against their interests for non-natural uses, such as in medical research. Less harm will be caused if a parent is prevented from donating tissue, even if the foetus is used in natural ways (such as for burial or cremation) against their donation interests. If one parent seeks to donate foetal tissue for a non-natural use and another parent objects to this, the law should uphold the parental objection. This should be adopted as a bright line rule without exception. Although this rule would interfere with the donor parent's Article 8 rights under the European Convention on Human Rights, it would be justified within the wide margin of appreciation that is afforded under Article 8(2) because this rule is necessary for the protection of the Article 8 rights of the objecting parent.

However, parental objections should not be upheld when they apply to natural uses of the foetal body, namely its disposal. Parental interests regarding methods of disposal or the use of bodies in religious rites should be upheld as far as is possible. However, they cannot prevent disposal or delay it indefinitely, such as if they fail to arrange for the body's disposal or disagree about the method for this. Their interests in this regard must be overridden by the legal requirement to bury bodies and dispose of human tissue in line with state and public health interests, as well as by the moral and legal obligation to respect the special moral status of the deceased foetus. If an agreement cannot be reached by the parents, the courts should assist them in this endeavour. The court should not direct how the body is disposed of on their behalf but should have the power to determine who will make the final decision.

The law must clarify who is classified as a parent and thus whose interests are parental interests. These legal provisions need only stipulate who is entitled to donate deceased foetal tissue and need not have wider implications for who is classified as a parent in other scenarios. It is therefore not necessary for them to align with existing limitations on how many legally recognised parents a living child can have. All the different types of parents that are recognised under the Human Fertilisation and Embryology Acts 1990 and 2008 – namely social, genetic, and gestational parents – can be harmed if foetal tissue is used against their interests. Thus, their Article 8 rights must be protected. Furthermore, it would not be legally consistent to recognise a person as a parent for the living foetus and future child but to deny this after death. Therefore, the law should recognise all these types of parents as having parental interests in foetal tissue, even if this means that more than two parents are recognised.

Recognising all deceased foetuses under a single legal category reflects both the liminal nature of the foetus and parental interests, which may be varied and variable. Some parents may recognise the foetus as a baby at a very early stage in gestation whereas others may see the foetus as a bunch of cells or may not want to recognise its existence at all. The legal classification of this material should use the neutral term of *foetus* and avoid language that classifies it in distinct ways, such as terms that personify the foetus (like *baby*) or undermine its special moral status (like *bunch of cells*). Nevertheless, different terminology should be used in law and in practice. Researchers and others seeking consent for tissue donation should adopt the terminology that is preferred by each parent. Furthermore, hospitals and funeral providers should improve the methods of disposal that are available for younger foetuses. Where possible, methods available for older stillborn foetuses

should be offered, and parental attendance at funerals should be facilitated. This must be a legal requirement as previous attempts to introduce these rules under non-legal guidelines has proved ineffective.

Parental interests and objections should be protected by a legal requirement for consent. Ideally, a deemed consent model should be adopted because this would avoid the distress that can be caused to parents when they are asked to give explicit consent in the difficult aftermath of pregnancy loss. This model would protect parental objections by allowing them to explicitly opt-out. However, a deemed consent model is only justified if there is sufficient public knowledge about a topic and public opinion is in favour of it. The first criterion is certainly lacking; there is a dearth of public information about foetal tissue use and a lack of social scripts to facilitate discussion of this topic. Education campaigns should be carried out to raise public awareness, after which public opinion should be canvassed to determine if the introduction of this model would be favourable. In the meantime, explicit consent must be sought from parents and information must be given as part of this process. Obtaining explicit informed consent following pregnancy loss can be challenging. To minimise the possibility of causing distress to parents during this process, researchers should seek to obtain realistic, rather than idealistic, informed consent. Moreover, methods of obtaining consent in bereavement contexts should be tested for foetal tissue donation, and consent should be sought at a timepoint that causes the least distress. This might include obtaining consent at an earlier timepoint, such as during pregnancy. The law should also only control the *provision* of information and should not scrutinise what parents choose to do with the information or to what extent they engage with it.

Parents should be permitted to modify or withdraw their consent at any time provided that this remains feasible. For example, consent for tissue use cannot be withdrawn after all the tissue has been used up. Parents should be permitted to donate tissue anonymously, provided that all parents are in agreement about this. If tissue is donated to a biobank or for use in unspecified future research, and it is not anonymised, then ongoing dynamic consent must be required. Consent can only be provided by parents who have the capacity to do so. If a parent temporarily lacks capacity, or it is in flux, they should be given sufficient time to regain this before being approached about giving consent. If capacity is not regained, any interests expressed in an advance directive should be respected. Otherwise, if the best interests of the parent cannot be ascertained, consent should not be given on their behalf. In lieu of their consent, foetal tissue cannot be donated. If a parent has died, their interests should no longer hold any legal weight in decisions about foetal tissue because they cannot be harmed by its use.

A consent requirement alone is not sufficient to protect interests; a comprehensive legal framework must also be implemented to govern the use of foetal tissue. The framework must achieve two fundamental aims: to protect the special liminal status of the deceased foetus and to protect and prioritise parental interests. It must also be capable of protecting against third party interferences with tissue, which cannot be achieved solely by a requirement to obtain consent or under privacy law models. A property law framework can satisfy all these requirements. This thesis has demonstrated that a property law framework can feasibly apply to foetal tissue and can protect the aforementioned aims. Parental interests can be effectively protected if tissue is held on bailment after donation, as the parents as bailors will retain property rights in the tissue. Property law can also

provide effective remedies for the recovery of misappropriated foetal tissue and compensation for psychiatric injury. Sanctions should also be included in this framework in the form of fines, which should primarily apply to organisations rather than individuals. Harsher sanctions under the criminal law, such as imprisonment, should only apply in rare cases for individuals committing offences on a large scale or to a great degree of severity. Finally, the oversight of all foetal tissue use by a regulatory authority should continue, and where possible, this should remain under the purview of the Human Tissue Authority. However, the Authority's current shortcomings, as identified in this thesis, must be addressed.

This thesis has laid the groundwork for the examination of the outstanding issues and questions surrounding the use of foetal tissue. Ultimately, it has argued that this material is distinct from other human tissues and should be governed purposively under bespoke legal provisions and a comprehensive framework that directly responds to the unique ethical and legal issues raised by its use.

Bibliography

– – ‘Body Worlds’ <https://bodyworlds.com/> accessed 14 July 2025

– – ‘Experiments on the Fetus’ (1970) 5707 BMJ 433

– – Human Developmental Biology Resource <https://www.hdbr.org/> accessed 24 July 2025

– – ‘Organ scandal doctors “presumed too much”’ *BBC* (23 September 1999) <http://news.bbc.co.uk/1/hi/health/background_briefings/the_bristol_heart_babies/455738.stm> accessed 26 July 2024

– – ‘The First Year of the Abortion Act,’ (1969) 293(7600) Lancet 867

Alghrani A, *Regulating Assisted Reproductive Technologies* (CUP 2018)

American College of Obstetricians and Gynaecologists, ‘Early Pregnancy Loss’ (Practice Bulletin, No 200, November 2018) <https://www.acog.org/clinical/clinical-guidance/practice-bulletin/articles/2018/11/early-pregnancy-loss> accessed 23 July 2025

Anderson F and others, ‘Attitudes of women to fetal tissue research’ (1994) 20 J Med Ethics 36

Aramesh K, ‘The Ownership of Human Body: An Islamic Perspective’ (2009) 2 J Med Ethics Hist Med 4

Asmussen IH and Ó Cathaoir KE, ‘Making Access to a Population of Bodies in the Name of Autonomy’ (2018) 25(5) EJHL 555

Austin J, ‘Retained organs and tissues: divergence of the law and practical humanity?’ (2002) 8(5) C Risk 185

Austin L and McGuinness S, ‘Reproductive loss and disposal of pregnancy remains’ (2019) 70(1) NILQ 131

– – and others, ‘Effective Communication Following Pregnancy Loss: A Study in England’ (2021) 30 Camb Q Healthc Ethic 175

Baby Loss HC Deb 13 October 2016, vol 615, cols 468-519

Banwell C, ‘Should I have property in my body?’ (1994) 1 UCL Juris Rev 1

Bentham J, *An Introduction to the Principles of Morals and Legislation* (Clarendon Press 1876)

Berkowitz JM, ‘Mummy was a fetus: motherhood and fetal ovarian transplantation’ (1995) 21 J Med Ethics 298

Björkman B and Hansson SO, 'Bodily rights and property rights' (2006) 32 J Med Ethics 209

Blok GA and others, 'Requesting Organ Donation: The Case of Self-Efficacy' (2004) 9 Adv Health Sci Educ 261

Bongso A and Richards M, 'History and perspective of stem cell research' (2004) 18(6) Best Pract Res Clin Ob 827

Bourianoff Bray M, 'Personalizing Personalty: Toward a Property Right in Human Bodies' (1990) 69 Tex L Rev 209

Brazier M, 'Retained Organs: Ethics and Humanity' (2002) 22 Legal Stud 550

– – 'Organ retention and return: problems of consent' (2003) 29 J Med Ethics 30

Bridge M, *Personal Property Law* (4th edn, OUP 2015)

British Museum, 'Human remains' <https://www.britishmuseum.org/our-work/departments/human-remains> accessed 18 July 2025

Brumbaugh J and others, 'Human fetal tissue is critical for biomedical research' (2023) 18 Stem Cell Rep 2300

Burn J and Strachan T, 'Human embryo use in developmental research' (1995) 11 Nat Genet 3

Burtchaell JT, 'University Policy on Experimental Use of Aborted Fetal Tissue' (1988) 10(4) IRB: Ethics & Human Research 7

Campbell AV, *Medicine, Health and Justice: The Problem of Priorities* (Churchill Livingstone 1978)

– – and others, 'Human tissue legislation: listening to the professionals' (2008) 34 J Med Ethics 104

– – and Willis M, 'They stole my baby's soul: narratives of embodiment and loss' (2005) 31 Med Humanit 101

Caulfield T and others, 'Research Ethics Recommendations for Whole-Genome Research: Consensus Statement' (2008) 6(3) PLoS Biology 0430

– – and Robertson GB, 'Xenotransplantation: Consent, Public Health and Charter Issues' (2001) 5 Med L Int 81

Charles E, Scales A, and Brierley J, 'The Potential for Neonatal Organ Donation in a Children's Hospital' (2014) 99(3) Arch Dis Child Fetal Neonatal Ed F225

Cleiren MPHD and Van Zoelen AJ, 'Post-Mortem Organ Donation and Grief: A Study of Consent, Refusal and Well-Being in Bereavement' (2002) 26 Death Stud 837

Council of Europe, 'Chart of signatures and ratifications of Treaty 164' <https://www.coe.int/en/web/conventions/full-list?module=signatures-by-treaty&treatynum=164> accessed 23 July 2025

Courts and Tribunal Judiciary, *Chief Coroner's Guidance No 45 Stillbirth, and Live Birth Following Termination of Pregnancy* (3 February 2023) <https://www.judiciary.uk/guidance-and-resources/chief-coroners-guidance-no-45-stillbirth-and-live-birth-following-termination-of-pregnancy/> accessed 23 July 2024

Dee O, *The Anti-Abortion Campaign in England, 1966-1989* (Routledge 2019)

Department of Health, *Human Bodies, Human Choices: The Law on Human Organs and Tissue in England and Wales: A Consultation Report* (Department of Health, 2002)

Department of Health and Social Care, *The Independent Pregnancy Loss Review - Care and support when baby loss occurs before 24 weeks gestation* (July 2023)

– – 'Baby loss certificate launched to recognise parents' grief' (22 February 2024) <https://www.gov.uk/government/news/baby-loss-certificate-launchedto-recognise-parents-grief> accessed 23 July 2025

Derbyshire S, 'Why I see no place for science in the abortion debate' *Times Higher Educational Supplement* (21 January 2005) <https://www.timeshighereducation.com/news/why-i-see-no-place-for-science-in-the-abortion-debate/193606.article> accessed 29 July 2025

Dickenson D, *Property, women, and politics: subjects or objects?* (Rutgers University Press 1997)

– – *Property in the Body: Feminist Perspectives* (1st edn, CUP 2009)

Dittmar JM and Mitchell PD, 'From cradle to grave via the dissection room: the role of foetal and infant bodies in anatomical education from the late 1700s to early 1900s' (2016) 229 J Anat 713

Dixon-Woods M and others, 'Human Tissue and 'the Public': The Case of Childhood Cancer Tumour Banking' (2008) 3 BioSocieties 57

Douglas S, 'Property Rights in Human Biological Material' in Goold I and others (eds), *Persons, Parts and Property: How Should We Regulate Human Tissue in the 21st Century?* (Hart 2014) 89

– – 'The Argument for Property Rights in Body Parts: Scarcity of Resources' (2014) 40 J Med Ethics 23

– – and Goold I, 'Property in Human Biomaterials: A New Methodology' (2016) 75(3) CLJ 478

Duxbury N, 'Do Markets Degrade?' (1996) 59(3) MLR 331

Dworkin R, *Life's Dominion: An Argument about Abortion and Euthanasia* (Harper Collins 1993)

– – *Taking Rights Seriously* (5th impression, Duckworth 1987)

Elger BS and Caplan AL, 'Consent and Anonymization in Research Involving Biobanks: Differing Terms and Norms Present Serious Barriers to an International Framework' (2006) 7(7) EMBO Reports 661

Ellis I, 'Beyond organ retention: the new human tissue bill' (2004) 364 The Lancet 42

Emson HE, 'It is immoral to require consent for cadaver organ donation' (2003) 29(3) J Med Ethics 125

Endicott T, 'The Impossibility of the Rule of Law' (1999) 19 OJLS 1

Engelhardt HT, 'Viability, abortion, and the difference between a fetus and an infant' (1973) 116(3) Am J Obstet Gynecol 429

English V and Sommerville A, 'Presumed consent for transplantation: a dead issue after Alder Hey?' (2003) 29 J Med Ethics 147

Erin CA and Harris J, 'An ethical market in human organs' (2003) 29 J Med Ethics 137

– – and Ost S, 'An Ill-Suited and Inappropriate Union? Exploring the Relationship Between the Criminal Justice System and Health Care' in Erin C and Ost S (eds), *The Criminal Justice System and Health Care* (OUP 2007) 1

Ernst LM, Gawron L, and Fritsch MK, 'Pathologic Examination of Fetal and Placental Tissue Obtained by Dilation and Evacuation' (2013) 137 Arch Pathol Lab Med 326

Finnerty AM, 'The Privilege of Information – An Examination of the Defence of Therapeutic Privilege and Its Implications for Pregnant Women' (2021) 29(4) Med L Rev 639

Forbe-Smith L, Haire M, and Doneley M, 'Social work practice in the donation of human tissue for transplantation: utilising social work values and competencies to achieve effective outcomes for transplant patients and donor families' (2002) 35(1-2) Soc Work Health Care 377

Franklin S, 'Embryonic Economies: The Double Reproductive Value of Stem Cells' (2006) 1 BioSocieties 71

– – and Jackson E, *The 14 Day Rule and Human Embryo Research: A Sociology of Biological Translation* (Routledge 2024)

Fuller D and others, 'Death Before Birth: Preliminary project findings for meeting with representatives of the Department of Health and Social Care' (24 August 2018) <https://testprojectwebsiteblog.wordpress.com/wp-content/uploads/2019/03/summary-of-project-findings-report-for-dhsc.pdf> accessed 26 July 2025

Furlong A, 'UK forges ahead with studies using foetal tissue' *Research Professional News* (1 November 2019) <www.researchprofessionalnews.com/rr-news-uk-politics-2019-9-uk-forges-ahead-with-studies-using-foetal-tissue/> accessed 14 July 2025

Gelber SE, McCullough LB, and Chervenak FA, 'Fetal tissue research: an ongoing story of professionally responsible success' (2015) 213(6) Obstetrics 819

Gibson R, 'Human Earrings' <https://www.rickgibson.net/o018-earrings.html> accessed 14 July 2025

Gilmour JM, '"Our" Bodies: Property Rights in Human Tissue' (1993) 8(2) Can JL & Society 113

Gimbel VN, 'Fetal Tissue Research & Abortion: Conscription, Commodification, and the Future of Choice' (2017) 40 Harv J L & Gend 229

Goodwin M, *Black Markets: The Supply and Demand of Body Parts* (CUP 2006)

Goold I, 'Abandonment and Human Tissue' in Goold I and others (eds), *Persons, Parts and Property: How Should We Regulate Human Tissue in the 21st Century?* (Hart 2014) 125

– – 'Property or Not Property? The Spectrum of Approaches to Regulating the Use of Human Bodily Material' (2013) 21 JLM 299

– – 'Why does it matter how we regulate the use of human body parts?' (2014) 40(1) J Med Ethics 3

– – and Quigley M, 'Human biomaterials: The Case for a Property Approach' in Goold I and others (eds), *Persons, Parts and Property: How Should We Regulate Human Tissue in the 21st Century?* (Hart 2014) 231

Granados Moreno P and Joly Y, 'Informed Consent in International Normative Texts and Biobanking Policies: Seeking the Boundaries of Broad Consent' (2015) 15(4) Med L Int 216

Greasley K, *Arguments About Abortion* (OUP 2017)

Griffiths J, 'Criminal Law is the Problem, Not the Solution' in Erin C and Ost S (eds), *The Criminal Justice System and Health Care* (OUP 2007) 119

Harmon SHE and Laurie GT, 'Yearworth v North Bristol NHS Trust: Property, Principles, Precedents and Paradigms' (2010) 69(3) CLJ 476

Harris J, 'Law and Regulation of Retained Organs: The Ethical Issues' (2002) 22 Legal Stud 527

– – 'Organ procurement: dead interests, living needs' (2003) 29(3) J Med Ethics 130

Hartlev M, 'Genomic databases and biobanks in Denmark' (2015) 43(4) JL Med & Ethics 743

Health Research Authority, 'HRA publishes new proportionate consent guidance' (updated 9 June 2017) <https://www.hra.nhs.uk/about-us/news-updates/hra-publishes-new-proportionate-consent-guidance/> accessed 24 July 2025

– – 'Step 1: Scoping - What are the data requirements for your project?' (updated 5 December 2022) <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/how-were-supporting-data-driven-technology/accessing-health-and-care-data-research-data-driven-technology-step-step-guide-and-glossary/step-1-scoping-what-are-data-requirements-your-project/> accessed 25 July 2025

– – 'Use of human tissue in research' (updated 1 February 2024) <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/use-tissue-research/> accessed 14 July 2025

– – 'Informing participants and seeking consent' (updated 19 June 2024) <https://www.hra.nhs.uk/planning-and-improving-research/best-practice/informing-participants-and-seeking-consent/> accessed 24 July 2025

Herring J and Chau PL, 'My Body, Your Body, Our Bodies' (2007) 15 Med L Rev 34

Hewer R, 'Vulnerability and the Consenting Subject: Reimagining Informed Consent in Embryo Donation' (2019) 27 Fem Legal Stud 287

Holdsworth WS, *A History of English Law* (4th edn, Vol 7, Methuen 1936)

Hooker B, 'Rule-Utilitarianism and Euthanasia' in LaFollette H (ed), *Ethics in Practice: An Anthology* (4th edn, Wiley Blackwell 2014) 76

Hope J, 'The ultimate transplant!' *Daily Mail* (London, 12 April 1988) 6

Human Fertilisation and Embryology Authority, 'Modernising fertility law' (November 2023) <https://www.hfea.gov.uk/about-us/modernising-the-regulation-of-fertility-treatment-and-research-involving-human-embryos/modernising-fertility-law/> accessed 14 July 2025

Human Tissue Authority, 'Codes of Practice' <https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/codes-practice> accessed 23 July 2025

– – 'Legislation' <https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/legislation> accessed 24 July 2025

– – 'Licences, inspections and fees' <https://www.hta.gov.uk/guidance-professionals/licences-inspections-and-fees> accessed 18 July 2025

– – 'Relevant material under the Human Tissue Act 2004' <https://www.hta.gov.uk/guidance-professionals/hta-legislation/relevant-material-under-human-tissue-act-2004> accessed 18 July 2025

– – 'Who are the HTA?' <https://www.hta.gov.uk/about-the-HTA/who-are-hta> accessed 23 July 2025

– – 'UK conviction for human trafficking organ removal offence' (23 March 2023) <https://www.hta.gov.uk/news/uk-conviction-human-trafficking-organ-removal-offence> accessed 18 July 2025

– – 'What is a HTA licence' (updated 5 November 2024) <https://www.hta.gov.uk/guidance-professionals/licences-inspections-and-fees/licensing/what-hta-licence> accessed 14 July 2025

Iltis AS, 'Organ Donation, Brain Death and the Family: Valid Informed Consent' (2015) 43(2) J Law Med Ethics 369

Institute of Medicine (US) Conference Committee on Fetal Research and Applications, *Fetal Research and Applications: A Conference Summary* (National Academies Press, 1994)

Integrated Research Application System, 'Model Material Transfer Agreement (mMTA)' (updated 12 June 2025) <https://www.myresearchproject.org.uk/help/hlptemplatesfor.aspx#mMTA> accessed 24 July 2025

Ishii T and Eto K, 'Fetal stem cell transplantation: Past, present, and future' (2014) 6(4) World J Stem Cells 404

Jackson E, *Regulating Reproduction* (Hart 2001)

Jones DG and Whitaker MI, *Speaking for the Dead: The Human Body in Biology and Medicine* (2nd edn, Routledge 2009)

Kaczor C, *A Defense of Dignity: Creating Life, Destroying Life, and Protecting the Rights of Conscience* (University of Notre Dame Press, 2013)

– – *The Ethics of Abortion: Women's Rights, Human Life, and the Question of Justice* (3rd edn, Routledge 2023)

Kapoor C, ‘The removal of organs from cadavers: a utilitarian perspective’ (1994) 1 UCL Juris Rev 104

Karpin I, ‘Legislating the Female Body: Reproductive Technology and the Reconstructed Woman’ (1992) 3(1) Colum J Gender & L 325

Katsikis D, ‘A philosophical justification of the individual's proprietary right to sell her body parts’ (2009) 15 UCL Juris Rev 72

Kaye J and others, ‘Biobank Report: United Kingdom’ (2016) 44 JL Med & Ethics 96

Keane H, ‘Foetal personhood and representations of the absent child in pregnancy loss memorialization’ (2009) 10(2) Fem Theor 153

Kemp P, ‘At-Home Early Medical Abortions Made Permanent in England and Wales’ *Oxford Law Blogs: Family & Medical Law Blog* (5 July 2023) <https://blogs.law.ox.ac.uk/family-and-medical-law/blog-post/2023/07/home-early-medical-abortions-made-permanent-england-and> accessed 14 July 2025

Kenny M, ‘You can’t put a ban on babies’ *Daily Mail* (London, 21 July 1984) 6

Kent J, ‘The fetal tissue economy: From the abortion clinic to the stem cell laboratory’ (2008) 67 Soc Sci Med 1747

– – and Pfeffer N, ‘Regulating the collection and use of fetal stem cells’ (2006) 332(7546) BMJ 866

– – Fannin M, and Dowling S, 'Gender dynamics in the donation field: human tissue donation for research, therapy and feeding' (2019) 41(3) Sociol Health Ill 567

Keown J, ‘The Polkinghorne Report on Fetal Research: nice recommendations, shame about the reasoning’ (1993) 19 J Med Ethics 114

Kinney JH, ‘Restricting Donative Choice: Fetal Tissue Transplantation and Respect for Human Life’ (1995) 10 JL & Health 259

Knoppers BM, ‘Biobanking: International Norms’ (2005) 33(1) J Law Med Ethics (2005) 7

Kola F, ‘Torture and terrorism: a case study’ (2007) 13 UCL Juris Rev 85

Kordower JH and others, ‘Neuropathological Evidence of Graft Survival and Striatal Reinnervation after the Transplantation of Fetal Mesencephalic Tissue in a Patient with Parkinson's Disease’ (1995) 332 N Engl J Med 1118

Kuberska K and others, ‘Death Before Birth: Liminal Bodies and Legal Frameworks’ in Dietz C, Travis M, and Thomson M (eds) *A Jurisprudence of the Body* (Palgrave Macmillan 2020) 149

Laurance J, 'New fertility treatment facing ban' *The Times* (Issue 64842, 3 January 1994)

Laurie G, *Genetic Privacy: A Challenge to Medico-Legal Norms* (CUP 2002)

– – and Postan E, 'Rhetoric or Reality: What Is the Legal Status of the Consent Form in Health-related Research?' (2013) 21 Med L Rev 371

Lee E, 'The abortion debate today' in Horsey K and Biggs H (eds), *Human Fertilisation and Embryology: Reproducing Regulation* (Routledge-Cavendish, 2007) 231

Lella JW and Pawluch D, 'Medical students and the cadaver in social and cultural context' in Lock M and Gordon D (eds) *Biomedicine examined* (Kluwer Academic Publishers 1988) 125

Leshern EA, 'Dead Bodies as Quasi-Persons' (2024) 77(4) Vand L Rev 999

Liao SM, 'The embryo rescue case' (2006) 27 Theor Med Bioeth 141

Liddell K and Hall A, 'Beyond Bristol and Alder Hey: The Future Regulation of Human Tissue' (2005) 13 Med L Rev 170

Limb M, 'Organisations voice concerns over plans to disband Human Tissue Authority' (2012) 345 BMJ 7897

Lindström NO and others, 'Conserved and Divergent Features of Human and Mouse Kidney Organogenesis' (2018) 29(3) J Am Soc Nephrol 785

Litchfield M and Kentish S, *Babies for Burning* (Serpentine Press, 1974)

Little M, 'Abortion and the margins of personhood' in Lizza JP (ed), *Potentiality: Metaphysical and Bioethical Dimensions* (Johns Hopkins University Press 2014) 174

Littlewood J, 'From the invisibility of miscarriage to an attribution of life' (1999) 6(2) Anthropol Med 217

López JS and others, 'Bereaved relatives' decision about deceased organ donation: An integrated psycho-social study conducted in Spain' (2018) 205 Soc Sci Med 37

Lord Darzi, *Independent Investigation of the National Health Service in England* (September 2024)

Lyons KS and others, 'Locating and Retaining Research Participants for Follow-up Studies' (2004) 27(1) Res Nurs Health 63

Mahmoud Z and Romanis EC, 'On Gestation and Motherhood' (2023) 31(1) Med Law Rev 109

Mansfield E, 'Utilitarianism and the allocation of NHS medical resources' (1994) UCL Juris Rev 136

Mason JK and Laurie GT, 'Consent or Property? Dealing with the Body and Its Parts in the Shadow of Bristol and Alder Hey' (2001) 64(5) MLR 710

Maynard-Moody S, 'Managing Controversies over Science: The Case of Fetal Research' (1995) 5(1) J-PART 5

McGuinness S and Brazier M, 'Respecting the Living Means Respecting the Dead too' (2008) 28(2) OJLS 297

– – and Kuberska K, 'Death Before Birth: Report to the Human Tissue Authority on disposal of pregnancy remains (less than 24 weeks' gestational stage)' (Spring 2017) <https://deathbeforebirthproject.wordpress.com/research/> accessed 27 July 2025

– – Kuberska K, and Fuller D, 'Pregnancy loss: consistent bereavement care pathways needed' (Policy briefing 47: October 2017) 2 < https://www.bristol.ac.uk/media-library/sites/policybristol/briefings-and-reports-pdfs/2017-briefings--reports-pdfs/PolicyBristol_Briefing_October_2017_Pregnancy_Loss.pdf> accessed 24 July 2025

McLean S*, Independent Review Group on the Retention of Organs at Post-Mortem: Final Report* (Edinburgh: Scottish Executive, November 2001)

Meeker HJ, 'Issues of property, ethics and consent in the transplantation of fetal reproductive tissue' (1994) 9(2) High Tech LJ 185

Merck, 'Stem Cells' <https://www.sigmaaldrich.com/GB/en/products/cell-culture-and-analysis/cell-lines-and-specialty-cell-culture/stem-cells> accessed 18 July 2025

Middlemiss A, 'Pregnancy remains, infant remains, or the corpse of a child? The incoherent governance of the dead foetal body in England' (2021) 26(3) Mortality 299

Miller RB, 'On Transplanting Human Fetal Tissue Presumptive Duties and the Task of Casuistry' (1987) 14(6) J Med Philos 617

Moses LB, 'The Applicability of Property Law in New Contexts: From Cells to Cyberspace' (2008) 30(4) Syd LR 639

Munzer SR, 'The Special Case of Property Rights in Umbilical Cord Blood for Transplantation' (1999) 51(3) Rutgers Law Rev 493

My Body My Life <https://www.mybody-mylife.org/> accessed 26 October 2025

– – ‘Real Stories of Abortion’ < https://www.mybody-mylife.org/post/real-stories-of-abortion-125> accessed 26 October 2025

Myers AJ, Lohr PA, and Pfeffer N, ‘Disposal of fetal tissue following elective abortion what women think’ (2015) 41 J Fam Plann Reprod Health Care 84

Nauert GM and Freeman TB, ‘Low-Pressure Aspiration Abortion for Obtaining Embryonic and Early Gestational Fetal Tissue for Research Purposes’ (1994) 3(2) Cell Transplant 147

Nebel K and Hurka S, ‘Abortion: finding the impossible compromise’ in Knill C, Adam C, and Hurka S (eds), *On the Road to Permissiveness? Change and Convergence of Moral Regulation in Europe* (OUP 2015) 58

Nelkin D and Andrews L, ‘Do the Dead Have Interests - Policy Issues for Research after Life’ (1998) 24 Am JL & Med 261

Nelson A and Romanis EC, ‘The Medicalisation of Childbirth and Access to Homebirth in the UK: COVID-19 and Beyond’ (2021) 29(4) Med L Rev 661

Nelson JS, ‘Developmental and Perinatal Neuropathology’ in Nelson JS, Mena H, and Parisi JE (eds), *Principles and Practice of Neuropathology* (2nd edn, OUP 2003) 24

NHS, ‘Conditions’ <https://www.nhs.uk/conditions/> accessed 24 July 2025

NHS Inform, ‘Miscarriage’ <https://www.nhsinform.scot/illnesses-and-conditions/pregnancy-and-childbirth/miscarriage/> accessed 23 July 2025

NHS Organ Donation, ‘Organ Donation Campaigns’ <https://www.organdonation.nhs.uk/get-involved/organ-donation-campaigns/> accessed 24 July 2025

Nwabueze RN, ‘Regulation of bodily parts: understanding bodily parts as a duplex’ (2019) 15(4) Int JLC 515

O’Gorman SL, ‘Foetal Brain Cell Transplants: A Utilitarian Perspective’ (1996) UCL Juris Rev 84

O’Neill O, ‘Some limits of informed consent’ (2003) 29 J Med Ethics 4

Paterson P, ‘Dilemma of spare-part babies’ *Daily Mail* (London, 5 January 1988) 19

Peel E, *Treitel: The Law of Contract* (15th edn, Sweet & Maxwell 2020)

Peel E and Cain R, ‘‘Silent’ miscarriage and deafening heteronormativity: A British experiential and critical feminist account’ in Earle S, Komaromy C, and Layne L (eds), *Understanding Reproductive Loss: Perspectives on Life, Death and Fertility* (Routledge 2012) 79

Petersen K, 'Abortion: Medicalisation and Legal Gatekeeping' (2000) 7(3) J Law Med 267

Pfeffer N, 'What British women say matters to them about donating an aborted fetus to stem cell research: A focus group study' (2008) 66 Soc Sci Med 2544

– – 'How work reconfigures an 'unwanted' pregnancy into 'the right tool for the job' in stem cell research' (2009) 31(1) Sociol Health Ill 98

– – 'What has happened to the review of the Polkinghorne Guidelines on research using fetal tissue?' *BioNews* (20 April 2009) <https://www.bionews.org.uk/page_91690> accessed 24 July 2025

– – and Kent J, 'Consent to the use of aborted fetuses in stem cell research and therapies' (2006) 1 Clinical Ethics 216

– – and Kent J, 'Framing Women, Framing Fetuses: How Britain Regulates Arrangements for the Collection and Use of Aborted Fetuses in Stem Cell Research and Therapies' (2007) 2 BioSocieties 429

Pickles C and Herring J (eds), *Childbirth, Vulnerability and Law: Exploring Issues of Violence and Control* (Routledge 2019)

Price D, 'The Human Tissue Act 2004' (2005) 68(5) MLR 798

Purshouse C, 'Utilitarianism as tort theory: countering the caricature' (2018) 38 LS 24

Quigley M, *Self-ownership, property rights and the human body* (CUP 2018)

Quinn W, *Morality and Action* (CUP 1994) 20

Radin MJ, 'Market-Inalienability' (1987) 100 Harv L Rev 1849

Radin MJ, 'Property and Personhood' (1982) 34(5) Stanford Law Rev 957

Rao R, 'Property, Privacy, and the Human Body' (2000) 80 BUL Rev 359

Redfern M, *The Royal Liverpool Children's Inquiry Report* (HC 2001, HC12-II, London: The Stationery Office 2001)

Richardson R, *Death, Dissection and the Destitute* (Routledge & Kegan Paul 1987)

Romanis EC and Adkins V, 'Artificial placentas, pregnancy loss and loss-sensitive care' (2023) 50(5) J Med Ethics 299

Roper J, 'Foetus denial by surgeon' *The Times* (London, 21 May 1970)

Rothstein MA, 'Ethical Issues in Big Data Health Research' (2015) 43(2) J Law Med Ethics 425

Rowland L, 'Registration of stillbirth' (Commons Library Research Briefing, 4 February 2025) <https://researchbriefings.files.parliament.uk/documents/SN05595/SN05595.pdf> accessed 23 July 2025

Royal College of Nursing, *Managing the Disposal of Pregnancy Remains: RCN Guidance for Nursing and Midwifery Practice* (5th edn, 2024)

Royal College of Obstetricians and Gynaecologists, *Fetal Awareness Evidence Review* (December 2022) <https://www.rcog.org.uk/media/gdtnncdk/rcog-fetal-awareness-evidence-review-dec-2022.pdf> accessed 12 July 2025

– – and Royal College of Pathologists, *Fetal and Perinatal Pathology: Report of a Joint Working Party* (June 2001)

Sands, 'Bereavement Support' <https://shop.sands.org.uk/en/products/bereavement-support> accessed 23 July 2025

Saunders B, 'Opt-out, mandated choice and informed consent' (2023) 37 Bioethics 862

Schlegel CP, 'Landmark in German Abortion Law: The German 1995 Compromise Compared with English Law' (1997) 11(1) IJLPF 36

Servick K, 'Biden administration scraps human fetal tissue research restrictions' *Science* (16 April 2021) <https://www.science.org/content/article/biden-administration-scraps-human-fetal-tissue-research-restrictions> accessed 14 July 2025

Sheikh AA and Cusack DA, 'Maternal Brain Death, Pregnancy and the Foetus: The Medico-Legal Implications for Ireland' (2004) 23 Med L 237

Singer P, *Animal Liberation* (New edn, Vintage Digital 2015)

Simmonds N and Neoh J, *Central Issues in Jurisprudence* (6th edn, Sweet & Maxwell 2022)

Simms M, 'The great foetus mystery' *New Scientist* (London, 31 December 1970) 592

Skene L, 'Proprietary rights in human bodies, body parts and tissue: regulatory contexts and proposals for new laws' (2002) 22(1) LS 102

– – 'Legal Rights in Human Bodies, Body Parts and Tissue' (2007) 4 Bioethical Inquiry 129

Spencer JR, 'Criminal liability for the desecration of a corpse' (2004) 6 Arch News 7

Steinbock B, *Life Before Birth: The Moral and Legal Status of Embryos and Fetuses* (2nd edn, OUP 2011)

Stephenson NL and others, 'Mitigation of Participant Loss to Follow-Up Using Facebook: All Our Families Longitudinal Pregnancy Cohort' (2019) 21(2) J Med Internet Res 1

Stewart C and others, 'The Problems of Biobanking and the Law of Gifts' in Goold I and others (eds), *Persons, Parts and Property: How Should We Regulate Human Tissue in the 21st Century?* (Hart 2014) 25

Streit S and others, 'Ten Lessons from the Spanish Model of Organ Donation and Transplantation' (2023) 36 Transpl Int 1

Suter SM, 'Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy' (2004) 72 Geo Wash L Rev 737

Takala T, 'Setting a Dangerous Precedent? Ethical Issues in Human Genetic Database Research' (2007) 8 Med L Int 105

The Lancet Respiratory Medicine, 'Fetal tissue research: focus on the science and not the politics' (2019) 7(8) Lancet Resp Med 639

Tooley M, 'Abortion and Infanticide' (1972) 2(1) Philos Public Aff 37

Trueba J and Huppertz B, 'A Snapshot on the Regulatory Activity of the Human Tissue Authority in the United Kingdom Research Sector' (2023) 21(1) Biopreserv Biobank 104

UK Government, 'Abortion statistics, England and Wales: 2021' (updated 24 July 2025) <https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2021/abortion-statistics-england-and-wales-2021> accessed 26 October 2025

– – 'Abortion statistics, England and Wales: 2022' (updated 9 April 2025) <https://www.gov.uk/government/statistics/abortion-statistics-for-england-and-wales-2022/abortion-statistics-england-and-wales-2022> accessed 26 October 2025

– – 'Register a stillbirth' <https://www.gov.uk/register-stillbirth> accessed 23 July 2025

– – 'Request a baby loss certificate' <https://www.gov.uk/request-baby-loss-certificate> accessed 23 July 2025

UK Parliament, 'Employment Rights Bill' <https://bills.parliament.uk/bills/3737> accessed 23 July 2025

University of Oxford, 'Continuing inequalities contribute to wide variation in rates of stillbirths and neonatal deaths across UK' (14 September 2023)

<https://www.ox.ac.uk/news/2023-09-14-continuing-inequalities-contribute-wide-variation-rates-stillbirths-and-neonatal> accessed 23 July 2025

Vanderpool H, 'Critical ethical issues in clinical trials with xenotransplants' (1998) 351 The Lancet 1347

Varelius J, 'Minimally Conscious State and Human Dignity' (2009) 2(1) Neuroethics 35

Venter B, 'A NHS Foundation Trust v MC [2020] EWCOP 33: Revisiting Best Interests and 'Altruistic' Incapacitous Stem Cell Donation' (2021) 29(2) Med L Rev 337

Wadman M, 'The Truth About Fetal Tissue Research' (2015) 528(7581) Nature 178

Wai-loon Ho C and Sheung-hung Kaan T, 'The Notion of Genetic Privacy' in Sheung-hung Kaan T and Wai-loon Ho C (eds), *Genetic Privacy: An Evaluation of the Ethical and Legal Landscape* (Imperial College Press 2013) 125

Walker W and Sque M, 'Family bereavement: A case study of controlled organ donation after circulatory death' (2019) 24 Nurs Crit Care 229

Walpole S, 'Property in human bodily products' (2019) 135 LQR 31

Wang C, 'Genetic Privacy: A Challenge to Genetic Testing in China' in Sheung-hung Kaan T and Wai-loon Ho C (eds), *Genetic Privacy: An Evaluation of the Ethical and Legal Landscape* (Imperial College Press 2013) 125

Warnock M, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (Cmnd 9314, London HMSO 1984)

Warren MA, 'On the moral and legal status of abortion' (1973) 57(1) The Monist 43

West Mercia Police, 'Hospital group fined £100k for illegal storage of human tissue' (23 October 2023) <https://www.westmercia.police.uk/news/west-mercia/news/2023/october/hospital-group-fined-100k-for-illegal-storage-of-human-tissue> accessed 18 July 2025

Wheatley S, 'Human rights and human dignity in the resolution of certain ethical questions in biomedicine' (2001) 3 EHRLR 312

Wilcox AJ and others, 'Incidence of Early Loss of Pregnancy' (1988) 319(4) New Engl J Med 189

Women and Equalities Committee, *Equality at work: Miscarriage and bereavement leave* (2024–25, HC 803)

Woods S and Taylor K, 'Ethical and governance challenges in human fetal tissue research' (2008) 3 Clinical Ethics 14

Wulff B and others, 'Post-mortem tissue donation at the Institute of Legal Medicine in Hamburg: Talking to the next of kin guidelines and first experiences' (2009) 11 Leg Med S141

Zimmern J, 'Consent and Autonomy in the Human Tissue Act 2004' (2007) 18(2) KLJ 313