

# REGULATING MEDICAL DECISION-MAKING:

A QUALITATIVE STUDY OF FETAL REDUCTION IN  
MULTIPLE PREGNANCY

Volume 1

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## **Abstract**

### **Jeffrey Ian Wale - Regulating Medical Decision-Making: A Qualitative Study of Fetal Reduction in Multiple Pregnancy**

This thesis examines and critically evaluates the regulation and practice of medical decision-making where the context is that of a multiple pregnancy and where the question is whether or not to carry out a fetal reduction procedure. Three principal lines of inquiry are pursued: first, to understand more about the nature of fetal reduction, its frequency, and the legal ground(s) for termination on which doctors typically rely; secondly, to assess the extent to which legal, ethical and professional norms guide and constrain this particular kind of decision-making; and, thirdly, to evaluate the adequacy of these norms. We use a critical realist lens to pursue our inquiries and to develop our analysis.

With regard to the first line of inquiry, the evidence suggests that fetal reduction (however defined) is a relatively rare event (fewer than 150 such reductions being undertaken each year) and that, by way of contrast with everyday terminations where the justifying ground is usually descriptively medical, it is fetal abnormality that is often given as the justifying ground.

In relation to the second line of inquiry, analysis shows that the legal, ethical, and professional norms offer little explicit guidance in relation to fetal reduction. In relation to the general question of termination, ethical norms suffer from a high level of contestation and a plurality of views, the key norms in the abortion legislation are both unclear and no longer properly connected to the practice of terminations, and professional norms are only marginally more adequate. Given the indeterminacy of these norms, it is no surprise that the empirical evidence indicates that doctors are only weakly guided by them in making their decisions about fetal reduction. In practice, doctors are guided by the views of their peers and by the sense that, in the final analysis, they will be held accountable and will need to be able to justify their actions.

Responding to the third line of inquiry, a number of recommendations are made. In particular, it is recommended that the fetal abnormality ground is so problematic that it should be removed from the abortion legislation; and that professional and ethical norms, while recognising that there is a legitimate place for professional medical discretion, should emphasise the importance of shared decision-making and patient-centred care.

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This thesis connects with my wider research on the regulation of reproductive healthcare and fertility control. Parts of chapter 1 have been adapted from a paper - "*Selective termination of pregnancy and fetal reduction in multiple pregnancy: terminology, blurred lines and ethical discourse*" - produced in the early stages of the research process.<sup>1</sup>

Finally, I am grateful to Elsevier for granting permission for the reproduction of figures 1 and 2 in the main body of this thesis (see appendix G).

**Jeffrey I. Wale**

**May 2019**

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<sup>1</sup> Jeffrey Wale, 'Selective termination of pregnancy and fetal reduction in multiple pregnancy: terminology, blurred lines and ethical discourse', (2015b), <[https://www.researchgate.net/publication/303882409\\_Selective\\_termination\\_of\\_pregnancy\\_and\\_fetal\\_reduction\\_in\\_multiple\\_pregnancy\\_terminology\\_blurred\\_lines\\_and\\_ethical\\_discourse](https://www.researchgate.net/publication/303882409_Selective_termination_of_pregnancy_and_fetal_reduction_in_multiple_pregnancy_terminology_blurred_lines_and_ethical_discourse)>accessed 20 July 2018.



## **Author's Declaration**

I confirm that this thesis adheres to the Bournemouth University rules and policies applicable to research degrees;

I declare that this thesis is my own work;

I acknowledge the support and advice of my supervisory team in the preparation of this thesis and during the research process.

**Jeffrey I. Wale**

**May 2019**

# Chapter 1 – Introduction

Contents:

- 1.1 Aims and objectives
- 1.2 The dilemma of multiple pregnancy
- 1.3 Definitions and terminology
- 1.4 Research context – some introductory considerations
- 1.5 Contribution to research knowledge
- 1.6 Structure and content of the thesis.

## 1.1 Aims and objectives

This research engages with medical decision-making at the beginning of possible 'human' life in the context of fetal reduction in multiple pregnancy. It explores the issues generated by these procedures, and examines a wide range of frameworks (moral, ethical, legal, professional, and cultural) potentially influencing decision-making, clinical developments and research in this context. This work is exploratory and correlational because it explores the relationship between the ethical, legal and professional norms and the practice of medical decision-making. There are three central research questions:

1. To establish how and why healthcare professionals (specifically Maternal and Fetal Medicine specialists) make decisions (fetal reduction) in response to specific dilemmas (multiple pregnancy).
2. To establish how existing norms and frameworks influence and direct the decision-making and behaviours of these individuals (to establish a connection/relationship between them).
3. To consider how future legal, ethical and professional rules/guidance might be framed, and how future clinical developments/research might be advanced.

At the outset, a research plan was devised which identified the following staged activities:

1. Identify and define the practice of fetal reduction in multiple pregnancy ('fetal reduction') (chapter 1).
2. Identify the legal, regulatory, professional and ethical frameworks around and impacting on fetal reduction (chapters 3-7).

3. Identify existing research, associated regulatory material, gaps in knowledge (chapter 8 and appendices E/F) and contemporary clinical issues relating to fetal reduction (appendix E).
4. Formulate and conceptualise a research design in response to these findings (chapter 2).
5. Construct data collection instruments (appendix A).
6. Identify a sample population for data collection.
7. Undertake a pilot interview. Reframe the data collection instruments as appropriate.
8. Contact potential research participants, complete access formalities and obtain informed consent from active participants.
9. Collect data from the participants using semi structured interviews.
10. Transcribe interviews and code data using thematic analysis and NVivo software (NVIVO 11). Continually adjust stage 9 as appropriate.
11. Write up the data and address research question number 3 in response to the findings for questions 1 and 2 (chapters 9 -10).

Although these matters will be addressed more fully in chapter 2, this research uses qualitative research methodology/ data collection methods to obtain new interview data from Maternal and Fetal Medicine specialists and their representative bodies.

## 1.2 The dilemma of multiple pregnancy

Clinical studies highlight that multiple pregnancy significantly increases the risk of fetal mortality, development issues, prematurity and associated complications.<sup>1</sup> In high order multiples there is a significant risk of whole pregnancy loss; and there are general elevated health risks for pregnant women associated with carrying a multiple pregnancy.<sup>2</sup> There were no reasonably safe methods to reduce many of these risks until the late 1970's/ early 1980's. During this period, clinicians evolved surgical procedures that made it possible to reduce some of the inherent risk by ending the life of one or more embryo/fetus, thereby preserving the pregnancy for the survivors, or at least increasing their chance of survival and a healthy life.<sup>3</sup>

Multiple pregnancy can present a real dilemma for the parents and healthcare professionals involved, and decisions to reduce may be very difficult when set against

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<sup>1</sup> See Table 2A/ appendix E. Multiples currently represent about 3% of all births in England and Wales (TAMBA Press Statement 10 January 2019, < <https://www.tamba.org.uk/document.doc?id=1018> >accessed 12 February 2019).

<sup>2</sup> Jane Denton and Elizabeth Bryan, *Multiple Birth Children & their families following ART, Current practices and conspiracies in assisted reproduction* (WHO Denton & Bryan 2002); Royal College of Obstetricians & Gynaecologists, *Multiple pregnancy: the management of twin and triplet pregnancies in the antenatal period (NICE Clinical Guidance)* (RCOG 2011a).

<sup>3</sup> See the pioneering work of Richard L. Berkowitz and others, 'Selective reduction of multifetal pregnancies in the first trimester', (1988) 318(16) *The New England Journal of Medicine* 1043. Also, Jennifer Kelland and Rosemary Ricciardelli, 'Mothers of Multiple Perspectives on Fetal Reduction and Medical Abortion', (2014) 5(2) *J Motherhood Initiative for Research and Community* 123, 124; R. Katie Morris and Mark D. Kilby, 'Fetal Reduction', (2010) 20(11) *Obs, Gynae & Reprod Med* 341.

a background of fertility treatment and longstanding desire for children. These 'reduction' procedures are far from routine and can involve technical/practical considerations around the 'selection' of the embryo to be 'reduced'.<sup>4</sup> Healthcare professionals need to consider their professional beliefs, training, ethical codes, relevant institutional policies and associated regulatory frameworks before, during and after undertaking these procedures.

### 1.3 Definitions and terminology<sup>5</sup>

Our working definition for fetal reduction is "*the interruption of the development of one or more probably normal fetuses in multiple pregnancy*".<sup>6</sup> Although there is some degree of clinical consensus, inconsistency and confusion still pervades the literature around the terminology and scope of these procedures.<sup>7</sup> Some healthcare professionals conceptualise fetal reduction narrowly as a distinct medical procedure,<sup>8</sup> whilst others take a broader approach conflating fetal reduction with selective termination of pregnancy ('*selective termination*').<sup>9</sup> Selective termination has been defined as a procedure:

*"used to interrupt the development of one of the fetuses affected by a serious and incurable pathology ... [or in the] case of less severe pathologies which could be affecting the fetus, pathologies which could be prejudicial to the development of the healthy fetus or foetuses"*.<sup>10</sup>

The obvious distinction is that fetal reduction involves the termination of ostensibly healthy life, whilst selective termination entails the termination of some form of anomalous life. However, in practical terms, both procedures can involve a choice against a background of overlapping risk to the fetal life or lives to be saved or preserved - a very real consideration in terminations of monochorionic pregnancies involving vascular connection between the fetuses.<sup>11</sup> Both procedures may require

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<sup>4</sup> Alan Cameron, *Fetal medicine for the MRCOG and beyond* (2nd ed, RCOG Press 2011).

<sup>5</sup> This section is developed from a working paper by Jeffrey Wale, 'Selective termination of pregnancy and fetal reduction in multiple pregnancy: terminology, blurred lines and ethical discourse', <[https://www.researchgate.net/publication/303882409\\_Selective\\_termination\\_of\\_pregnancy\\_and\\_fetal\\_reduction\\_in\\_multiple\\_pregnancy\\_terminology\\_blurred\\_lines\\_and\\_ethical\\_discourse](https://www.researchgate.net/publication/303882409_Selective_termination_of_pregnancy_and_fetal_reduction_in_multiple_pregnancy_terminology_blurred_lines_and_ethical_discourse)> accessed 20 July 2018.

<sup>6</sup> Claire-Marie Legendre and others, 'Differences between selective termination of pregnancy and fetal reduction in multiple pregnancy: a narrative review' (2013) (26(6) *Reproductive Bio-Medicine Online (Elsevier Science)* 542, 543.

<sup>7</sup> Ibid.

<sup>8</sup> Ibid.; Royal College of Nursing (RCN), *Termination of Pregnancy: An RCN nursing framework* (RCN 2017). See also <<https://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Ethics/Multifetal-Pregnancy-Reduction>> accessed 1 June 2018.

<sup>9</sup> See for eg, Caroline M. Ogilvie, 'Multiple pregnancy, fetal reduction and selective termination', (2013) 26(6) *Reproductive BioMedicine Online (Elsevier Science)* 52; Morris & Kilby (n3); and Wale (n5).

<sup>10</sup> Legendre (n6), 543 (words in brackets added).

<sup>11</sup> A monochorionic multiple pregnancy has 2 or more embryos sharing a single placenta. See Cameron (n4); Aris Antsaklis and Eleftherios Anastasakis, 'Selective reduction in twins and multiple pregnancies' (2011) 39(1) *Journal of Perinatal Medicine* 15; B R Toneto, *Complications in Monochorionic Pregnancies* (Intechopen 2018), <

consideration of the associated maternal risks, and intervention in high order multiple pregnancies<sup>12</sup> often engages overlapping goals and motivation. Finally, these procedures require active and deliberate steps by a healthcare professional to bring about the end of at least one embryo or fetal life, although it has been claimed that from the woman's perspective these procedures involve an omission because they enable her to:

*“decline the medical technology that would otherwise be required to sustain a pregnancy associated with severe fetal morbidity”.*<sup>13</sup>

This narrative framing presumes a need for technology that is foreseen by the intervening agent as necessary to sustain the ongoing pregnancy, and side steps the active steps necessary to remove the need for technological support. The claim is also predicated on the risk of severe fetal morbidity – a point that is doubtful in most low order multiple pregnancies.

We shall now examine the terminological distinction in a little more detail. First, with selective termination, we have an elected procedure usually requiring informed agreement by the pregnant woman. The prospective parents will probably have no responsibility for the existence of the anomaly, although a conscious decision will need to be made by the treating doctor and the pregnant woman<sup>14</sup> to terminate a specific entity. If the primary goal of the parties is to target the 'affected' fetus, then it necessarily requires a conscious assessment and decision concerning the nature/severity of the anomaly. In Great Britain, the relevant legal ground for termination requires two registered medical practitioners (doctors) to certify in good faith:

*“that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped”.*<sup>15</sup>

Accordingly, when the doctors use this ground, they are primarily responsible for deciding whether the risk/anomaly meets the permissible criteria and they cannot be realistically challenged unless there is evidence of bad faith.

Secondly, there is no doubt that selective termination involves termination of life, although we can debate the nature and value of that life. However, it is plainly arguable that it is specific life, and not the pregnancy that is being terminated. If that

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<https://www.intechopen.com/books/multiple-pregnancy-new-challenges/complications-in-monochorionic-pregnancies>  
>accessed 7 February 2019.

<sup>12</sup> 3+ embryos or fetuses.

<sup>13</sup> Mary B. Mahowald, 'The fewer the better? Ethical issues in multiple gestation'. In: Donna Dickenson (ed), *Ethical issues in Maternal-Fetal Medicine*, (Cambridge University Press 2002), 258.

<sup>14</sup> On the assumption of free and informed patient consent.

<sup>15</sup> As per Abortion Act 1967, s1(1)(d). There may be concurrent grounds under s1(1)(a) up to the 24<sup>th</sup> week of the pregnancy.

view is accepted, '*selective fetal or embryo termination*' may be a better description of the procedure.

Thirdly, the phrase "*interrupt the development*" obscures or avoids the practical reality of what is being undertaken, namely the active termination of embryo or fetal life.<sup>16</sup>

Fourthly, the working definition of selective termination frames the procedure either as the means to prevent the birth of an entity with abnormality/disease or to protect other embryo/fetal life in the multiple pregnancy. Whilst these are distinct ends, they may also be collective aims of the healthcare professionals and pregnant women involved. Our working definition of selective termination does not explicitly identify the prevention of maternal morbidity or mortality as a core aim, but the welfare of the pregnant woman is likely to be a central concern even if serious complications are uncommon and the risk of maternal death is very low<sup>17</sup>

By comparison, Legendre et al. have described fetal reduction as the means to three possible ends: reducing maternal morbidity, lessening fetal mortality and socio-economic indications or ends.<sup>18</sup> First, the fetal reduction label expressly includes the context (multiple pregnancy), whereas that specificity is missing from the selective termination label.

Secondly, it is notable that the terminology for fetal reduction drops the word 'selective'. In no sense does the healthy fetus choose to be terminated, and the term 'select' might be something of a misnomer because it probably overstates the actual choice available to pregnant women in this context.<sup>19</sup> However, Judith Daar would retain the term 'selective' because it accurately reflects "*what is transpiring when a woman elects to undergo the procedure*" in the sense that she chooses to have it.<sup>20</sup> The pregnant woman's involvement in the selection of the targeted life may depend on clinical practice, but if a choice is available, respect for her bodily autonomy dictates that she should be given this option.<sup>21</sup> In any event, the pregnant woman will probably want to improve fetal/ personal outcomes and is unlikely to desire or want to terminate a healthy fetus.

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<sup>16</sup> Mahowald (n13).

<sup>17</sup> Legendre (n6) 547.

<sup>18</sup> Legendre (n6), 546.

<sup>19</sup> Stacey Pinchuk, 'A Difficult Choice in a Different Voice: Multiple Births, Selective Reduction and Abortion', (2000) 7(29) *Duke J Gender L & Policy* 31.

<sup>20</sup> Judith F. Daar, 'Selective reduction of multiple pregnancy: lifeboat ethics in the womb'. (1992) 25(4) *Davis LR* 773, 779-780.

<sup>21</sup> Cf Jane Fisher and others, 'Termination for fetal anomaly: Are women in England given a choice of method?' (2015) 35(2) *Journal of Obs & Gynae* 168.

In terms of the doctor's decision-making, the literature shows that there is a clinical selection based on medical criteria, access and location.<sup>22</sup> However, Patkos argues that "*embryonic reduction is not a selective procedure but a numerical reduction of embryo*",<sup>23</sup> relegating the entity to a problem to be managed. Berkowitz and Lynch claim that selective reduction is:

*"innaccurate and may be psychologically damaging because it implies that specific fetuses have been targeted".<sup>24</sup>*

This framing may be driven by beneficent concern for the women involved, and there is some evidence that clinicians prefer to emphasise the positive rather than the negative aspects of the fetal reduction procedure.<sup>25</sup> Variable moral beliefs and differentiated goals probably underpin these different views and the evident inconsistency around terminology.

Thirdly, an important feature of the fetal reduction label is the explicit focus on 'reduction' rather than on the termination of life. Mahowald argues that the term 'reduction' is misleading or ambiguous<sup>26</sup> because it obscures the fact that the procedure kills at least one entity, and in rare cases, makes it impossible for the others to survive. Similarly, David Price asserts that:

*"Selective reduction/limitation, no matter how justifiable in the circumstances, is nothing more than a euphemism for selective abortion. Linguistic juggling cannot alter the nature of the act."<sup>27</sup>*

Mahowald concludes that the "*simplest, clear and accurate*" terminology is "*fetal termination with pregnancy preservation*".<sup>28</sup> However, this terminology is only appropriate where pregnancy preservation is a necessary condition of fetal reduction, and again this may be contestable in low order multiples.<sup>29</sup> Legendre et al. implicitly acknowledge this when claiming that pregnancy preservation "*is sometimes conditional on the interruption of the development of one or several fetuses*".<sup>30</sup>

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<sup>22</sup> Cameron (n4); Antsaklis et al. (n11).

<sup>23</sup> P, Patkos, 'Embryonic reduction, selective termination' (2003) 3 *Ultrasound Rev. Obstet. Gynecol* 290.

<sup>24</sup> Richard L. Berkowitz and Lauren Lynch, 'Selective reduction: An unfortunate misnomer' (1990) 75(5) *Obstetrics and Gynecology* 873.

<sup>25</sup> Eg, FIGO Committee for the Ethical Aspects of Human Reproduction & Woman's Health, 'Ethical Recommendations on multiple pregnancy and multifetal reduction' (2006) 92 *International Journal of Gynecologists & Obstetricians* 331.

<sup>26</sup> Mahowald (n13), 250.

<sup>27</sup> David P T. Price, 'Selective reduction and feticide: the parameters of abortion' (1988) *Crim L. R.* 199, 206

<sup>28</sup> Mahowald (n13), 251.

<sup>29</sup> See for example, Fanny Kuhn-Beck and others, 'Fetal reduction of triplet pregnancy: One or two?' (2012) 32(2) *Prenatal Diagnosis* 122.

<sup>30</sup> (n6), 548 [emphasis added].

These terminological inconsistencies also pervade the associated legal rules and professional ethical codes. UK law does not formally differentiate between the procedures, although selective termination requires the authorising ground to apply to the target (anomalous) fetus when anomaly is the decisive ground.<sup>31</sup> However, fetal mortality and the risk of fetal mortality, do not provide direct and lawful grounds for termination. The use of ‘intention’ based crimes to regulate these procedures may also contribute to the narrative issue because this mental element encompasses consequences that are foreseen as a virtually certain result of conduct (oblique intention).<sup>32</sup> Consequently, the criminal law may capture conduct where there is a primary goal (the preservation of life) and a foreseeable and virtually certain secondary outcome (death). This jurisdictional approach is combined with a general reluctance to consider the agent’s motive/ desire, and consequently beneficent purposes ought not to shield an individual from criminal liability. However, the courts have tended to show a deferential approach where the key actors are beneficent healthcare professionals, again impacting on the overall coherence of the law in this area.<sup>33</sup>

This thesis does not dispute that differences can be drawn between fetal reduction and selective termination – as to medical indications, context or timing - but the work does claim that there is a substantial overlap in many cases. Indeed, whether these distinctions are regarded as important will turn, to some degree, on the ethical framing of the procedures involved.<sup>34</sup> It is also important that we recognise that healthcare professionals may deploy specific language and labels for technical reasons; out of beneficent concern for their patient;<sup>35</sup> to distinguish these procedures from the polarised abortion debate;<sup>36</sup> or to distract societal attention from what is being done. A good example comes from the FIGO Committee for the Ethical Aspects of Human Reproduction and Woman’s Health:

*“Multifetal reduction is not medically considered as terminating that pregnancy but rather as a procedure to secure its best outcome”.*<sup>37</sup>

This definition explicitly emphasises the ends rather than means and is potentially misleading if you believe that we should always consider the means to our ultimate ends.

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<sup>31</sup> Abortion Act 1967, s 5(2)(a). This Act does not apply to Northern Ireland.

<sup>32</sup> The law in England and Wales as per *R v Nedrick* [1986] 1 WLR 1025.

<sup>33</sup> *Gillick v West Norfolk & Wisbech AHA* [1986] AC 112; Roger Brownsword and Jeffrey Wale, ‘Compromise Medicalisation’ in C. Stanton and others (eds), *Pioneering Health Care Law Essays in honour of the work of Professor Margaret Brazier* (Routledge 2015).

<sup>34</sup> Mark I. Evans and David W. Britt, ‘Multifetal Pregnancy Reduction: Evolution of the Ethical Arguments’ (2010) 28(4) *Seminars in Reproductive Medicine* 295.

<sup>35</sup> Berkowitz and Lynch (n24).

<sup>36</sup> Price (n27), 7.

<sup>37</sup> FIGO (n25), 332.



We make repeat reference to ‘embryo’ and ‘fetal’ life in this thesis. Although these terms denote different periods of gestational development, they have been used interchangeably on occasion. Fetal reduction and selective termination procedures often occur at the fetal stage but that is not always the case. There are different jurisdictional spellings of ‘foetus’ and ‘fetus’ but the latter scientific usage has been adopted for consistency wherever possible. Whilst the term ‘abortion’ has been used in conjunction with ‘termination of pregnancy’, it is recognised that the former carries connotations and conveys possible meaning(s) beyond the immediate descriptor. Similarly, we have tried to avoid references to ‘mother’, ‘baby’ or ‘child’, and instead, used the terms ‘pregnant woman’, ‘embryo/ fetus’ or ‘unborn entity’ wherever possible. Finally, we have used the term, or variants of ‘paternalism’ throughout this work to denote or describe circumstances or behaviours that create or promote medical exceptionalism (ie where special exceptions or rules are made for medical actors/ healthcare professionals).

#### 1.4 Research context – some introductory considerations

In Great Britain, fetal reduction sits within the same basic legal framework as singleton termination – a model complicated by jurisdictional variation and the separate framing of criminal offences and defences. Section 5 of the Abortion Act 1967 (AA 1967) was amended to explicitly address selective termination and fetal reduction in multiple pregnancy<sup>38</sup>. Clinical research and practice on fetal reduction does consider fetal outcome(s), although this specific end is not a ground for termination under the AA 1967. Although it is arguable that all multiple pregnancies involve a greater risk to the pregnant woman than the termination procedure, there is a potential mismatch between medical practice and the legal grounds authorising abortion in this context. Unlike singleton abortions,<sup>39</sup> fetal reduction is necessarily a hospital based surgical procedure typically undertaken in specialist (NHS) tertiary fetal medicine centres. Although procedures vary, in most cases, feticide by thoracic injection is the clinical option employed often in the early second trimester of the pregnancy.<sup>40</sup>

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<sup>38</sup> Human Fertilisation & Embryology Act 1990, s 37.

<sup>39</sup> In 2017, 66% of pregnancy terminations were performed by medical as opposed to surgical methods (Department of Health and Social Care (DHSC), *Abortion Statistics, England and Wales: 2017: Summary information from the abortion notification forms returned to the Chief Medical Officers of England and Wales* (DHSC Revised December 2018)).

<sup>40</sup> Legendre (n6). Morris & Kilby (n3). There are global variations over timing.

Considerations around place, method, timing and authorising ground all feed into the legal foundation for these procedures in Great Britain.

Departmental statistics do not differentiate between fetal reduction and selective termination, and the following references to 'selective termination' encompass both sets of procedure.<sup>41</sup> Although there has been some variation, the overall number of procedures in England and Wales has remained under 150 per annum:

- The numbers of selective terminations increased from around 50 to 82 per annum between 2002-2012,
- Increased to 125 in 2013,
- Increased to 132 in 2014,
- Dropped back to 119 in 2015,
- Increased again to 141 in 2016,
- Before dropping back to 111 in 2017.<sup>42</sup>

The proportions of reductions (eg 3 reduced to 2, 3 reduced to 1 etc) has stayed roughly the same over the years. In 2017 there were 73 cases (where 2 fetuses were reduced to 1), 25 cases (where 3 were reduced to 2), 11 cases (where 3 were reduced to 1) and 2 cases (where 4 or more fetuses were involved). In the same year, 84% of the selective terminations were performed under the anomaly ground (ground E) - a marked divergence from terminations in singleton pregnancies that primarily utilise ground C.<sup>43</sup> This data is important because of the distinctive clinical and ethical considerations that apply to low order reductions of ostensibly healthy embryos or fetuses (see table 2A/ appendix E).

## 1.5 Contribution to research knowledge

The regulation of healthcare professionals and medical decision-making is a rapidly changing and highly topical area. The boundary of human life is under increasing focus with technological and clinical advances in maternal and fetal medicine. These advances have already impacted on the evolution of these medical procedures; and developments have occurred with fairly limited public discourse. The availability of prenatal testing (and genetic testing generally), and our ability to choose when and

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<sup>41</sup> DHSC (n39), paras 2.43-2.45.

<sup>42</sup> Ibid.

<sup>43</sup> Ground E= Abortion Act 1967, s 1(1)(d) and ground C=Abortion Act 1967, s 1(1) (a) but limited to consideration of the pregnant woman.

what type of human life we develop, has ethical and regulatory implications that no society can sensibly ignore.<sup>44</sup> Maternity service frameworks, shared decision-making and person-centred care are also important features of the latest NHS Long Term Plan.<sup>45</sup>

It is important that research concerns and addresses the perspectives of stakeholders in this medical ‘theatre’. Understandably discussion around parental, and specifically maternal autonomy features heavily in the reduction narrative, although parental choices require medical intervention prior to lawful realisation in the UK. Our aim is to analyse existing research involving a range of relevant stakeholders and to capture new perspectives from the healthcare professionals involved directly in these procedures. Although qualitative research has inherent limitations (see chapter 2), this study endeavours to make a novel contribution to the discourse by exploring and establishing relationships between norms, frameworks and medical decisions. This research is undertaken against the shadow of a distinctive, if not unique legal regulatory framework. By engaging with and obtaining new data from the medical participants, we aim to move the discourse and understanding of regulatory impact from the abstract. Ultimately, this research has generated original and illuminating data from specialist participants; evidence of regulation in action; and a platform for informing future research and regulatory sources. This work connects with the author’s wider work on reproductive healthcare and fertility control;<sup>46</sup> contributes directly to the contemporary debate about patient autonomy and the wider practice ramifications of the Supreme Court decision in *Montgomery v Lanarkshire Health Board*.<sup>47</sup> This thesis offers exactly the kind of situational empirical evidence that some commentators have called for in light of *Montgomery*,<sup>48</sup> and which is in short supply in the regulatory context.<sup>49</sup>

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<sup>44</sup> See for eg, Roger Brownsword and Jeff Wale, ‘Testing Times Ahead: Non-Invasive Prenatal Testing and the Kind of Community We Want to Be’, (2018) 81(4) *MLR* 646; Jeffrey Wale, ‘Don’t forget the legal framework: the public provision of non-invasive prenatal testing in England and Wales’ (2015) 15 *Medical Law International* 203.

<sup>45</sup> *The NHS Long Term Plan* (NHS 2019), paras 1.35-1.42 and 3.8-3.15 < <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf> > accessed 9 January 2019.

<sup>46</sup> Brownsword and Wale (n33; n44); Sam Rowlands and Jeffrey Wale, ‘Sterilisations at delivery or after childbirth: addressing continuing abuses in the consent process’, (2019) *Global Public Health* <<https://doi.org/10.1080/17441692.2019.1583265>> accessed 10 May 2019; Jeffrey Wale, ‘Regulating disruptive technology and informational interests in the arena of reproductive tests’, (2019) 3(1) *Journal of Information Rights, Policy and Practice* <<https://jirpp.winchesteruniversitypress.org/articles/abstract/24/>> accessed 10 May 2019.

<sup>47</sup> [2015] UKSC 11.

<sup>48</sup> Michael Dunn and others, ‘Between the Reasonable and the Particular: Deflating Autonomy in the Legal Regulation of Informed Consent to Medical Treatment’, (2019) 27(2) *Health Care Anal.* 110.

<sup>49</sup> Oliver Quick, *A scoping study on the effects of health professional regulation on those regulated: Final report submitted to the Council for Healthcare Regulatory Excellence* (2011), 3 & 22.

## 1.6 Structure and content of the thesis

This thesis is divided into 11 chapters, starting with this introduction which begins to address the first research question. Chapter 2 addresses methodology, rationale, data collection and all matters related to research design. Together chapters 3-6 explore the norms/ frameworks that influence these procedures and starts to address the second research question. Specifically, chapter 3 examines the relevant moral and philosophical ethical frameworks. A large part of this chapter is concerned with the question of the moral status of the embryo/fetus and what this might mean for medical decision-making in our research context. Chapter 4 moves on to consider the relevant UK legal regulatory frameworks, with specific focus on England and Wales. In chapter 5, we examine regulation using the concept of pregnancy and the wider legal framework regulating healthcare providers and professionals. We also introduce some possible reform options that will be developed more fully later in the thesis. Chapter 6 examines general principles of medical ethics, and the role of personal, professional and cultural norms in healthcare delivery. We also consider the role of professional regulation, medical deference and the complexity of medical decision-making in our research context. Chapters 3 and 6 are interconnected and complement one another because they are concerned with the guidance that healthcare professionals might derive from the ethical frameworks and general ethical principles.

We then pick up the first and third (and further develop the second) research questions in chapters 7-10. Chapter 7 frames healthcare professionals as ‘choice architects’ and evaluates possible models, mechanisms and priorities for regulating decision-making in the clinical encounter. We also consider contemporary responses to regulation across the wider healthcare system. Chapter 8 examines existing research studies involving a range of stakeholder perspectives; helps situate our research and provides a platform to identify gaps in knowledge. In chapter 9, we move on to analyse our interview data and to identify emergent themes. In chapter 10, we complete a triangulation exercise before revisiting the research questions and suggesting possible regulatory solutions. Finally, in chapter 11, we make some closing remarks.

## Chapter 2 – Research Design

Contents:

- 2.1 Primary methodology
- 2.2 Ontology
- 2.3 Epistemology
- 2.4 Data collection method
- 2.5 Sampling and research participants
- 2.6 Data coding and analysis
- 2.7 External verification
- 2.8 Steps to enhance quality and trustworthiness
- 2.9 Ethical and practical considerations
- 2.10 Conclusions

This chapter seeks to address and defend all aspects of the research design, including the chosen methodology and data collection methods employed.

### 2.1 Primary methodology

Qualitative and socio-legal research methodologies have been used in this research because they offer the most appropriate strategy for examining how things come about in a context – specifically how medical decision-making occurs within and between the gaps in the regulatory frameworks.<sup>1</sup> This is a correlational study exploring and seeking to establish possible relationships and connections between norms, frameworks and decision-making. The chosen methodology enables the research to address “*the lived experience of those who encounter and subjectively interpret the law*,”<sup>2</sup> and to examine how regulatory arrangements are selectively used or avoided in practice.<sup>3</sup> Importantly,

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<sup>1</sup> For wider discussion of unregulated space, see Samuel Taylor-Alexander and others., ‘Beyond Regulatory Compression: Confronting the Liminal Spaces of Health Research Regulation’ (2016) 8(2) *Law, Innovation and Technology* 149.

<sup>2</sup> Michael Salter and Julie Mason, *Writing Law Dissertations: An Introduction and Guide to the Conduct of Legal Research* (Pearson 2007), 90. See also Oliver Wendell Holmes, ‘The Path of the Law’, (1897) 10 *Harvard Law Review* 457; David Cowan, ‘Legal Consciousness: Some Observations’, (2004) 67(6) *MLR* 929.

<sup>3</sup> Salter and Mason (n2), 125. In the abortion context, see Sally Sheldon and others, ‘The Abortion Act (1967): a biography’ (2019) 39(1) *Legal Studies* 18.

the research seeks to answer questions that cannot be answered by exclusively (black letter) doctrinal legal approaches.<sup>4</sup>

Underlying theory influences the nature of any research,<sup>5</sup> and theoretical assumptions ought to be stated and made transparent whenever possible.<sup>6</sup> In this research, we have used a critical (legal) theoretical lens<sup>7</sup> to analyse and interpret the interview data, the regulatory environments and available literature. Critical legal theory embodies a sub set of socio-legal traditions - including critical legal studies, critical legal realism and feminist theory - although their overarching purpose:

*“is to contest the universal rational foundation of law which, it maintains, clothes the law and legal system with a spurious legitimacy”.*<sup>8</sup>

These theoretical traditions advance several claims, including the assertion that the law is indeterminate, non-autonomous, subjective and reliant on myths.<sup>9</sup> Indeterminacy challenges the view that the law, either as a system or set of binding and enforceable rules, is sufficiently clear and capable of solving every issue. These claims are often misunderstood or overstated, and do not necessarily mean that the law is incapable of having any fixed shared meaning or purpose. Roberto Unger - a key figure in the critical legal studies movement - asserts that the central concern of indeterminacy is the covert, and occasionally self-interested nature by which legal actors share their ways of thinking about the law and society.<sup>10</sup> For our purposes, this concern about shared thinking might also be extended to the workings of the medical profession or to medical teams within a specific healthcare institution. It is also fair to acknowledge that even legal positivists generally accept some scope for the discretionary interpretation of the law because:

*“the will of the state cannot be translated into particular decisions without creating space for the conflict among interests and among visions to reappear in smaller form at the moment of decision”.*<sup>11</sup>

Claims that the law is non-autonomous highlight the influence and constraints imposed by socio-political, cultural and institutional factors in legal reasoning and outcomes. It is important to consider the operation of these constraints on individual autonomy/

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<sup>4</sup> Mandy Burton 'Doing empirical research. Exploring the decision-making of magistrates and juries', chp 3 in Dawn Watkins and Mandy Burton, *Research Methods in Law* (2nd ed, Routledge 2017); Michael McConville and Wing Hong Chui, *Research Methods in Law* (2<sup>nd</sup> ed, Edinburgh University Press 2017).

<sup>5</sup> Burton (n4).

<sup>6</sup> Salter and Mason (n2),179.

<sup>7</sup> See for eg, Ian Ward, *Introduction to Critical Legal Theory* (2<sup>nd</sup> ed, Routledge Cavendish 2004); Roberto M. Unger, *The Critical Legal Studies Movement* (Verso 2015); William Ewald, 'Unger's Philosophy: A Critical Legal Study' (1988). *Faculty Scholarship (Penn Law)*. Paper 1284 < [http://scholarship.law.upenn.edu/faculty\\_scholarship/1284](http://scholarship.law.upenn.edu/faculty_scholarship/1284) >accessed 3 October 2018.

<sup>8</sup> Raymond Wacks, *Philosophy of Law* (2nd ed, Oxford University Press 2014),107.

<sup>9</sup> Ibid.,108; Ewald (n7), 668-669.

<sup>10</sup> Unger (n7) 26-28;73-75.

<sup>11</sup> Ibid., 57.

liberty, especially when individual human agency is emphasised, and consequently, legal realists are keen to emphasise the “*operation of law in its social context*”.<sup>12</sup> The interaction between legal and other regulatory mechanisms and professional/ institutional culture is especially important in the healthcare context.<sup>13</sup>

The claim that the law is subjective - rather than objective - is self-explanatory and builds upon the belief that you cannot unravel and disconnect political, cultural and social considerations from the interpretative process.<sup>14</sup> Further, any claim that social norms - even in areas of consensus - are necessarily the sole product of the law or legal system can be challenged on the basis that social action is heavily influenced by matters external to the law. It is claimed that the use of myths – most notably the idea that the law is an “idealised” and coherent system<sup>15</sup> – aims to reinforce the power of legal actors in the system.

Not all of these ideas are especially controversial – certainly legal realism has long formed part of modern legal jurisprudence:

*“The idea that law is malleable, a human creation, an instrument for serving social ends has been a central tenet of [American] legal thought for generations. It is not news.”*<sup>16</sup>

However, there is a destructive quality to some of these claims when taken to extremes;<sup>17</sup> and we acknowledge that the law/ legal system does have a legitimate role to play in society. We believe that our chosen methodology offers a suitable vehicle for examining the regulatory environment/ frameworks, because of the power imbalance between key stakeholders, the importance of culture in healthcare and the wider use of critical theory in our research. Our theoretical perspective is otherwise aligned with the central subject matter (termination of pregnancy) in which societal, cultural and professional contexts have proved so important to the regulatory environment and stakeholder experience.<sup>18</sup>

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<sup>12</sup> Wacks (n8), 109.

<sup>13</sup> The Francis Report - *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (HC 947, 2013); Roger Cotterrell, ‘Theory and Values in Socio-legal Studies’, (2017) 44(1) *Brit J Law & Soc* S19-36;

<sup>14</sup> Unger (n7), chp 4. See also Sheldon et al. (n3), in the context of abortion.

<sup>15</sup> *Ibid.*, 97.

<sup>16</sup> Ewald (n7), 670. (emphasis added)

<sup>17</sup> Unger(n7); Ewald (n7), 671/730.

<sup>18</sup> Sheldon et al. (n3); Cotterrell (n13); Roger Brownsword and Jeffrey Wale, ‘Compromise Medicalisation’, in C. Stanton and others (eds), *Pioneering Health Care Law Essays: In honour of the work of Professor Margaret Brazier* (Routledge 2015).

As a footnote, we rejected the use of ground up theoretical approaches because the advance evaluation of sources was considered a valuable preparatory step in light of the 'elite' nature of the participants in this research.<sup>19</sup>

## 2.2 Ontology

In using a critical theoretical lens,<sup>20</sup> we accept the existence of an independent reality, albeit one shaped by social, political and cultural values ("*critical realism*"<sup>21</sup>). We explore the importance of culture and social/professional values in healthcare; and critical theory fits with our overall aims of seeking insights, critiquing frameworks/norms, transformation and ethical revelation.<sup>22</sup> Critical theorists are concerned with equity, justice, construction of knowledge and the organisation of power at a macro, meso and micro level;<sup>23</sup> offering an appropriate lens for challenging settled norms and master narratives,<sup>24</sup> with a view to illuminating:

*"the relationship between [these] public and private discourses and the gaps between what people say and what they in fact do".<sup>25</sup>*

This theoretical lens should address any divergence between regulatory norms and practice, is unbound to any single methodological approach and suitable for a qualitative research study.<sup>26</sup>

We evaluated the possible use of a 'professional' theoretical lens due to the nature and status of the participants in this research. Whilst there are various articulations of 'professionalisation' theory, the contemporary focus in medicine has been on the power of clinicians, their organising bodies and their interactions with key stakeholders.<sup>27</sup> Two specific aspects of professional power have been identified - the ability of a profession to control their own work activities (at a macro/micro level<sup>28</sup>) and the ability to control

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<sup>19</sup> Virginia Braun and Victoria Clarke, *Successful Qualitative Research: A Practical Guide for Beginners* (Sage 2013), 89.

<sup>20</sup> Critical theory has its roots in the Frankfurt School and was later developed by Michael Foucault and others (Stephen Bronner, *Critical Theory: A Very Short Introduction* (1<sup>st</sup> ed, OUP 2011)).

<sup>21</sup> Braun & Clarke (n19), 26-27.

<sup>22</sup> For the importance of culture/ values to regulation and socio-legal investigation, see Cotterrell (n13).

<sup>23</sup> R, Barbour, *Introducing Qualitative Research* (Sage 2008); S. Reeves and others, 'Qualitative Research – Why use theories in qualitative research?' (2008) 337 *BMJ*, <<https://doi.org/10.1136/bmj.a949>> accessed 9 May 2019.; Bronner (n20).

<sup>24</sup> Bronner (n20) 90/107.

<sup>25</sup> Karen F. Keenan, Edwin Van Teijlingen and Emma Pitchforth, 'The analysis of qualitative research data in family planning and reproductive healthcare', (2004) 31 *J Fam Plan Reprod Health Care* 40, 42.

<sup>26</sup> Reeves et al. (n23).

<sup>27</sup> Patrick B. Forsyth and Thomas J. Daniesiewicz, 'Toward a Theory of Professionalisation', (1985) 12(1) *Work & Occupations* 59, 60. See also the seminal work of Eliot Friedson, *Profession of Medicine* (Harper & Row 1970); Eliot Friedson, *Professional Dominance* (Atherton Press Inc 1970).

<sup>28</sup> Oliver Quick, *Regulating Patient Safety. The End of Professional Dominance?* (Cambridge University Press 2017), 12.



the work of others.<sup>29</sup> Whilst control is important, trust is also required for professionalism to flourish,<sup>30</sup> an aspect that has proved especially challenging for the medical profession in the wake of recent scandals.

The view of the medical profession as all powerful and dominant, has been attacked by the 'de-professionalisation' thesis, which maintains that there has been a substantive decline in medical professional power and deference to the medical profession, partly because of increasing patient expectation, knowledge and choice; and partly due to the fractured and institutional delivery of public healthcare and the increasing focus on structural and systemic failures.<sup>31</sup> Oliver Quick claims that the rise of managerialism in healthcare has led to internal and regulatory reforms that may have eroded the professional dominance of the medical profession.<sup>32</sup> Again, scandal and increased public scrutiny of the medical profession have probably played a part in the erository process.<sup>33</sup> Further, the impact of de-professionalisation may have been experienced by the medical profession in a fractured manner - with the retention of significant control over training and the right to practice, combined with the cessation of power over the evaluation and surveillance of actual clinical practice<sup>34</sup>. One response has been the development of medical specialisation(s) as a means to preserve power and control over others.<sup>35</sup> In this research, we are concerned with Maternal and Fetal Medicine which is a subspecialty of Obstetrics and Gynaecology. These subspecialisms can have an exclusionary affect within a sphere of practice, although there may also be consequential benefits and gains for patient safety due to increased clinical knowledge, skills and experience.

On reflection, professionalisation theory has been used to inform, but not as the sole theoretical lens in this research.

### 2.3 Epistemology

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<sup>29</sup> Janine Morgall Traulsen and Paul Bissell, 'Theories of professions and the pharmacist', (2004) 12 *IJPP* 107, 108

<sup>30</sup> Quick (n28), 11.

<sup>31</sup> Marie R. Haug 'De-professionalisation: an alternative hypothesis for the future', (1993) 20 *Socio Rev Monograph* 195. See also Royal College of Physicians, *Doctors in Society – Medical professionalism in a changing world – Report of a working party* (2015); Royal College of Physicians, *Future Physician Changing doctors in changing times* (RCP 2010); Quick (n28), 24-28; Karen Yeung and Mary Dixon-Woods, 'Design-based regulation and patient safety: A regulatory studies perspective' (2010) 71 *Social Science & Medicine* 502.

<sup>32</sup> Quick (n28), 19-21.

<sup>33</sup> Quick (n28), 21-24.

<sup>34</sup> Quick (n28); Haug (n31). See also Sarah Devaney, 'The Transmutation of Deference in Medicine: An Ethico-Legal Perspective', (2018) 26(2) *Med L. Rev* 202.

<sup>35</sup> Haug (n31). For a discussion of the stratification of the medical profession in the context of abortion services, see Ellie Lee, Sally Sheldon Sheldon and Jan Macvarish, 'The 1967 Abortion Act fifty years on: Abortion, medical authority and the law revisited.' (2018) 212 *Social Science and Medicine* 26, <<https://doi.org/10.1016/j.socscimed.2018.07.010>> accessed 18 May 2019; Sheelagh McGuinness and Michael Thomson, 'Medicine and Abortion Law: Complicating the Reforming Profession', (2015) 23(2) *Med L. Rev* 177.

This research acknowledges the subjective nature of knowledge and the value-laden findings of the interview process.<sup>36</sup> This theoretical approach is consistent with the central subject matter (decision-making) and the determination of how things come about in a social, cultural and political context. It is consonant with critical legal theory and is an important differentiating approach given the positivist and outwardly objective traditions of much legal scholarship. There is explicit recognition that regulatory frameworks cannot exist in isolation, and have to operate in a social, cultural and political context. The aim of this research is to ensure that the structures, institutions and relationships of power are reconsidered unobscured by the outwardly objective guise of law and regulation.<sup>37</sup> This is important where the power dynamic between key stakeholders – including relationships between healthcare professionals and patients, and between interviewer and interviewee<sup>38</sup> - is sensitive and subject to modification over time.

## 2.4 Data collection method

New data has been collected using semi-structured interviews, enabling the capture of information that is relevant to both participants and interviewer. An interview framework facilitated the collation of core data (appendix A) but participants were not provided any questions in advance, and the actual structure of questioning was influenced by the responses during the interview process. Each interview helped shaped the next, and emerging thematic patterns influenced the form and structure of subsequent questioning. However, all participants were given the liberty to expand upon or explore any area of choice.

Face-to-face interviews were the default option although other options were available, and one SKYPE interview was undertaken in the research.<sup>39</sup> The informed consent of participants was managed through advance information sheets and agreement forms (appendix A), and these documents were circulated by letter to all participants in advance of the interview. The consent process was addressed at the beginning of each interview and no incentives were offered to participants. Anonymity was

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<sup>36</sup> Svend Brinkmann and Steinar Kvale, *Interviews: Learning the Craft of Qualitative Research Interviewing* (3rd Ed, Sage 2014). 106-122.

<sup>37</sup> For discussion, see Unger (n7).

<sup>38</sup> Braun & Clarke (n19), 88-89.

<sup>39</sup> For Skype as a data collection method, see: Paul Hanna, 'Using internet technologies (such as Skype) as a research medium: A research note', (2012) 12(2) *Qualitative Research* 239; Hannah Deakin and Kelly Wakefield, 'Skype Interviewing: reflections of two PHD researchers', (2014) 14(5) *Qualitative Research* 603.

promised to the subspeciality population subject to the usual requirements of the law and the terms of the participant agreement. The pool of possible participants was small, and so particular care has been taken to redact any identifying data. For that reason, geographical location and gender identity have not been disclosed, although effort was made to secure geographical representation from across England and Wales. Anonymity could not be guaranteed to the membership/ representative participants - due to limited population size – and this was made clear before and at interview.

The interview data was captured by protected digital audio media and using written field notes. Ethnography was ruled out for practical access reasons, and because the observation of participants was considered unlikely to yield sufficiently useful data in relation to decision-making.<sup>40</sup> We did consider using focus groups, but this method of data collection was not pursued given the practice context, and the practical difficulties of organising large groupings of volunteer participants.

In terms of the existing literature and research data, we concentrated on legal, medical and ethical sources. As a starting point, we undertook a range of key word searches across the Bournemouth University Library E-Resource database (EBSCO). Our key words included 'regulation', 'medical decision-making', 'fetal reduction', 'selective termination', 'multiple pregnancy', 'abortion', 'professional medical ethics' and 'healthcare regulation'. Our legal searches included the main law databases including Westlaw, LexisNexis and Lawtel. We carried out additional searches using a wide range of medical and sociological databases including Scopus, Science Direct, Web of Science, PubMed and Soc Index. In addition, we set up automated default key word searches against the main obstetric, human reproduction, fetal medicine and medical law journals and more general databases including Google Scholar. The findings from these automated searches were filtered and sorted on a regular basis, initially by abstract review and followed by whole paper reviews where warranted. In addition, we undertook regular online searches against the websites operated by the primary representative bodies and related journals (BMJ, Journal of Medical Ethics). This search method enabled us to collate a wide range of relevant literature/ data and facilitated the early collation of specialist clinical publications relating to fetal reduction. Although we did not exclude material related to medical and regulatory practices outside the UK, we prioritised inclusion to relevant domestic sources. Relevant sources are identified and analysed in chapters 3-8 and appendices E and F. For

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<sup>40</sup> It also unnecessarily complicates access to participants in this research.

completeness, we also undertook additional keyword searches relating to research methodology and data collection methods.

## 2.5 Sampling and research participants

Careful consideration was given to the appropriate research perspective given the involvement of multiple stakeholders, including healthcare professionals, parents and their proxies. A pilot interview was undertaken with an Obstetric Consultant and this enabled the researcher to gain a better understanding of the operation of Maternal and Fetal Medicine within the UK. However, no specific data from this interview has been used in this thesis.

As indicated, Maternal and Fetal Medicine subspecialists<sup>41</sup> were identified as the primary research participants. The majority undertake medical roles within tertiary NHS Fetal Medicine centres operating predominantly in large urban centres within the UK. There are also a few fetal medicine service providers operating in the independent sector across the UK.<sup>42</sup> There are relatively few doctors qualified in this subspecialism, and national statistics reveal that less than 150 multi fetal reduction/ selective termination procedures are recorded each year within England and Wales.<sup>43</sup> Due to the discordant legal frameworks operating across the UK, a decision was made to restrict the subspeciality population to those currently practising within England and Wales. Officers from relevant professional membership/ representative bodies were also identified as an additional sample population. All participants from this sub group were qualified Obstetricians or Gynaecologists within England and Wales. Accordingly, this research was undertaken using a very small and specialist sample population.

Possible participants were identified from information in the public domain, including membership details from the British Maternal & Fetal Medicine Society (BMFMS) and the Royal College of Obstetricians & Gynaecologists (RCOG). All participants were recruited using a targeted written approach and a staggered regional recruitment strategy. Positive responses were followed up by telephone and/or email as appropriate; and all participant interviews were undertaken by the researcher between

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<sup>41</sup> A subspeciality of Obstetrics & Gynaecology.

<sup>42</sup> Eg Fetal Medicine Centre, <<https://fetalmedicine.com/>> accessed 5 November 2018.

<sup>43</sup> Department of Health and Social Care (DHSC), *Abortion Statistics, England and Wales: 2017 Summary information from the abortion notification forms returned to the Chief Medical Officers of England and Wales* (DHSC Revised December 2018).

2017 and 2018 (see appendix B). Overall 6 participants were interviewed for this study and this appears appropriate given the limited size of the sample population and the specific context of this research.<sup>44</sup> There was early evidence of data saturation and the interview participants claim to have past/ current involvement in a notable proportion of the termination procedures undertaken on an annual basis (see chapter 9 – frequency). It is clear that the interviews have yielded data not otherwise available and were intended to supplement existing data from a range of stakeholders (see chapter 8). These further points reinforce the belief that the interviews have yielded a sufficient platform for the research.<sup>45</sup>

It is acknowledged that the research interviews were intended to yield a healthcare professional perspective. This is not a unique approach - there are a wide range of quality single perspective/ stakeholder research studies relating to abortion,<sup>46</sup> maternity care<sup>47</sup> and healthcare.<sup>48</sup> Single or selective stakeholder perspectives in a multi stakeholder scenario are not automatically partisan, subjective or uncritical. What is important is that mechanisms are deployed, wherever possible to enhance the trustworthiness of the research,<sup>49</sup> which are consistent with the aims, purposes and theories being used.<sup>50</sup> New interview data from parents (or their proxies<sup>51</sup>) seemed unlikely to yield or validate answers to the first two research questions, and were more likely to tell us what was communicated in fact specific scenarios, rather than provide information about the underlying rationale. Although parental perspectives are relevant to the third research question, the legality of fetal reduction ultimately rests on the operation of the medical exception for proper medical treatment,<sup>52</sup> and clinical/ technological advances are largely in the gift of the healthcare professionals concerned.

Against this backdrop, it was decided that the ex-ante and ex post perspectives of parental stakeholders would be addressed through the use of existing research data,

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<sup>44</sup> Braun and Clarke (n19),50. Cf also Oliver Quick, *A scoping study on the effects of health professional regulation on those regulated: Final report submitted to the Council for Healthcare Regulatory Excellence* (2011), 7-12, <[https://www.professionalstandards.org.uk/docs/default-source/publications/research-paper/study-on-the-effects-of-health-professional-regulation-on-those-regulated-2011.pdf?sfvrsn=77c47f20\\_6](https://www.professionalstandards.org.uk/docs/default-source/publications/research-paper/study-on-the-effects-of-health-professional-regulation-on-those-regulated-2011.pdf?sfvrsn=77c47f20_6)>accessed 20 July 2018.

<sup>45</sup> Braun & Clarke (n19), 55.

<sup>46</sup> See appendix E and chapter 8.

<sup>47</sup> Carrie H. Jacobson and others, 'Nurses' Perspectives on the Intersection of Safety and Informed Decision Making in Maternity Care', (2013) 42 (5) *JOGNN* 577.

<sup>48</sup> Oliver P. Thomson and others, 'Qualitative Research: Exploring the Multiple Perspectives of Osteopathy', (2011) 14(3) *Int J Osteopathic Medicine* 116, 120

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

<sup>50</sup> Hope Pius Nudzor, 'A Critical Commentary on Combined Methods Approach to Researching Education & Social Issues', (2009) 19(2) *Issues in Educational Research* 114.

<sup>51</sup> Paternal, maternal and proxy perspectives may not be aligned as evidenced in *Paton v Trustees of BPAS* [1979] QB 276 and *C v S* [1988] QB 131.

<sup>52</sup> Mary Neal, 'Locating lawful abortion on the spectrum of "proper medical treatment"', in Sara Fovargue & Alexander Mullock (eds), *The legitimacy of Medical Treatment: What role for the medical exception?* (1<sup>st</sup> ed, Routledge 2015)

including material involving singleton terminations of pregnancy.<sup>53</sup> This material is reasonably current, and in some cases, uses similar qualitative methods and methodology. Although most of this research relates to pregnant women, we have included broader parental data where available. Existing research data addresses a range of issues including the decision-making difficulty for those contemplating fetal reduction;<sup>54</sup> the available choices presented by clinicians;<sup>55</sup> and the attitudes displayed by healthcare professionals to patients.<sup>56</sup>

## 2.6 Data coding and analysis

A thematic analytical approach was employed because it aligns with the selected ontology, data collection method and the wider aims of this research.<sup>57</sup> It is an appropriate analytical method for “*identifying themes and patterns of meaning across a dataset in relation to a research question*”,<sup>58</sup> and has been utilised by other researchers in the field.<sup>59</sup> The chosen method facilitates an interpretation of the broader meaning embedded in participant responses.<sup>60</sup> Discourse analysis was considered as an alternative, but this method did not fit as neatly with the chosen ontological approach and primary research aims.

The Braun and Clarke staged approach to thematic analysis was used:<sup>61</sup>

1. Transcription of interviews;
2. Reading and familiarisation of the interview transcripts;
3. Coding of the data;

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<sup>53</sup> See chapter 8.

<sup>54</sup> David W. Britt and Mark I. Evans, ‘Sometimes doing the right thing sucks: Frame combinations and multi-fetal pregnancy reduction decision difficulty’, (2007) 65 *Social Science & Medicine* 2342.

<sup>55</sup> Jane Fisher and others, ‘Termination for fetal anomaly: Are women in England given a choice of method?’ (2015) 35(2) *Journal of Obs & Gynae* 168

<sup>56</sup> Edna Astbury-Ward, Odette Parry and Ros Carnwell, ‘Stigma, Abortion, and Disclosure – Findings from a Qualitative Study’, (2012) 9 *IJ Sex Med* 3137.

<sup>57</sup> Braun and Clarke (n19), 27/46; Marie Crowe, Maree Inder and Richard Parker, ‘Conducting qualitative research in mental health: Thematic and Content analyses’, (2015) 49(7) *ANZJP* 616; Mojtaba Vaismoradi, Hannele Turunen and Terese Bondas, ‘Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study’, (2013) 15(3) *Nurs Health Sci* 398.

<sup>58</sup> Braun & Clarke (n19), 175.

<sup>59</sup> Helen Statham, Wendy Solomou and Jasper B. Green, J, ‘Late termination of pregnancy: law, policy and decision making in four English fetal medicine units’, (2006) 113(12) *BJOG: An International Journal of Obstetrics and Gynaecology* 1402; Ruth H. Graham and others, ‘The role of feticide in the context of late termination of pregnancy: a qualitative study of health professionals’ and parents’ views’, (2009) 29 *Prenat Diagn* 875; Katie Gallagher, Davina Porock and Alison Edgley, ‘The concept of nursing in the abortion services’, (2010) 66 *Journal of Advanced Nursing* 849.

<sup>60</sup> Crowe et al. (n57).

<sup>61</sup> (n19), 202-203.

4. Searching for themes;
5. Reviewing themes;
6. Defining and naming themes;
7. Writing the data report and relating back to the research questions.

It is important to appreciate that this is not a completely linear process – it is necessary to cycle through the stages as points and themes arise, and all stages involve ongoing analysis of the data.<sup>62</sup>

Interview transcripts were prepared from the audio recordings. This process was undertaken over a concentrated period and assisted the process of transcription, coding, searching for themes and subsequent analysis. The transcription process involved at least two complete passes over the audio recordings – on each occasion the audio recording was paused regularly to facilitate the accuracy of the typed transcript. During the transcription process, obvious identifying information was removed for anonymity purposes. All participants were allocated a letter in place of their name and their real names are known only to the researcher. Although there are different views about the use of pseudonymisation, it was not felt necessary to humanise the participants using replacement names or titles on this occasion.<sup>63</sup>

The transcripts were read and then re-read to enhance familiarity. ‘Codes’ (called ‘nodes’ within NVivo 11) were identified and selected from the interview transcripts, and this process was undertaken using NVIVO 11 Pro software<sup>64</sup>. Codes are simply sections, sentences, phrases or words from the interview data that were considered relevant and useful to answering or capturing the essence of the research questions. The codes were organised and grouped in a thematic way. At the beginning these themes were selected in a deductive way using existing knowledge of theory and their apparent importance to the research questions, and expanded inductively from interpretation of the data.<sup>65</sup> This approach is consistent with the first cycle coding method described by Saldana as “*Themeing the Data*”.<sup>66</sup> These initial themes were fairly broad and did not attempt to segment positive or negative responses. The coding process and search for themes was further refined, and the transcripts were reviewed on several further occasions to develop and maintain a consistent but inclusionary

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<sup>62</sup> Braun and Clarke (n19), 218; Johnny Saldana, *An Introduction to Codes and Coding* (3rd ed, Sage 2016), 9-14.

<sup>63</sup> Braun & Clarke (n19), 251.

<sup>64</sup> For an overview of the software, see QSR International, NVIVO<<http://www.qsrinternational.com/product>>accessed 22 March 2017. Version 11 was used in this research. See also Surrey University, NVIVO 11 Distinguishing Features, <[https://www.surrey.ac.uk/sites/default/files/NVivo11\\_distinguishingfeatures\\_Mar2016-FINAL.pdf](https://www.surrey.ac.uk/sites/default/files/NVivo11_distinguishingfeatures_Mar2016-FINAL.pdf)>accessed 23 May 2018.

<sup>65</sup> Saldana (n62), 204.

<sup>66</sup> Saldana (n62), 198-206.

approach. Each thematic group was actively reviewed to examine coverage and selection across participants looking for areas of similarity and difference. If a participant was missing thematic coverage, the transcript was re-examined to consider whether there was a case for inclusion or exclusion. Word cluster and frequency analysis was undertaken within NVivo to further refine the thematic groupings (see appendix B). This process of review (stage 5) acted as a form of quality review and refinement,<sup>67</sup> and enabled the researcher to look for broader patterns including connections and relationships. Some thematic groups contained few concepts, ideas or elements, whilst others were much broader and therefore justified the introduction of sub themes. An attempt was then made to define the selective themes – narrowing the definition to a few sentences. Where this was not possible, or where the definition was too vague, that thematic grouping was revisited and modified appropriately. These thematic definitions can be found at appendix C (Table 1A). Consideration was also given to the themes developed in other relevant qualitative research studies (see appendix E/ chapter 8). Finally, the write up stage involved more detailed analysis, and connection with the research questions, the academic literature and existing research.

## 2.7 External verification

Participant consent allowed for sample coding and thematic grouping by the research supervisors as an objective check on the coding/analysis stage. Member checks and triangulation by data were also undertaken (see 2.8 below).

## 2.8 Steps to enhance quality and trustworthiness

There is no definitive criteria for assessing the quality and trustworthiness of qualitative research but Figure 1<sup>68</sup> offers a helpful framework contrasting quantitative and qualitative research terminology:

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<sup>67</sup> Braun & Clarke (n19), 233.

<sup>68</sup> Thomson et al. (n48), 119. Reproduced with permission (Appendix G).



<b>Table 1</b> Comparison of criteria for quality in quantitative and qualitative research.			
Quantitative Rigour <sup>64</sup>		Qualitative Trustworthiness <sup>61</sup>	
Internal Validity	Causal relationship between two variables and whether the study measured that which it was intended to measure.	The research has obtained an accurate interpretation of the meaning of the data which reflects the experience of participants.	<i>Credibility</i>
External Validity	Being able to generalize to a Larger population associated with one's research sample.	The extent to which the ideas generated may be applied to other populations or situations.	<i>Transferability</i>
Objectivity	The absence of bias, by the researcher maintaining 'distance' between researcher and research.	The degree to which the researcher can demonstrate that the findings relate to the data.	<i>Confirmability</i>
Reliability	The extent to which results are consistent over time and an accurate representation of the total population under study.	Whether the findings of the study offer a dependable and realistic interpretation of the view held by the participants.	<i>Dependability</i>

**Figure 1 – Comparison of Quantitative and Qualitative Research**

Each criterion will be examined using the appropriate qualitative research terminology:

### **Credibility**

It is acknowledged that each interview subtly influenced the phrasing of questions/ prompts to subsequent participants and is a feature of the qualitative interviewing process. However, steps were taken to enhance the credibility (and dependability) of this research through the consistent application of research methods, relatively inconspicuous forms of data collection, and the provision of clear pathways from data collection to analysis. High quality transcripts have been produced which facilitate and offer an appropriate platform for subsequent analysis.<sup>69</sup> A reflective account has been produced by the researcher to enhance credibility (and dependability) and to acknowledge the capacity for researcher bias and influence on participant contribution (appendix B).<sup>70</sup> Summary member checks were also undertaken with the participants to check the accuracy of interpretation and to offer the opportunity for feedback on the research findings (appendix B).<sup>71</sup>

### **Transferability**

Most qualitative research has an indicative, rather than generalisable, value.<sup>72</sup> This research did use a small but arguably representative sample population.<sup>73</sup> Whilst the nature of the decision-making process involves elements of individual subjectivity, the

<sup>69</sup> Brinkmann and Kvale (n36), 300. See also Braun & Clarke (n19), 287.

<sup>70</sup> Keenan, Van Teijlingen and Pitchforth (n25), 42. See also Cynthia A. Lietz and Luis E. Zayas, 'Evaluating Qualitative Research for Social Work Practitioners', (2010) 11(2) *Advances in Social Work* 188

<sup>71</sup> This involves securing participant feedback on findings (Lietz and Zayas (n70),194).

<sup>72</sup> On generalising from interview studies, see Brinkmann and Kvale (n36), 295-300.

<sup>73</sup> Based on estimated number of procedures undertaken and national abortion statistics (n43).

use of transparent data collection/coding/analytical mechanisms (including auditable pathways<sup>74</sup> and interview plans<sup>75</sup>) were intended to enhance the overall trustworthiness of the research.<sup>76</sup> Concerns about transferability can be overstated where the aims are 'to expand knowledge about the things that can happen and how they are interpreted in a particular social world'.<sup>77</sup>

## Confirmability

Research should be objective, neutral and unbiased wherever possible, and to the extent that such criteria are consistent with the selected research aims, theories and purposes.<sup>78</sup> However, 'objectivity' is a positivist concept that may not make adequate provision for the social and subjective construction of knowledge and reality.<sup>79</sup> As this research recognises and supports the role of subjective construction, it should be acknowledged and given pre-eminence at a methodological level.<sup>80</sup> For that reason, many qualitative researchers prefer the term 'confirmability'<sup>81</sup> in the place of 'objectivity'.<sup>82</sup> Further, critical legal theory is troubled by objectivity because it can be used to mask the social realities manifest in legal discourse.<sup>83</sup>

The following active steps were taken to address and demonstrate the connecting relationships between the data and research findings:

1. Clear dissemination of research aims to participants.
2. Consistent and transparent application of data coding.
3. The selection and use of a reliable, appropriate and objective method of data analysis.<sup>84</sup>
4. Summary member checks were undertaken with the participants.
5. Sample coding was undertaken by a research supervisor and the results were considered by the researcher.
6. Whilst familiarity with ethical theories can help reduce personal bias, ultimately it is the '*integrity of the researcher – his or her knowledge, experience, honesty*

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<sup>74</sup> A written account of the research process (Lietz and Zayas (n70), 196).

<sup>75</sup> Appendix A

<sup>76</sup> Sharan B. Merriam, *Qualitative Research: A Guide to Design & Implementation* (3rd Edition, Wiley 2014), 222-223.

<sup>77</sup> Burton (n4).

<sup>78</sup> Nudzor (n50), 123.

<sup>79</sup> Vincent A. Anfara, Kathleen M. Brown and Terri L. Mangione, 'Qualitative Analysis on Stage: Making the Research Process More Public', (2002) October *Education Researcher* 28.

<sup>80</sup> Nudzor (n50), 123.

<sup>81</sup> As per Thomson et al. (n48).

<sup>82</sup> Ibid (table 1); Anfara et al.(n79); Merriam (n76), 211.

<sup>83</sup> See for eg, Unger (n7).

<sup>84</sup> Crowe et al. (n57).

*and fairness – that is the decisive factor*'.<sup>85</sup> The provision of a reflective account aims to provide transparency for the reader (appendix B).

7. The term 'triangulation' is inconsistently defined in the literature but has been used to describe alignment at the **inquiry** and **verification** phases of the research process. Its central purpose is to enhance the confirmability and the overall quality of the research. Denzin describes 4 distinct categories of triangulation - triangulation by data/person, by investigator, by method and by theory.<sup>86</sup> Although care needs to be exercised when triangulating stakeholder perspectives involving a significant imbalance of power (as per fetal reduction<sup>87</sup>), it has been used in following ways. Triangulation by investigator was undertaken at the verification phase to provide an internal check on the researcher's interpretation of data.<sup>88</sup> Additionally, triangulation by data was undertaken at the verification stage using the interview data and existing data from stakeholders. This process was subject to satisfactory alignment at a theoretical and methodological level and looks for divergence/ convergence between datasets.

## Dependability

Dependability is concerned with whether the research findings "*offer a dependable and realistic interpretation of the view held by the participants*".<sup>89</sup> This was addressed by member checks, a reflective account and many of the points already discussed. We have attempted to strike a fair balance between the analytical segments and the data extracts used in chapter 9.<sup>90</sup> Overall, the theoretical and methodological choices were rational and consistent with other qualitative research undertaken in this field of research.<sup>91</sup>

## 2.9 Ethical and practical considerations<sup>92</sup>

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<sup>85</sup> Brinkmann & Kvale (n36), 97.

<sup>86</sup> Norman K. Denzin, *Sociological Methods: A Sourcebook* (McGraw Hill 1978)

<sup>87</sup> Michael Thomson, 'Abortion Law and Professional Boundaries' (2013) 22(2) *Social and Legal Studies* 191.

<sup>88</sup> See Merriam (n76), 216.

<sup>89</sup> Thomson et al. (n48).

<sup>90</sup> Braun & Clarke (n19), 287

<sup>91</sup> eg John Cresswell and Dana Miller, 'Determining validity in qualitative inquiry', (2000) 139(3) *Theory into Practice* 124, 126-1277; Merriam (n76), 209-235; Lietz and Zayas (n70), 188-202.

<sup>92</sup> Bournemouth University ethics approval was granted for this research on the 24 February 2014.

In this final section, we address a range of ethical and practical considerations:

### **Funding and conflicts of interest**

No external funding has been made available or used in this research. Internal Bournemouth University funding has been made available for certain travel and related expenses necessarily incurred in the interviewing process. There are no known conflicts of interest (whether actual or potential) and no gatekeeper controlled our access to the medical participants.

### **Data protection**

The requirements of the Data Protection Acts 1988/ 2018, the General Data Protection Regulation<sup>93</sup> and the data processing requirements of Bournemouth University have been complied with.

### **Subject matter**

The topic of fetal reduction is controversial and ethically debated. Moral, cultural and religious considerations feed into this discourse, but should not detract from or prevent academic research in this area. Care was taken around the transcription of participant characteristics to provide anonymity (where indicated) and compliance with data protection legislation. This included the secure collection, storage, dissemination, retention of data and diarised timescales for the destruction of any identifying data. All of this is addressed in the participant information sheet (appendix A). Those documents was modified slightly for representative participants to clarify the point on anonymity made earlier.

### **Human participants**

Human participants were involved in this research, but no patient, parent or donor has been directly involved/ interviewed and there has been no consideration of specific clinical records. No data on any individual patient, parental, fetal or donor characteristics has been captured. Informed consent was obtained from all human' participants using advance participant information sheets and written agreement forms

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<sup>93</sup> Regulation (EU) 2016/679

(appendix A). Embryos/fetuses have not been treated as human participants for the purposes of this research, although their legal and moral status is ethically debated.<sup>94</sup>

### **NHS research requirements**

Participants were recruited on the basis of their professional qualifications, memberships, experience, and not on the basis of any role they currently hold within the NHS. No NHS data has been used or collated in this research save where freely available in the public domain. This was not a research project based within an NHS organisation, and did not involve any circumstances where the NHS would have an explicit duty of care to the participants as employer.<sup>95</sup> NHS REC approval was not required in these circumstances<sup>96</sup> (the standardised Medical Research Council questionnaires are included at appendix D). NHS Research and Design approval was considered unnecessary because no physical NHS systems or non-public domain documents were used in this research. There has been no attempt to evaluate professional behaviours or the decision-making processes within any identifiable NHS body or organisation.

### **Audio media**

Digital audio media and handwritten notes were used during the interview process. The audio data was stored in a secure UK based digital environment with suitable password protection. Transcription was undertaken in a secure and confidential environment, and all paper records are/were held in a locked and secure location. All identifying research data will be destroyed within the timescales agreed with participants and future diary entries have been made by way of reminder.

## **2.10 Conclusions**

We acknowledge that the qualitative elements of this research have some limitations. First, we acknowledge that we have used a relatively small sample of clinicians and so

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<sup>94</sup> Bournemouth University has no explicit policy on the research treatment of embryos/fetuses.

<sup>95</sup> See <<https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/>>accessed 31 October 2018)

<sup>96</sup> NHS Health Research Authority, *Governance arrangements for research ethics committees: 2018 edition* (HRA 2018), Section 2.3.14. <<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/governance-arrangement-research-ethics-committees/>>accessed 31 October 2018.

cannot rule out divergence across regional practice. Secondly, this work highlights the importance of local cultural context and this may limit the transferability of some of our findings. Nonetheless, we believe that this research does make an important contribution to knowledge and understanding around the central research questions. We now move on to consider the normative frameworks and regulatory environment(s) (research question 2).

# Chapter 3 – Moral and Ethical Frameworks

Contents:

- 3.1 Introduction.
- 3.2 Why does it matter whether an embryo/ fetus has moral status?
- 3.3 Human biological development.
- 3.4 Who and what should be protected by a moral norm?
- 3.5 What 'properties' of an entity should we attach moral significance too?
- 3.6 Multiple property approaches.
- 3.7 Permissibility of pregnancy termination – the arguments.
- 3.8 Permissibility of selective termination and fetal reduction in multiple pregnancy.
- 3.9 The connections between moral norms/ status and legal protection/ interests.
- 3.10 Conclusions

## 3.1 Introduction

In this chapter, we examine relevant moral and philosophical ethical frameworks. These frameworks will become important when we address the role of personal values in medicine and wider professional ethical norms in chapter 6. Both chapters are interconnected because they are concerned with the guidance that healthcare professionals might derive from the ethical frameworks and general ethical principles. In this chapter, our aims are to offer a flavour of the arguments around entity moral status, the ethical considerations underpinning pregnancy termination and the possible connections to legal regulation. A large part of this chapter is concerned with the question of the moral status of the embryo/fetus and what this might mean for medical decision-making in our research context. Clearly, this is a very important question for healthcare professionals because they need to know whether, in their decision-making, they should treat an embryo/fetus as having (a) no interest (b) an interest that grows with development or (c) an equal interest to a born human. Whilst, we have evaluated many of the competing claims, it is not our intention to resolve any specific moral or ethical issue definitively in this work. Rather, our primary goal is to convey a sense of the values and views that might influence stakeholders in our research context; and to give an impression of the moral/ethical frameworks in which medical practice operates.

Discussion about the morality of abortion, typically starts with consideration of the beginnings of human life, and the recognition or ascription of particular moral status to the embryo or fetus. The framing of these issues is vitally important, although too often discourse becomes polarised and entrenched in pro-life/pro-choice<sup>1</sup> or fetal/maternal rights-based arguments. Such approaches have tended to distort debate, made it harder to forge any meaningful consensus, and in many cases the “*views on the moral status of abortion are part of a ‘package deal’.*”<sup>2</sup> This can make it difficult to make progress or achieve compromise, even when the foundations of resistance or support appear unsound or otherwise weak. Although there have been many attempts to overcome these entrenched positions,<sup>3</sup> they have found it difficult to forge any meaningful and lasting degree of societal consensus.

At the outset, we should make a distinction between the ethical norms and debate applied to the termination of a pregnancy in general and the ethical norms applied specifically to the question of fetal reduction and selective termination. To be sure, there is some overlap, but there is also added tension and possible conflict flowing from the presence and development of multiple unborn lifeforms. As we shall see, what we make of these circumstances will depend, to a large extent, on the value and weight attributed to certain forms of human life and to broader consequentialist type arguments. However, because of the overlap, we will start our analysis in general terms, before focussing upon the distinctive issues arising from fetal reduction and selective termination.

### 3.2 Why does it matter whether an embryo/ fetus has moral status?

According to the ethicists, Beauchamp and Childress:

*“moral norms are principles and rules that state obligations and, correlatively, rights... criteria of moral status are moral norms in the generic sense of “moral norm”. A norm in the most general sense is a (prima facie) standard that has the authority to judge or direct human belief, reasoning, or behaviour. A norm guides, commands, requires, or commends. Failure to follow a norm warrants*

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<sup>1</sup> Claire-Marie Legendre and others, ‘Differences between selective termination of pregnancy and fetal reduction in multiple pregnancy: a narrative review’ (2013) (26(6) *Reproductive Bio-Medicine Online (Elsevier Science)* 542; M L. Maroto, ‘The Never-Ending Dispute: How Framing and Language Have Prolonged the Abortion Debate in America’, *Conference Papers – American Sociological Association*. 2005 Annual Meeting, Philadelphia, 1, available via SocINDEX (accessed 12 January 2015).

<sup>2</sup> Michael Tooley, ‘Philosophy, critical thinking and ‘after-birth abortion: why should the baby live?’ (2013) 39(5) *J Med Ethics* 266, 267.

<sup>3</sup> Eg Judith J Thomson, ‘A Defense of Abortion’, (1971) (1) *Philosophy & Public Affairs* 47; Ronald Dworkin, *Life’s Dominion: An Argument about Abortion and Euthanasia* (Harper Collins 1993).



*censure, criticism, disapproval or some other negative appraisal. Criteria of moral status satisfy this description.”<sup>4</sup>*

So being accorded the moral status of a ‘human person’ ought to provide that entity with the same prima facie obligations, rights and protection that apply to other ‘human persons’. The issue then becomes whether we categorise all human life in the same way or restrict ‘personhood’ to a narrower band of human life. Warren claims that when an entity has moral status, it is:

*“an entity towards which moral agents have, or can have, moral obligations. If an entity has moral status, then we may not treat it in just any way we please; we are morally obliged to give weight in our deliberations to its needs, interests, or well-being. Furthermore, we are morally obliged to do this not merely because protecting it may benefit ourselves or other persons, but because its needs have moral importance in their own right”<sup>5</sup>*

According to Warren the function of moral status involves the setting of minimum standards “*towards entities of a given sort*” or the establishment of moral ideals.<sup>6</sup> This means that if embryos hold relevant moral status, it ought to impact on the obligations owed and moral protection afforded to these entities. In the context of pregnancy termination, concern about moral status might extend to consideration of the unborn entity’s right to life and the right not to be killed or left to die. Your response is likely to be influenced by the priority given to minimum or idealised moral standard setting, and according to Warren the “*strategies that we use to resolve the tension between these two functions...will influence our attitudes towards many practical moral issues*”.<sup>7</sup> These tensions and strategies will become evident as we proceed but we now move on to consider the stage at which human life might attain moral significance.

### 3.3 Human biological development

There is a considerable degree of consensus around human biological and related developmental issues. In-vivo human conception takes place when the sperm enters the egg. Fertilisation takes place later when the zygote is formed and the nuclear material from the gametes fuse. The zygote goes on to form the morula, and

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<sup>4</sup> Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, (7th edition, Oxford University Press 2013), 85.

<sup>5</sup> Mary A. Warren, *Moral status: obligations to persons and other living things* (Oxford University Press 1997), 3. See also, David R. Lawrence and Margaret Brazier, ‘Legally Human? ‘Novel Beings’ and English Law’, (2018) 26(2) *Med L. Rev* 309, 313-314.

<sup>6</sup> Warren(n5), 13-14.

<sup>7</sup> Warren (n5), 14.

subsequently the blastocyst, as it moves from the fallopian tube to the womb and implants (in-utero implantation). The primitive streak forms approximately 14-15 days after fertilisation.<sup>8</sup> In-vitro fertilisation (IVF) involves some modification as the process takes place outside of the woman in an ex-vivo environment.

How do we go about timing the start of pregnancy? The medical profession conventionally uses the first day of the woman's last menstrual period to calculate the duration of the pregnancy.<sup>9</sup> However, this starting date is approximately 2 weeks before ovulation, and consequently, discourse on the duration of fetal or embryo development normally runs from 2 weeks after the first day of the woman's last period. For example, 7 weeks of development corresponds to 9 weeks of pregnancy.<sup>10</sup> A more technical dating exercise may now occur following ultrasound scanning.<sup>11</sup> To add to the confusion, the legal starting point of pregnancy in the UK is implantation and this point cannot be determined precisely. Timing is particularly important for the regulation of medication interfering with the natural processes following conception and prior to implantation.

The human embryonic stage ends after 7 weeks of development/ 9 weeks of pregnancy, and the fetal stage starts at 8 weeks of development/10 weeks of pregnancy.<sup>12</sup> The first trimester covers the first 12 weeks of the pregnancy. The second trimester runs between weeks 13 to 28 of the pregnancy. Viability - when the fetus becomes technically capable of independent existence from its mother - is currently around 24 weeks in most developed countries.<sup>13</sup> This is not a fixed point in time, and necessarily depends on a range of socio-economic factors including available technology and medical skills. Fetal pain response is believed to occur sometime after 24 weeks although the literature is not conclusive on the starting point,<sup>14</sup> and moral precaution has been claimed for pregnancies between 20-23 weeks gestation.<sup>15</sup> The third trimester starts in the 29<sup>th</sup> week of pregnancy and the pregnancy is viewed as full term from the 37-38th week.

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<sup>8</sup> Warnock Committee Report, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (HMSO Reprint 1988) 66.

<sup>9</sup> See Department of Health and Social Care, *Clarification of time limit for termination of pregnancy performed under Grounds C and D of the Abortion Act 1967* (DHSC 23 July 2018); Also NHS – Your pregnancy and baby guide, <<http://www.nhs.uk/Conditions/pregnancy-and-baby/pages/due-date-calculator.aspx>> accessed 1 June 2017.

<sup>10</sup> Legendre et al. (n1), 544.

<sup>11</sup> In multiple pregnancy, this should take place between 11 and 13 weeks 6 days (Royal College of Obstetricians & Gynaecologists, *Multiple pregnancy: the management of twin & triplet pregnancies in the antenatal period* (NICE Clinical Guidance) (RCOG 2011a)).

<sup>12</sup> Legendre et al. (n1), 544.

<sup>13</sup> See for eg, BMA, *The Law & Ethics of Abortion, BMA Views* (BMA November 2014 (Updated October 2018)), 5.

<sup>14</sup> Royal College of Obstetricians & Gynaecologists, *Fetal Awareness: Review of Research & Recommendations for Practice* (RCOG 2010)

<sup>15</sup> E. Christian Brugger, 'The Problem of Fetal Pain and Abortion: Toward an Ethical Consensus for Appropriate Behavior' (2012) 22(3) *Kennedy Institute of Ethics Journal* 263.

### 3.4 Who and what should be protected by a moral norm?

Beauchamp and Childress suggest that the mainstream approach to the question of who or what should be protected by a moral norm:

*“has been to ask whether a being is the **kind of entity** to which moral principles or other moral categories can and should be applied and, if so, based on which **properties of the being**”.*<sup>16</sup>

This assumes that moral status or principles should and can be determined by the ‘essential nature of beings’ or *intrinsic* considerations.<sup>17</sup> In turn, this raises an issue over the appropriate emphasis to be placed on ‘*what an entity is*’ and ‘*what that entity can do*’. Whilst some philosophers have suggested that a simple shift in ontological status can result in a change in moral rights,<sup>18</sup> it can be problematic to use a fixed-point reference in a transformative physiological process.<sup>19</sup> Others have claimed that moral status can be determined by circumstances external to the nature of the being,<sup>20</sup> asserting that moral protection can be independent of intrinsic moral status and value.<sup>21</sup> Once again, framing is critical – we need to understand how the terms are being deployed,<sup>22</sup> and be alert to the possible narrative message(s) conveyed by terms like ‘abortion’, ‘human being’ and ‘human person’.

In the next section, we examine some of the core arguments advanced in relation to gestational development:

#### Conception

Religious, quasi-religious<sup>23</sup> and secular<sup>24</sup> arguments have been advanced that claim full human moral status should and does start from conception. Conception is the point at which the sperm penetrates the egg, and some secular claims maintain that the

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<sup>16</sup> Beauchamp & Childress (n4), 65 [emphasis added].

<sup>17</sup> Alan Clune, ‘Deeper problems for Noonan’s probability argument against abortion: On a charitable reading of Noonan’s conception criterion of humanity’ (2011) 25(5) *Bioethics* 280, 283. See also Lawrence and Brazier (n5), 317-318.

<sup>18</sup> John T. Noonan, ‘An Almost Absolute Value in History’, In the *Morality of Abortion: Legal and Historical Perspectives*, (Harvard University Press 1970) 51; Stephen Smith, ‘Dignity: The difference between abortion and neonaticide for severe disability’ chp10 in C A. Erin & S Ost (eds), *The Criminal Justice System and Health Care* (Oxford University Press 2007).

<sup>19</sup> See generally Samuel Taylor-Alexander and others, ‘Beyond Regulatory Compression: Confronting the Liminal Spaces of Health Research Regulation’ (2016) 8(2) *Law, Innovation and Technology* 149.

<sup>20</sup> Thomson (n3) 57.

<sup>21</sup> Beauchamp & Childress (n4); Carson Strong, ‘Overview: a framework for reproductive ethics’, chp 2 in Donna Dickenson (ed), *Ethical Issues in Maternal-fetal Medicine*, (Cambridge University Press 2002).

<sup>22</sup> Tooley (n2), 269.

<sup>23</sup> Peter Kreeft, ‘The Apple Argument Against Abortion’ (2001) 27(1) *Human Life Review* 81.

<sup>24</sup> Francis J. Beckwith, *Defending life: a moral and legal case against abortion choice* (Cambridge University Press 2007); Christopher Kaczor, *The ethics of abortion: women’s rights, human life, and the question of justice* (Routledge 2011)

genetic components of human life are complete at this stage of creation.<sup>25</sup> For example, Beckwith argues that at conception we have:

*“a unified organism with its own intrinsic purpose and basic capacities, whose parts work in concert for perfection and perpetuation of its existence as a whole.”*<sup>26</sup>

Marquis counters that there is biologically human life before conception - the sperm and unfertilised egg - although moral claims are rarely made for the gametes in isolation.<sup>27</sup> Opponents of the conception starting point, often advance a moral distinction between human life and the human person – the latter occurring some after conception. The typical counter response argues that we should still recognise the potential human person that the conception entity will become irrespective of the low statistical certainty of birth at that juncture. For Noonan, conception should be the criterion of moral rights due to the ‘sharp shift’ in the probability of the entity becoming possessed of human reason at that point.<sup>28</sup> Others have claimed that even if we cannot be sure or definite about status, we should play it safe and use conception because it is the clearest place to draw the line.<sup>29</sup>

## Fertilisation

Fertilisation is often confused with conception but involves the actual creation of the zygote and the fusion of the nuclear material (the chromosomes) from each gamete.<sup>30</sup> Whilst it is notable that fewer than 15% of fertilised eggs actually result in birth,<sup>31</sup> Kaczor maintains that this fact should not have any bearing on moral status.<sup>32</sup> However, one obvious problem for fertilisation as a starting point is that a zygote gives rise to a placenta and a human being and *“it cannot already be both a human being and a placenta.”*<sup>33</sup> It might also be possible for the zygote to split prior to implantation and give rise to multiple embryos,<sup>34</sup> although this may not preclude independent moral status for the zygote.<sup>35/36</sup>

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<sup>25</sup> Ibid.

<sup>26</sup> Beckwith (n24), 182.

<sup>27</sup> Don Marquis, ‘Abortion and the beginning and end of human life’, (2006) 34 *Journal of Law, Medicine and Ethics* 16, 19.

<sup>28</sup> Noonan (n18); For a critique of Noonan’s argument, see Clune (n17).

<sup>29</sup> C E., Koop, ‘The Sanctity of Life’ (1978) 75(1) *The Journal of the Medical Society of New Jersey* 62.

<sup>30</sup> Michael Tooley, Celia Wolf-Devine, Philip E. Devine and Alison M. Jaggard, *Abortion: Three Perspectives* (OUP 2009) 45

<sup>31</sup> Highlighted in *R (John Smeaton on behalf of the Society for the Protection of Unborn Children) v Secretary of State for Health* [2002] EWHC 610.

<sup>32</sup> Kaczor (n24), 131-133.

<sup>33</sup> John A. Burgess, ‘Could a zygote be a human being’, (2010) 24(2) *Bioethics* 61.

<sup>34</sup> Ibid., 62.

<sup>35</sup> Kaczor (n24), 127-130.

<sup>36</sup> The language we deploy here is also critical: terms like zygote, embryo and fetus distinguish and separate those entities from human persons with full moral status.

## **Implantation**

The UK criminal law offers some qualified legal protection following implantation of the fertilised egg in the uterus, and the pregnancy is then recognised as being established.<sup>37</sup> However, the ex-vivo embryo does have some legal protection prior to implantation,<sup>38</sup> and neither legal position necessarily reflects the moral status of the embryo at this point of gestation. As we have seen, it may be difficult to establish the timing of this point with absolute certainty.

## **Formation of the 'primitive streak'**

Following the formation of the primitive streak – a base or foundation from which the embryo develops - we can definitively identify the number of embryos. Many abortion opponents recognise the inherent difficulties presented by claims for earlier starting points for moral status.<sup>39</sup> The formation of the primitive streak has been used as a legally significant point for embryo protection in the context of in vitro storage and research in the UK.<sup>40</sup> Again, whilst formation occurs approximately 14 days after fertilisation, it is not a precise point in time.

## **Heartbeat and formation of the cardio-vascular system**

At approximately 6 weeks of gestation, a rudimentary cardio-vascular system develops in the embryo.<sup>41</sup> It has been argued that there should be symmetry between our conceptions of when and what causes life to begin and end.<sup>42</sup> However, as we now tend to use brain stem death as the definitive test for the end of human life, a more consistent approach might be to focus on the formation and subsequent functioning of the fetal brain stem which occurs at a later stage of development.<sup>43</sup>

## **Quickening**

The concept of 'quickening' has historical significance in the abortion debate and denotes the point when embryo movement is first detected by the pregnant mother.<sup>44</sup> Again, quickening does not occur at a fixed point in time and relies on external perception by the pregnant woman. It is therefore a potentially problematic starting

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<sup>37</sup> Offences Against the Person Act 1861, ss 58-59; *R (Smeaton)* (n31).

<sup>38</sup> Cf Human Fertilisation & Embryology Act 1990

<sup>39</sup> Wolf-Devine & Devine in Tooley et al.2009 (n30), 87-88.

<sup>40</sup> Human Fertilisation and Embryology Act 1990, s 3(3); Warnock (n8), 66.

<sup>41</sup> Burgess (n33), 69.

<sup>42</sup> For critique, see Marquis (n27).

<sup>43</sup> For critique of the brain stem test, see Jeff McMahan, *The ethics of killing: problems at the margins of life* (Oxford University Press 2002), 426.

<sup>44</sup> For discussion, see John Keown, *The Law and Ethics of Medicine: Essays on the Inviolability of Human Life* (Oxford University Press 2012) and *R (John Smeaton)* (n31).

point for moral status or protection and is rarely argued in modern ethical discourse. We will consider the moral relevance of external or extrinsic factors shortly.

### **Fetal stage and appearance**

From about 8 weeks of development the embryo starts to look human and to possess some physical human characteristics. However, Kaczor says that we should base our judgements on moral status “*not on what appears to be the case, but on what is in reality the case*”.<sup>45</sup> One of the reasons that the use of 3/4D scan imagery has become so contentious during pregnancy is because of its impact and role in constructing the fetus as a human person through physical similarity to early neonates.<sup>46/47</sup>

### **Achieving capacity**

A popular claim is that human personhood and full moral status is only achieved once life become viable and has the capacity for independent existence. Herring points out that viability relativises moral status, and even a child born at full term could not survive if left alone without support.<sup>48</sup> Marquis correctly highlights that ‘*independence is not a necessary condition of being alive*’,<sup>49</sup> and the future prospect of ectogenesis poses practical challenges for moral claims built on the capacity for separate existence.<sup>50</sup> Although there is some evidence of survival at 22 weeks gestation, the BMA has maintained that survival rates and the rates of severe disability have not improved amongst babies born at 23 weeks or less in recent years.<sup>51</sup>

Others base moral status on the existence of sentient life – where there is the capacity to experience discomfort, sensation or desires. Warren describes sentience as the capacity to feel pleasure or pain; and something more than a consciousness.<sup>52</sup> Again it is difficult to pin down a precise starting point, and capacity based claims do need to be able to address fluctuations in capacity and the exercise of capacity over time.<sup>53</sup>

Boonin claims that we should use organised cortical brain activity as the measure of moral significance,<sup>54</sup> treating the start of life in the same way we measure the end of

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<sup>45</sup> Kaczor (n24), 79.

<sup>46</sup> Kristin L. Savell, ‘Life & death before birth: 4D ultrasound & the shifting frontiers of the abortion debate’, (2007) 15(1) *Journal of Law & Medicine* 103.

<sup>47</sup> Cf embryo research in France (Stephanie H. Henneute-Vauchez, ‘Words count: how interest in stem cells has made the embryo available--a look at the French law of bioethics’, (2009) 17(1) *Med L. Rev* 52, 69-70.)

<sup>48</sup> Jonathan Herring, *Medical Law & Ethics* (4th edition, Oxford University Press 2012) 322.

<sup>49</sup> Marquis 2006 (n27), 18.

<sup>50</sup> Amel Alghrani and Margaret Brazier, ‘What Is It? Whose It? Re-Positioning the Fetus In the Context of Research’, (2011) 1 *Cambridge Law Journal* 51.

<sup>51</sup> BMA, *The Law and ethics of abortion: BMA Views* (BMA November 2014), 4. Nb not asserted in the updated version (n13).

<sup>52</sup> Warren (n5), 52-56. Cf. Lawrence and Brazier (n5), 312-213.

<sup>53</sup> Beauchamp & Childress (n4), 75-76. Warren (n52).

<sup>54</sup> David Boonin, *A Defense of Abortion* (Cambridge University Press 2002)

life.<sup>55</sup> He argues that prior to conscious experience, a being has no desires but claims dispositional conscious experience is present from the point of organised cortical brain activity.

Lawrence and Brazier prefer to use 'sapience' because the term 'sentience' focuses primarily on whether an entity is capable of suffering.<sup>56</sup> Whilst they accept that suffering or the potential to suffer may be a relevant factor for the determination of moral protection, sapience as a concept goes further, and includes consideration of the capacity for reasoned thought and insight.<sup>57</sup> However, it is important to recognise that sapience has a greater exclusionary effect meaning certain forms of adult human life will potentially fall outside it's remit.

### **Birth and post birth**

Birth is the obvious point at which the 'child' becomes an entirely separate entity from its mother but why should physical separation be morally significant? The obvious point is that the child's interests and any associated rights can be asserted and enforced independently, and without direct physical impact on the mother. McMahan adds:

*"Because infants exist independently, the sacrifices that they may require from others in order to survive and flourish are of a fundamentally different and usually less burdensome kind".<sup>58</sup>*

Herring raises the issue of relativism - why should the 30-week (in-utero) fetus have a different moral status from a similar aged child born and kept alive in an incubator?<sup>59</sup> On the face of it, extrinsic (environmental) factors separate the two cases, but Greasley claims that that the intrinsic qualities of the unborn fetus and the born neonate are not the same - birth produces intrinsic transformative physical changes in the entity that cannot be ignored, and that account should be taken of the individuation of embodiment.<sup>60</sup>

Some philosophers claim that full human personhood may not be achieved until after birth because only at this point does the entity possess the morally relevant features of

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<sup>55</sup> Julian Savulescu, 'Abortion, Embryo Destruction and the Future of Value Argument' (2002) 28 *Journal of Medical Ethics* 133-135.

<sup>56</sup> Lawrence and Brazier (n5), 312-313.

<sup>57</sup> Ibid.

<sup>58</sup> McMahan 2002 (n43), 344.

<sup>59</sup> Herring (n48), 323; Jeff McMahan, 'Infanticide and moral consistency', (2013) 39 *J Med Ethics* 273. Cf, Kate Greasley, *Arguments about Abortion: Personhood, Morality and Law* (Oxford University Press 2017), 191-195.

<sup>60</sup> Greasley (n59), 191-199.

a human person.<sup>61</sup> For example, John Harris claims that the moral status of a human entity:

*“is determined by its possession of those features which make normal adult human individuals morally more important than sheep or goats or embryos”*<sup>62</sup>

For Harris, that core feature is the capacity of an entity to value ones’ own existence and life.<sup>63</sup> Similarly, Tooley says we should focus on the capacity for thought,<sup>64</sup> an attribute that needs to be more than a momentary experience.<sup>65</sup> These cognitive properties may not exist until after birth and later in infancy, potentially deferring full moral status for the new born child. We might also infer from these positions, that full human personhood can, in certain circumstances, be lost prior to formal death.<sup>66</sup>

Tooley seeks to address concern about this potential loss of moral status by utilising a ‘neo-lockean’ person - someone who has variable conscious states at different times that are nonetheless *“psychologically connected by such things as memories, desires and intentions”*<sup>67</sup> - although ultimately he defers questions of cognition and capacity to the scientists.<sup>68</sup>

Alternative cognitive approaches have been developed, including McMahan’s Time Relative Interest Account (TRIA) that we will consider shortly.<sup>69</sup>

### 3.5 What ‘properties’ of an entity should we attach moral significance to?

In this section, we examine some of the arguments that have been advanced claiming moral significance for specific or aggregated ‘properties’ of an entity.

#### **Membership of a biologically defined species**

Some opponents of abortion claim that moral significance should attach to those entities possessing genetic or biologically human characteristics, but Burgess rejects

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<sup>61</sup> For eg, Alberta Giubilini and Francesca Minerva, ‘After Birth Abortions: Why should the baby live?’ (2012) *J Med ethics* 2011-100411.

<sup>62</sup> John Harris, *Clones, Genes & Immortality: Ethics and the Genetic Revolution* (Oxford University Press 1998), 79.

<sup>63</sup> John Harris, ‘The concept of the person and the value of life’, (1999) 9(4) *Kennedy Institute of Ethics Journal* 293.

<sup>64</sup> Tooley 2013 (n2), 272. See also Lawrence and Brazier (n5).

<sup>65</sup> Tooley 2009 (n30), 60.

<sup>66</sup> Daniel R A. Cox, ‘The problems with utilitarian conceptions of personhood in the abortion debate’ (2011) 37(5) *Journal of Medical Ethics* 318.

<sup>67</sup> Tooley 2013 (n2) 271.

<sup>68</sup> Tooley 2009, (n30) 61-64; Tooley 2013 (n2). Tooley has shifted his position on this issue (Wolf-Devine & Devine (n39), 198-202).

<sup>69</sup> McMahan 2002 (n43), 360.



the notion that the formation of the human zygote can be a morally significant event.<sup>70</sup> Indeed, species centric claims to moral status are generally contested<sup>71</sup> because they involve an arbitrary selection of species “*without reference to morally differentiating characteristics*”.<sup>72</sup> The obvious alternative is to concentrate on morally significant characteristics that exclude species membership – for example, Peter Singer prefers a sentience test for moral status encompassing some higher functioning creatures (but not all animals) within its remit.<sup>73</sup> These species considerations are likely to become especially important, when and if, we are confronted with genetically modified or enhanced humans (posthumans), synthetic humanoid life and artificially intelligent beings.<sup>74</sup>

## Potentiality

The focus of potentiality is on the future human person that the entity will become, and the importance of not depriving the future life of that being.<sup>75</sup> This interest in the protection of future potential life permeates many important legal rulings, including Blackmun J’s judgment in the seminal US case of *Roe v Wade*.<sup>76</sup> A leading supporter of potentiality, Donald Marquis, claims that it is morally wrong to deprive “*futures of value*”.<sup>77</sup> Ronald Dworkin rejects this approach because the human embryo is neither a current rights bearer or interest holder.<sup>78</sup> There is also an important difference between saying that an entity may or will become a future human being.<sup>79</sup> Further, Savulescu highlights the potential of many precursors to human life - including the egg and sperm - in an attempt to show the absurdity of Marquis’ approach.<sup>80</sup> Smith claims that the fact that all humans have the potential to be a corpse, does not necessitate treatment of the current person as a future corpse.<sup>81</sup> Potentiality arguments also present a problem for the equality of all human beings - anomalous embryos may never have the capacity to become a human person - and cannot be applied equally without some form of qualification.<sup>82</sup>

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<sup>70</sup> Burgess (n33).

<sup>71</sup> Peter Singer, *Practical ethics* (2nd ed, Cambridge University Press 1979); Marquis (n26); Tooley ((n30); (n21)).

<sup>72</sup> Greasley (n59), 110.

<sup>73</sup> Singer (n71). See also Tooley 2009 (n30), 21-33.

<sup>74</sup> For discussion, see Lawrence and Brazier (n5).

<sup>75</sup> See Warnock (n8), 66. For wider discussion, see Lynn M. Morgan, ‘The Potentiality Principle from Aristotle to Abortion’, (2013) 54: S7 *Current Anthropology* S15-S25.

<sup>76</sup> [1973] 410 US 113 (US Supreme Court); See also *In the matter of an application by the Northern Ireland Human Rights Commission for Judicial Review (Northern Ireland)* [2018] UKSC 27, [119] (Lord Mance).

<sup>77</sup> Marquis (n27), 23.

<sup>78</sup> Dworkin (n3).

<sup>79</sup> Derek Parfit, *Reasons and Persons* (Clarendon Press 1984).

<sup>80</sup> Savulescu (n55).

<sup>81</sup> Stephen Smith, ‘Precautionary reasoning in determining moral worth’, chp 11 in M, Freeman (ed), *Law & Bioethics* (OUP 2008)

<sup>82</sup> Tooley 2009 (n30), 36.

Various counter responses have been advanced. Nobbs claims that the increasing likelihood of human personhood should be linked to increasing moral value.<sup>83</sup> Finnis requires active potentiality - the ability of the entity to develop/ activate their potential without external interference - to circumvent the Savulescu argument because becoming an entity would no longer rely upon extrinsic causes.<sup>84</sup> Marquis limits his potentiality claims to the deprivation of “futures of value” in respect of the “very same individual”.<sup>85</sup> McMahan counters that Marquis’ argument fails “*to take account of the difference in the ways that fetuses and adults are related to their own future selves*”.<sup>86</sup> Further, McMahan concludes that we never existed as a pre-sentient fetus - that such entities are not the very same individual - and instead offers his TRIA (Time-Relative Interest Account) theory which considers the extent to which an entity is psychologically invested in or connected with its possible future. By doing so, he seeks to play to our intuitions on the relative ‘wrongness’ of killing at different stages of a pregnancy and post birth life.<sup>87</sup> However McMahan does not rely on a single property or characteristic to advance his claims, and this is an issue to which we will return.

### **Moral agency**

These approaches claim that moral status comes from the capacity of an entity to act as a moral agent, involving the capacity to make judgements about the rightness or wrongness of actions and the ability to hold motives that can be judged morally.<sup>88</sup> Again this has exclusionary implications for adult human beings that do not have the relevant capacity. One response has been to distinguish between ‘*potential*’ (someone who we think might be an agent) and ‘*ostensible*’ agents (someone we are fairly certain is an agent).<sup>89</sup> This distinction is combined with a ‘*precautionary principle*’ requiring agents, as far as possible, to extend generic rights to anything that is even conceivably a moral agent.<sup>90</sup> On this basis, we might claim that the late stage fetus is a ‘potential’ moral agent, although any fetal rights would remain subject to the rights of ostensible agents (the pregnant woman) when there is real and significant risk to that individual’s life (by continuance of the pregnancy).

### **Capacity or cognitive properties**

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<sup>83</sup> Christopher Nobbs, ‘Probability Potentiality’, (2007) 16(2) *Cambridge Quarterly of Healthcare Ethics* 240.

<sup>84</sup> John Finnis, ‘The rights and wrongs of abortion’, (1973) 2 *Philosophy and public affairs* 117.

<sup>85</sup> Marquis (n27), 24.

<sup>86</sup> McMahan (n43), 271. See also Greasley (n59), 154-159.

<sup>87</sup> For critique of McMahan and defence of Marquis, see P. Nichols, ‘Abortion, Time-Relative Interests and Futures Like Ours’, (2012) 15 *Ethic Theory Moral Prac* 493.

<sup>88</sup> Beauchamp & Childress (n4), 72.

<sup>89</sup> Derek Beyleveld and Roger Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford University Press 2001).

<sup>90</sup> Ibid. See also Stephen Smith, ‘Dignity: The difference between abortion and neonaticide for severe disability’, chp 10 in Charles A. Erin and Suzanne Ost (eds), *The Criminal Justice System and Health Care* (OUP 2007).

These theoretical approaches claim that full moral status and human personhood should be reserved to those entities possessing certain capacities (eg viability or sentience) or specific cognitive properties (eg self-awareness, control, consciousness, reason).<sup>91</sup> There has been criticism that such theories create inequality for the very young, elderly and mentally disabled if applied consistently across human life.<sup>92</sup> Some of these arguments may unnecessarily conflate moral status with moral/legal protection, because there are cases when we afford greater moral/legal protection than might otherwise be justified by strict entity status (eg for prevention of animal cruelty). Some assume that capacity needs to be exercised in a continuum to count, although such arguments fail to adequately account for repetitive and temporary variations in our consciousness due to sleep, anaesthesia etc. However, capacity or cognitive approaches do have the potential for over inclusion (when applied beyond human life) unless they are able to defeat the speciest objections discussed earlier.<sup>93</sup>

### **Relational properties**

With relational properties, the focus is on the relationship between the pregnant woman and developing entity; and the consequential affect on the moral and legal consequences of pregnancy. Judith Thomson points out that opponents of pregnancy termination:

*“have tended to overlook the possible support they might gain from making out that the fetus is dependent on the mother, in order to establish that she has a special kind of responsibility for it, a responsibility that gives it rights against her which are not possessed by any independent person”<sup>94</sup>*

This statement links fetal dependence with moral responsibility on the part of the pregnant woman. Herring has suggested that this relationship reflects the way women look at pregnancy in the real world,<sup>95</sup> and Dworkin frames the relationship in the following emotive terms:

*“her foetus is not merely ‘in her’ as an inanimate object might be, or something alive but alien that has been transplanted into her body. It is ‘of her and is hers and is hers more than anyone’s’ because it is, more than anyone else’s, her creation and her responsibility; it is alive because she has made it come alive.”<sup>96</sup>*

However, this narrative shifts the emphasis away from dependence and infers that the pregnant woman can assume moral responsibility for the unborn entity because of her

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<sup>91</sup> We have already addressed many of the key arguments (eg from Harris; Tooley; Singer).

<sup>92</sup> Elizabeth Wicks, 'Terminating life & Human Rights: The fetus and the neonate', chp 11 in C. A. Erin and S. Ost (eds), *The Criminal Justice System in Health Care* (OUP 2007); Cox (n66); Beauchamp & Childress (n4), 69-75.

<sup>93</sup> Greasley (n59), 160.

<sup>94</sup> Thomson (n3), 58.

<sup>95</sup> Herring 2012 (n48), 325.

<sup>96</sup> Dworkin (n3), 55.

role in its creation.<sup>97</sup> Clearly, this has no place in non-consensual pregnancies, and is controversial in conceptions arising from contraceptive failure.

Boonin distinguishes responsibility for an entities' existence from the continuing neediness for care and support; claiming that pregnant women are not responsible for the latter.<sup>98</sup> Any responsibility is not open ended - even if a pregnant woman has some moral obligation for the development of the unborn entity, it ought not be converted into a legal duty to maintain life at all costs.<sup>99</sup> However, the real challenge is whether relational approaches in isolation provide a sufficient and necessary condition for moral status. Some claim that extrinsic properties are neither sufficient or necessary,<sup>100</sup> and even if extrinsic properties can supply a sufficient moral criterion, few are prepared to accept that such properties can be an exclusive and necessary criterion for full moral status.<sup>101</sup> By example, Warren claims that our moral obligations are not "*entirely contingent upon the prior existence of social or ecological relationships between ourselves and them*".<sup>102</sup>

### 3.6 Multiple property approaches

Whilst there is an obvious simplicity to these unitary property approaches, they tend to unduly narrow the exclusion process, artificially separate the constituent properties of life, and fail to adequately recognise the various states in which human life functions.<sup>103</sup>

Two key points are emphasised by supporters of an alternative multiple property approach. First, whilst individual properties may provide "*a sufficient basis for a particular sort of moral status*", none of them "*in isolation from the others yields a plausible account of moral status*".<sup>104</sup> Secondly, singular property approaches tend to use intrinsic factors or properties as a sole criterion of moral status.<sup>105</sup> Warren defines intrinsic properties as those which the entity has and "*which it is logically possible for it*

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<sup>97</sup> Francis J. Beckwith, 'Defending Abortion Philosophically: A Review of David Boonin's 'A Defense of Abortion'', (2006) 31 *Journal of Medicine & Philosophy* 177, 191. For discussion of parental responsibility for multiple pregnancy following fertility enhancement, see Helen Watt, *The Ethics of Pregnancy, Abortion and Childbirth: Exploring Moral Choices in Childbearing* (Routledge 2017), 109.

<sup>98</sup> Boonin (n54), 175.

<sup>99</sup> Laura Purdy, 'Genetics and Reproductive Risk: Can having children be immoral', chp 11 in Helga Kuhse & Peter Singer (eds), *Bioethics: An Anthology*, (Blackwells 2006); Bonnie Steinbock, 'Mother-Fetus Conflict', chp 15 in Helga Kuhse & Peter Singer(eds), *A Companion to Bioethics* (Wiley 2009).

<sup>100</sup> Beauchamp & Childress (n4), 76; Greasley (n59).

<sup>101</sup> Warren (n5), 241-242.

<sup>102</sup> *Ibid.*, 123.

<sup>103</sup> Elizabeth Wicks, *The State and the Body: Legal Regulation of Bodily Autonomy* (Hart 2016), 12; Beauchamp & Childress (n4), 79; Warren (n5), 17; Greasley (n59), chp 7-8.

<sup>104</sup> Warren (n5), 122.

<sup>105</sup> *Ibid.*

to have even if it were the only thing in existence”.<sup>106</sup> Extrinsic properties, however, are not “logically possible for it to have had were it the only thing in existence”.<sup>107</sup> On this basis, relational aspects – including the relationship between embryo and pregnant woman – are extrinsic considerations. Multiple property theories often combine intrinsic and extrinsic properties to reach conclusions about the moral status of an entity.<sup>108</sup> In doing so, they acknowledge the importance of intrinsic properties to the evaluation of extrinsic factors. Warren claims, with some force, that:

*“Only a multi-criterial account of moral status can incorporate the sound ethical considerations that underlie each of the uni-criterial accounts, while avoiding the distortions of moral common sense that result from the attempt to make all valid judgements about moral status follow from a single principle”.*<sup>109</sup>

Gradualism is closely linked to multi-property approaches and we will come to these theoretical positions shortly. Further, it is claimed that intrinsic centred approaches tend to distort the discussion of abortion:

*“Opponents of abortion commonly spend most of their time establishing that the fetus is a person, and hardly any time explaining the step from there to the impermissibility of abortion. Perhaps they think the step too simple and obvious to require much comment. Or perhaps instead they are simply being economical in argument. Many of those who defend abortion rely on the premise that the fetus is not a person, but only a bit of tissue that will become a person at birth; and why pay out more arguments than you have to? Whatever the explanation, I suggest that the step they take is neither easy nor obvious, that it calls for closer examination than it is commonly given, and that when we do give it this closer examination we shall feel inclined to reject it.”*<sup>110</sup>

For that reason, we now move on to examine the arguments around the permissibility of pregnancy termination.

### 3.7 Permissibility of pregnancy termination – the arguments

Moral permissibility does not necessarily require normative action or mean that permissible acts cannot be subject to criticism.<sup>111</sup> Similarly, moral permissibility does not dictate that a State should offer no legal protection against actual or threatened harm, even in circumstances when it might be technically permissible to inflict or

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<sup>106</sup> Ibid.

<sup>107</sup> Ibid.

<sup>108</sup> Ibid, chp 6.

<sup>109</sup> Ibid., 177.

<sup>110</sup> Thomson (n3), 48. For a contrary view emphasising the importance of personhood, see Greasley (n59).

<sup>111</sup> Boonin (n54), 5-8; Greasley (n59), 180.

threaten that harm. In this section, we will concentrate on the key arguments that have been advanced in relation to pregnancy termination:

### **No moral status and no right to life**

If a human embryo/ fetus has no moral status, or at least no status as a 'human person', it should follow that there is no right to life and any consequential termination of that entity would be prima facie permissible. In Tooley's early work, he defended the killing of early neonates on the basis that they were not yet 'human persons',<sup>112</sup> although his argument has become more nuanced over time.<sup>113</sup> More recently, Giubilini and Minerva have asserted that neither a human fetus or newborn child "is a 'person' in the sense of 'subject of a moral right to life'",<sup>114</sup> generating a largely adverse global response.<sup>115</sup> Indeed, it is rare to see contemporary denials of 'personhood' coupled with unqualified opposition to legal protective mechanisms.<sup>116</sup>

### **Rights oriented**

This ethical discourse centres on the existence of rights and the resolution of rights-oriented conflict between the pregnant woman and her unborn baby(ies); encompassing a range of claims including opposition to the termination of innocent beings with a right to life, to maternal rights as trumps, through to the blanket denial of unborn entity interests or rights. Such arguments require clarity about the content and scope of any claimed right to life, and the conflicting maternal rights in play (eg the right to bodily integrity, to autonomy or to privacy). In our context, we might want to consider whether a distinction should be made between a possible right to avoid continued pregnancy/ birth and a possible right to determine the type or future of an unborn entity. The latter might prove important should removal of an unborn fetus prove a viable alternative to termination.

Your theory of rights is likely to prove important in this discourse. The choice (or will) theory of rights,<sup>117</sup> is unlikely to assist an entity without the necessary understanding and capacity to exercise or waive choice. However, if you subscribe to the interest (or benefit) theory,<sup>118</sup> it is likely to prove easier to treat these entities as rights holders,

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<sup>112</sup> Michael Tooley, *Abortion & infanticide* (OUP 1983)

<sup>113</sup> Tooley 2013 (n2).

<sup>114</sup> Giubilini and Minerva (n61), 2.

<sup>115</sup> Tooley 2013 (n2).

<sup>116</sup> For example, McMahan 2002 (n43).

<sup>117</sup> H.L.A. Hart, 'Are There Any Natural Rights?', in J. Waldron (ed.), *Theories of Rights* (OUP, 1984).

<sup>118</sup> Joseph Raz, 'Right-based Moralities' (1982) in J. Waldron (ed.), *Theories of Rights* (OUP 1984).

although any approach would still need to address the interests at play and the content of any embryo/ fetal right.<sup>119</sup> Either way, we should never forget that:

*“a considerable amount is on the line for women in securing reproductive control, and that denying them that control is inexorably damaging – damaging to their health, life, happiness, and equality”.*<sup>120</sup>

In her seminal paper, *A Defense of Abortion*,<sup>121</sup> Judith Thomson claims that even if we assume that the human embryo/ fetus has a prima facie moral status and a right to life, it does not follow that it is always morally impermissible to act in a way that results in the death of that entity. Using a series of analogies - the hooked-up violinist, the burglar and the people seeds/plants - she sets out to demonstrate that there is no automatic conflict between maternal and fetal rights. Essentially, Thomson maintains that any embryo/fetal right to life does not include an open-ended right to life support, or unqualified use of the woman’s body; casting pregnancy as an act of good samaritanism.<sup>122</sup> However, Thomson does not maintain that termination is always permissible,<sup>123</sup> or claim an unqualified “*right to secure the death of the unborn child*”:

*“You may detach yourself even if this costs him his life; you have no right to be guaranteed his death, by some other means, if unplugging yourself does not kill him.”*<sup>124</sup>

So, whilst it may sometimes be permissible to terminate a pregnancy, it does not follow that the mother has a right to terminate viable fetal life. This has implications for the termination method, the permissibility of late stage terminations and for the cost of supporting life.<sup>125</sup> Whilst there are many attacks on Thomson’s paper,<sup>126</sup> there is no doubting the central force, creativity and longevity of her central claims.

If the unborn entity is not a rights bearer, the position appears to be much clearer. The pregnant woman - as an autonomous rights bearer - should be able to make her own decision about the continuance of the pregnancy unless there is some basis for legitimate state interference with that right. Interventions restricting bodily autonomy (and specifically reproductive choices) and based upon a Millian concept of harm prevention, would only be justified if the actual or threatened harm to the ‘other’ is both

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<sup>119</sup> Joseph Millum, *The Moral Foundations of Parenthood* (OUP 2018), 15-17. For hybrid theories, see Rosamund Scott, ‘Choosing between Possible Lives: Legal and Ethical Issues in Preimplantation Genetic Diagnosis’, (2006) 26(1) *OJLS* 153.

<sup>120</sup> Kate Greasley (n59), 5-6.

<sup>121</sup> Thomson (n3).

<sup>122</sup> Greasley (n59), 37; Boonin (n54).

<sup>123</sup> Thomson (n3), 65-66.

<sup>124</sup> Thomson (n3), 66.

<sup>125</sup> McMahan (n43), 157.

<sup>126</sup> For a comprehensive summary, see Boonin (n54), chp 4.

morally indefensible (neither excusable or justifiable) and rights violating.<sup>127</sup> The former (moral indefensibility) gives rise to the arguments advanced by Thomson above, and the latter (rights violating) is of no concern on the basis of our initial assumption.<sup>128</sup> Further, it should make no difference that the exercise of private reproductive choice will “*cause offence to others, or harm to the person making the autonomous choice*”.<sup>129</sup> However, there might still be grounds justifying State intervention in reproductive choices, for example, to prevent adverse consequences for the dignity or future of the human species as a whole.<sup>130</sup>

### **Maternal permission and responsibility**

Discourse on maternal permission focuses on how specific life was created.<sup>131</sup> Clearly, there will not be any permission in pregnancies that arise from sexual crime. However when the pregnancy arises from consensual sexual intercourse, it has been argued that the woman has given permission and/or assumed the foreseeable risk and responsibility for that pregnancy.<sup>132</sup> These are distinct arguments - the former will be of no concern for those who claim that a woman’s rights outweigh those of the unborn entity, or to those who say that consent/ permission is a conditional thing that can be withdrawn at any time. Also, Wilkinson stresses that we should not conflate parental obligations owed to current children with those that might be owed by prospective parents.<sup>133</sup> Whilst it might make sense to have some degree of convergence, much will depend on the extent to which obligations have been voluntarily assumed by the parents concerned. In the case of unwanted pregnancy, it is probably artificial to claim that voluntariness extends to the continuation of the pregnancy. Of course, the point about current/ prospective parents is a circular one for those that maintain that the fetus is a current child with existent and correlative rights against their parents.

What about the parental role in creation of the unborn entity? Although Thomson does not explicitly consider a failure to take reasonable precautions,<sup>134</sup> she does address pregnancy following a failure of contraception using her people seed/plant analogy. In those circumstances, she claims that the embryo/ fetus does not have a right to use of the woman’s body.<sup>135</sup> Indeed a key facet of Thomson’s thesis is that a special

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<sup>127</sup> Wicks (n103),48-52; Joel Feinberg, *Moral Limits of the Criminal Law* (OUP 1984).

<sup>128</sup> For Wicks, the issue turns on viability ((n103), 52).

<sup>129</sup> *Ibid.*, 157.

<sup>130</sup> *Ibid.*, 58/155.

<sup>131</sup> Boonin (n54),188.

<sup>132</sup> Wolf-Devine & Devine (n39), 93. Cf competing arguments advanced by Millum (n119), chp 4.

<sup>133</sup> Stephen Wilkinson, *Choosing Tomorrow’s Children: the ethics of selective reproduction* (Oxford University Press 2010), 55.

<sup>134</sup> She talks in terms of ‘*reasonable precautions*’ (n3), 65.

<sup>135</sup> Thomson (n3), 59. A right to unplug does not extend to a right to terminate life (Boonin (n54), 233).



responsibility to support/aid the unborn entity only exists if it is explicitly or implicitly assumed and, in most scenarios, that will not be the case.<sup>136</sup> This volunteer theory of obligations leaves a vulnerable entity (potentially) unprotected,<sup>137</sup> although it does create space for social conventions to play a role in the acquisition of parental responsibilities.<sup>138</sup> Finally, Scott makes this telling observation about the interconnection between fetal interests and maternal duties:

*“The moral status of the fetus cannot be settled ‘in advance’, without regard to its location inside a pregnant woman: the question of the interests and rights, if any, of the fetus is related to the question of the duties, if any, that the pregnant woman owes it.”<sup>139</sup>*

### **Killing and letting die**

In this discourse, the focus is on how the embryo/ fetal life is brought to an end.<sup>140</sup> In an attempt to differentiate Thomson’s violinist analogy from the termination of pregnancy, Finnis draws upon the claimed moral distinction between killing and letting die.<sup>141</sup> He argues that Thomson needs to establish that the unhooking of the violinist<sup>142</sup> is a direct killing before it can be used as an analogy for abortion. He claims that unhooking life support is a case of letting someone die, whereas abortion always involves direct killing. The claimed moral distinction between killing and letting die is controversial - Thomson claims that there is no relevant or meaningful moral distinction,<sup>143</sup> whilst others contend that letting die can be morally worse than killing.<sup>144</sup>

In any event, does the termination of a pregnancy or specific entity life necessarily involve a positive act to end life, or is it more akin to a refraining or a failure to rescue or otherwise volunteer support? Some methods of termination (eg surgical dilation and evacuation) do not closely resemble the ‘unplugging’ analogy offered by Thomson, and arguably “*involve something more like a direct attack on the body of the fetus*”.<sup>145</sup> Similarly feticide by lethal injection (prevalent in fetal reduction) may give rise to different considerations to medical termination by drugs (prevalent in the majority of

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<sup>136</sup> Kaczor (n24), 149. For discussion of the difference between ‘special’ and ‘general’ responsibilities (Millum (n119), 18-22).

<sup>137</sup> Wolf-Devine & Devine (n39).

<sup>138</sup> Millum (n119), chp 4.

<sup>139</sup> Rosamund Scott, ‘Reproductive Health: Morals, Margins and Rights’, (2018) 81(3) *MLR* 422. See also Watt (n97) on the importance of relational considerations.

<sup>140</sup> Boonin (n54), 188.

<sup>141</sup> Finnis (n84). See also Greasley (n59), 39-56.

<sup>142</sup> The analogy uses a scenario where a person wakes up to discover they have been hooked up effectively as life support to an unconscious violinist. Thomson argues that it is permissible for you to unhook that support even though it will result in the violinist’s death.

<sup>143</sup> Boonin (n54), 199.

<sup>144</sup> Helga Kuhse and Peter Singer, *Should the baby live?* (OUP 1985)

<sup>145</sup> Greasley (n59), 47.

singleton terminations).<sup>146</sup> Wider extrinsic considerations may impact on our perspective and assessment of moral responsibility. For example, if we contrast the direct administration of a lethal fetal injection with circumstances where a doctor prescribes abortifacient medication which is taken or administered directly by the pregnant woman. Here, extrinsic factors undoubtedly feed into whether we frame these as direct or assisted killings, or as a failure to prevent the death of the unborn entity.<sup>147</sup> If we presume, for one moment, (1) that there is a moral distinction between killing/ letting die, (2) relevant personhood and (3) that termination of pregnancy is a “*prima facie violation of a strict duty not to kill other people*” then:<sup>148</sup>

*“its moral and legal responsibility depends on the applicability of a special dispensation to kill in order to end a pregnancy, rather than on the absence of a duty to volunteer gestational services”.*<sup>149</sup>

An alternative distinction is between ‘harming’ and ‘not helping’,<sup>150</sup> although this probably does not resolve the issues already highlighted. The existence of pre-existing obligations to assist or rescue may be central to the ‘not helping’ category, but in the absence of positive duties to act, we probably have to question whether it is ever permissible to kill when the option to let die is also available without additional burden on the agent.<sup>151</sup> Ultimately, these considerations have implications for the termination methods selected and become important when external fetal support becomes a routine reality.

### **Self or private defence**

If termination of pregnancy is characterised as a positive act (killing), it might be morally permissible for the pregnant woman to defend herself against an imminent threat to her life. If we set aside the woman’s potential responsibility for the creation of that threat, this would limit permissible termination to circumstances involving an imminent threat to the life of the agent bringing about the death of the entity. For 3<sup>rd</sup> party intervenors, the moral foundation cannot be based on the defence of their own personal right to life because the threat is not being made against them. In any event, the intervening agent is limited to a necessary, immediate and proportionate response, which may not involve bringing about the death of the viable fetus. It is also doubtful whether self/ private defence can provide a moral excuse or justification, when the

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<sup>146</sup> cf Greasley (n59), chp 3.

<sup>147</sup> Cf *Bland v Airedale NHS Trust* [1993] AC 789.

<sup>148</sup> Greasley (n59), 57.

<sup>149</sup> Ibid.

<sup>150</sup> Philippa Foot, ‘The Problem of Abortion and the Doctrine of the Double Effect’, (1967). *Oxford Review*, No. 5; cf Greasley (n59), 54.

<sup>151</sup> See Greasley (n59), 55-57.

threat comes from an innocent, non-culpable and potentially 'non-responsible' entity.<sup>152</sup> It is also problematic to characterise the embryo or fetus as an active aggressor.<sup>153</sup>

### **Gradualist and aggregation theories**

Gradualism challenges any claim or belief that human personhood occurs or is otherwise acquired at a single determinate point in time.<sup>154</sup> Gradualist theories claim a progressive shift in moral status rather than using a single fixed point in development. For example, Michael Lockwood claims that there is a gradual progression from human organism to human being to human person with differential rights and moral status acquired during development.<sup>155</sup> He is unable to state precisely when these shifts occur and offers a graduated rather than an 'all or nothing' approach. On the face of things, gradualism offers a pragmatic approach, avoids arbitrary cut offs and plays to our intuitions about pregnancy. However, these theoretical positions will never satisfy those who argue for clear and determinate lines around moral status.<sup>156</sup>

Notably, Kate Greasley asserts that many gradualist accounts are not actually claiming that the unborn entity is "*continuously accruing moral status*" during pregnancy.<sup>157</sup> In many cases, it is the acquisition of specific attributes or capacities that tip the balance in favour of human personhood. Indeed, Greasley claims that chronological closeness to personhood cannot (on its own) provide a sufficient basis for a change in moral status.<sup>158</sup> Gradualism needs to demonstrate the basis for a progressive shift in moral status,<sup>158</sup> and the answer may come from the aggregated cluster or multi-property approaches discussed earlier. For her part, Greasley attaches specific weight to the concept of individuated human embodiment – the extent to which the unborn entity takes on the archetypal form of an embodied human person - claiming that this helps explain why we might regard "*earlier and later developed fetuses differently*", and associate increasing moral respect to growing human embodiment.<sup>159</sup> Similarly, Carson Strong connects increasing moral status with the "*the acquisition of an increasing number of morally relevant similarities to the paradigm*".<sup>160</sup> These specific approaches enable gradualists to answer speciesist claims challenging capacity or attribute centric theories of moral status.

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<sup>152</sup> McMahan 2002 (n43), 398-421; Greasley (n59), 59-66.

<sup>153</sup> Greasley (n59), 61-63.

<sup>154</sup> See for eg Greasley (n59), 7; Scott (n119), 160; McMahan (n43).

<sup>155</sup> Michael Lockwood, 'When does life begin?' chp 1 in *Moral Dilemmas in Modern Medicine* (OUP 1985).

<sup>156</sup> Wolf-Devine and Devine (n39), 89-90.

<sup>157</sup> Greasley (n59), 148-149.

<sup>158</sup> *Ibid.*, 178.

<sup>159</sup> *Ibid.*, 172.

<sup>160</sup> Carson Strong, 'Overview: a framework for reproductive ethics', chp 2 in Donna Dickenson (ed), *Ethical Issues in Maternal-fetal Medicine* (Cambridge University Press 2002), chp 2.

The other significant difficulty for gradualism to overcome is the fact of variation in capacity and attributes during the course of human life. As discussed, transient variation may be easier to address than more permanent states of affair. Greasley attempts to circumvent the issue by claiming that personhood is a “*range property*” which allows for some variation across the human race,<sup>161</sup> thereby avoiding the impression of arbitrariness when selecting a single point (eg birth) as the basis for making moral distinctions. This does not provide a solution without some consensus on the scope of the “range property” but it does provide a broader platform for negotiating compromise.

### **Procreative beneficence<sup>162</sup>**

Beneficent theories claim parental (moral) obligations to create children with the best possible chance of the best life and these obligations can be divided into negative duties not to cause harm and positive duties to maximise available benefits. These theories assert that there are circumstances (eg certain anomalies) when causing death, or allowing an entity to die, provides a positive benefit and involves no actual harm to the entity involved. The concept of ‘best life’ is contentious because it involves ostensible moral judgements about different kinds of human life and exposes these approaches to accusations of unwarranted discrimination and the expression of hurtful beliefs. Indeed, ethicists like Savulescu and Kahane are keen to distance themselves from such attacks and reject any claim that their articulation ‘*expresses a discriminatory and hurtful attitude towards people with species atypical traits.*’<sup>163</sup> .

The concept of ‘death as a benefit’ maintains that the wrongness of killing is fundamentally due to the harm it inflicts on the victim. So, if death brings benefit to that entity, killing that being should not be a prima-facie wrong. However, these approaches require an assessment of benefit/ harm for an entity that is unable to communicate or exist independently. Anomalous conditions might cause suffering but not all such conditions involve immediate or continuous pain and discomfort. Things get even more complicated if we introduce possible future disability or deterioration, or the risk of false positive diagnostic findings prior to termination. Of course, there is a danger in using abstract or consequential concepts of harm or benefit to justify the ending of life; and any satisfactory theory needs to address the appropriate degree of harm that would qualify for the “*better off dead*” outcome.<sup>164</sup> Consequential

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<sup>161</sup> Greasley (n59), 183.

<sup>162</sup> Julian Savulescu and Guy Kahane, ‘The moral obligation to create children with the best chance of the best life’, (2009) 23(5) *Bioethics* 274; Guido Pennings, ‘Selective termination, fetal reduction and analogical reasoning’ (2013) 26(6) *Reproductive Bio-Medicine Online (Elsevier Science)* 525.

<sup>163</sup> Ibid.

<sup>164</sup> Wilkinson (n133), Chp 3.

articulations may dwell on broader societal good or benefit, but still run the risk of being pejoratively labelled 'eugenic'.<sup>165</sup> However, if the entity has no relevant moral status, there is no need to count or assess the benefit or harm to that being when taking or omitting to take steps against it.

### **Private v public morality**

The basic claim here is that reproductive health decisions should be a matter for private rather than public morality, and accordingly, it is inappropriate to regulate terminations and the pregnancy relationship using public law.<sup>166</sup> However, the private/public dichotomy is problematic because it is not always possible to draw a precise boundary between the two areas.<sup>167</sup> Indeed, Wicks argues that an activity can remain private "*even when conducted partially in public*",<sup>168</sup> and to determine the issue:

*"it is necessary to question the nature of the activity, the nature of the choice made by all parties, and the potential consequences of the conduct."*<sup>169</sup>

Further, she claims that where "*choices about the body...cause harm to others*", it is unnecessary to "*dismantle the entire dividing line between public and private spheres*";<sup>170</sup> instead determining the issue by reference to the impact on 'other' entities. Wick's approach still leaves the difficulty of determining that impact and the status of those 'other' entities.

MacKinnon claims that that there are clear public interests at stake in this arena - the need to secure gender equality – and confining matters to the private sphere is problematic if women are not actually free and equal in that domain.<sup>171</sup> Greasley counters that the sex equality interest is insufficient (by itself) to justify terminations of pregnancy<sup>172</sup> because she maintains that it is child rearing and related obligations, and not pregnancy that chiefly undermine or disadvantage women. However, Greasley's argument takes a fairly broad view of disadvantage and discounts any impact during the pregnancy period.

### **Intuition**

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<sup>165</sup> Ibid., 18.

<sup>166</sup> A. Jaggar in Tooley et al. 2009 (n30).

<sup>167</sup> Wicks (n103), 21.

<sup>168</sup> Ibid., 27.

<sup>169</sup> Ibid., 31.

<sup>170</sup> Ibid., 33.

<sup>171</sup> Catharine A. MacKinnon, 'Privacy v Equality: Beyond Roe v Wade', in Catharine A. MacKinnon, *Feminism Unmodified: Discourses on Life and Law* (Harvard University Press 1987).

<sup>172</sup> Greasley (n59), 98-100.

Intuitive approaches claim that moral status is a matter of common sense,<sup>173</sup> rely upon substantial consensus within a community,<sup>174</sup> and clearly link to extrinsic considerations. These approaches do not provide a solid moral foundation or establish the correctness of any moral theory without independent justification;<sup>175</sup> and fail in circumstances where there is significant cultural or religious variation around the value of specific life.<sup>176</sup>

### **Intrinsic value of human life**

In *Life's Dominion*, Ronald Dworkin claims that there are two distinct questions that are often, and mistakenly, conflated in the abortion debate: (1) when does a human creature acquire interests and rights; and (2) when does the life of a human creature acquire intrinsic value independent of use and with what consequences?<sup>177</sup> The first question generates polarised answers to the question of human personhood. However, Dworkin claims that there is a large degree of agreement over the second question, although, we interpret the idea of 'intrinsic value' in different ways. Ultimately, what we deplore is the frustration of life, not its mere absence and any wrong involves a disregard of that intrinsic value. This approach seeks to highlight where and why we disagree, and to demonstrate that those disagreements are "*as at bottom spiritual*".<sup>178</sup> Dworkin argues that the interpretation of 'intrinsic value' will determine our legal and moral responses to abortion.

McMahan claims that this approach (if restricted to humans) is speciesist because it "*groundlessly attributes greater value to a human organism than to comparable organisms*".<sup>179</sup> He also challenges Dworkin's assessment of value by the reference to investments in life by those other than the entity itself. Greasley's principally objects to Dworkin's circumvention of the personhood issue and claims that his second question still requires us to:

*"hypothesize a point in the development of human life when terminating that life for anything other than saving the lives of a greater number is an impermissible affront to life's sacred value, the obvious question then being just what it is that ushers in this enhanced moral status. In other words, whose life is sacred, and why?"*.<sup>180</sup>

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<sup>173</sup> Wolf-Devine & Devine (n39), 83.

<sup>174</sup> Warren (n5), 4-5.

<sup>175</sup> Millum (n119), 7-13.

<sup>176</sup> Warren (n5); Tooley et al 2009 (n30), 189-191.

<sup>177</sup> Dworkin (n3), 511.

<sup>178</sup> Ibid.

<sup>179</sup> McMahan (n43), 268.

<sup>180</sup> Greasley (n59), 31.

## Conferred moral standing

If an entity has no intrinsic moral status, can we confer moral standing on them for consequentialist or other reasons?<sup>181</sup> Some precautionary theories answer in the affirmative - for example, the 'golden rule' claims:

*"my life is worth living; I was once like you; you are the vehicle through which I came into existence; I am glad I was not terminated"*.<sup>182</sup>

This has links to potentiality, although the focus is on a backward, rather than a forward-looking assessment of the value of life. Interestingly, the Roman Catholic Church have claimed that a human embryo '*must be treated from conception as a person*',<sup>183</sup> a statement attempting to confer moral personhood to that entity.<sup>184</sup>

## Avoiding the issue of moral status

David Boonin contends that two separate questions need to be addressed in the debate: (1) is abortion moral or immoral and (2) should abortion be legal or illegal.<sup>185</sup> So far, we have concentrated on the first question but Boonin claims there are legitimate reasons for offering legal protection to the fetus even absent any moral claim to that protection.<sup>186</sup> One of the key societal issues is whether the law should compel a person to be a good samaritan or even a minimally decent one.<sup>187</sup> Is it legitimate for the law to compel a woman to continue a pregnancy and can we go to Boonin's second question, without properly addressing the first?<sup>188</sup> Agreement on the former is unlikely within pluralistic society but this has not prevented many States from addressing the second question. Keown accuses the Warnock Committee<sup>189</sup> of fudging the question of embryonic human status and going "*straight to the question of how it is right to treat the embryo*",<sup>190</sup> although Scott reminds us that the "*language of rights is not the only valid moral or legal currency*".<sup>191</sup>

## Combined approaches

Some theories combine permissibility arguments in an attempt to deliver the decisive blow. For example, McMahan seeks to combine his TRIA theory with Judith

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<sup>181</sup> Strong (n160). Cf Watt (n97), 24.

<sup>182</sup> Boonin (n54), chapter 5.4; see also McMahan 2002 (n43), 269.

<sup>183</sup> Roman Catholic Church, *The Catechism of Church* (1997) 2274.

<sup>184</sup> Tooley 2009 (n30), 16.

<sup>185</sup> Boonin (n54), 4.

<sup>186</sup> Boonin (n54), 7.

<sup>187</sup> Thomson (n3), 65.

<sup>188</sup> Cf Greasley (n59), Part 1.

<sup>189</sup> Warnock (n8).

<sup>190</sup> Keown (n44), chapter 8.

<sup>191</sup> Scott, (n119) 161.

Thomson's rights-based theory.<sup>192</sup> The most effective combined theories work hard to address the following issues: (1) what entities and with what properties have a moral status and a right to life and when? (2) what does that right to life entail/include?;(3) is killing an entity with a right to life and letting that same entity die a prima facie wrong?; (4) if so, are any exceptions morally justified and in what circumstances?; (5) what do we do when moral and/or metaphysical status is unclear or controversial?; (6) should assessment of moral status, value etc focus solely on the entity or on matters extrinsic to that entity?; (7) what matters should we take into account when assessing the 'wrongness' of killing and/or letting die?; (8) when and in what circumstances do humans no longer possess the full moral status of a human person?

### 3.8 Permissibility of selective termination and fetal reduction in multiple pregnancy

In this section, we examine the permissibility arguments for selective termination and fetal reduction in multiple pregnancy. First, we should consider whether the ethical/moral issues for selective termination differ from singleton terminations on the grounds of fetal anomaly? In many cases, the only distinguishing feature will be the technical issues associated with managing a 'selective' procedure, but there may be differences associated with the maternal health risks of multiple pregnancy, the targeted fetus and the clinical procedure. The health risks for the unborn entity may differ because multiple pregnancy elevates fetal mortality and prematurity rates and those risks increase with the numeric order. The termination procedure may involve some risk for the planned survivors especially in monochorionic pregnancies. We also find ourselves confronted by uncomfortable beneficent arguments seeking to differentiate the value of certain unborn life. Our working definition of selective termination also embraces conditions in the anomalous fetus that could be "*prejudicial to the development*" of the ostensibly healthy ones.<sup>193</sup> These procedures may therefore entail mixed or differentiated goals - to avoid future suffering for the anomalous fetus and at the same time preserve/ protect the life of the healthy remainers. Socio-economic (extrinsic) considerations may also feature – are the parents likely to cope and afford the caring responsibility of a child with disability in combination with their responsibility for additional and existing children.

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<sup>192</sup> McMahan (n43).

<sup>193</sup> Legendre et al. (n1), 543.



Again, the distinguishing features of fetal reduction may be technical/ numerical, but may engage consideration of ‘if and when’ it is ever appropriate to terminate a healthy fetus to save the ‘lives’ of others?<sup>194</sup> This is frequently characterised as the ‘lifeboat dilemma’,<sup>195</sup> although the analogy is often misapplied and presupposes relevant moral status for each entity in the scenario.<sup>196</sup> The analogy is essentially deployed to support a goal orientated, and specifically utilitarian argument, about achieving the greatest good for the least harm. Pennings contends that the lifeboat analogy can only be deployed in a utilitarian argument if the chances for the remaining fetuses increase significantly by the termination; the termination does not hold a significant risk for the surviving fetuses; and scarcity is such that all cannot survive.<sup>197</sup> These conditions may not be satisfied in lower order multiples, especially where singleton preservation is planned.<sup>198</sup>

These procedures involve multiple participants: the pregnant woman, the healthcare professionals and the embryo/fetuses. Realistically, the treating clinicians cannot be said to be in or on the lifeboat. The embryos or fetuses may be on the lifeboat but they do not have the capacity or liberty to decide whether to stay or go. The pregnant woman usually requires medical assistance but is she in the boat or is her body the lifeboat in this analogy? Users of the analogy need to make the position clear. If we take one oft-cited example:

*“After the loss of a vessel at sea, when a life boat is absolutely full, but some passengers remain in the water, a decision must be made about whether it is appropriate to refuse admission to one or more people who are in danger of drowning. In that situation, if additional passengers are brought on board, the life boat might sink and the lives of all those in the boat may be lost. On the other hand, refusing to lift someone out of the ocean may very well be a condemnation to death for that individual.”<sup>199</sup>*

This variant does not make things clear because even if the lifeboat is the womb, it is artificial to suggest that the fetuses are capable of making decisions or letting others on board. If the analogy places the fetal lives at ‘sea’, who or what is the lifeboat and who is the person making the decision to save?

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<sup>194</sup> Jeffrey Wale, ‘Selective termination of pregnancy and fetal reduction in multiple pregnancy: terminology, blurred lines and ethical discourse’, <[https://www.researchgate.net/publication/303882409\\_Selective\\_termination\\_of\\_pregnancy\\_and\\_fetal\\_reduction\\_in\\_multiple\\_pregnancy\\_terminology\\_blurred\\_lines\\_and\\_ethical\\_discourse](https://www.researchgate.net/publication/303882409_Selective_termination_of_pregnancy_and_fetal_reduction_in_multiple_pregnancy_terminology_blurred_lines_and_ethical_discourse)> accessed 20 July 2018.

<sup>195</sup> Richard L. Berkowitz, ‘Ethical Issues Involving Multifetal Pregnancies’, (1998) 65(3) *Mount Sinai Journal of Medicine* 185; Bernard Dickens and Rebecca Cook, 2008, ‘Multiple pregnancy: legal & ethical issues’, (2008) 103(3) *Int Journal of G & O* 270; Jacques Milliez and Bernard Dickens, ‘Ethical aspects of multiple pregnancy’, (2009) 3(1) *Int J of Fertility & Sterility* 41; R. Katie Morris and Mark D. Kilby, ‘Fetal Reduction’, (2010) 20(11) *Obs, Gynae & Reprod Med* 341.

<sup>196</sup> Wale (n194).

<sup>197</sup> Pennings (n162), 526.

<sup>198</sup> See Table 2A/ appendix E.

<sup>199</sup> Berkowitz (n195), 189.

However, the real problem with the lifeboat analogy is that it presupposes that the participants have a morally relevant status. Without this status, there is no conflict between the pregnant woman and the unborn entities or between them.<sup>200</sup> In the absence of relevant moral status, the permissibility arguments come back to maternal rights, intrinsic value and conferred moral protection. If some moral status is assumed or otherwise conferred to the unborn entities, the interaction between fetal and maternal rights and interests becomes far more complex than in a singleton pregnancy. In many terminations there will be an autonomous choice; but with high order multiples the choice to terminate may not be an entirely free one due to the health risks associated with the multiple pregnancy. The fetuses will probably have equal moral status (and comparable rights) but a determination will still need to be made as to which entity to reduce. In artificial conception, we might focus on possible parental foresight of the risk of multiple gestation to maintain a special obligation to gestate, although we would still need to address competing considerations threatening that pregnancy and wider entity survival or health.

So, can it ever be permissible to terminate the life of an ostensibly healthy life to save, preserve or improve the life of another, and how should we go about resolving any conflict?

**[The following discussion presupposes relevant moral fetal status]**

A goal orientated and specifically utilitarian ethical approach would claim that it is legitimate to achieve the greatest good for the least harm, subject to the limitation identified by Pennings above.<sup>201</sup> It is legitimate to count the benefit/harm in relation “to all those affected by an action” but on one account, only “to those judged capable of experiencing pain or pleasure, having preferences and so on”.<sup>202</sup> It is unlikely that the doctor can count as an affected party, although the pregnant woman will not be able to access the procedure without significant medical assistance.

A differentiated goal argument based on the preservation of life would exclude cases where there is a primary socio-economic reason for the reduction.<sup>203</sup> These arguments focus on the ‘end’ or outcome rather than the ‘means’ or side effects of an action, and are frequently advanced under the guise of the ‘double effect’ doctrine which claims that it is sometimes permissible to undertake an act that has a bad

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<sup>200</sup> Pennings (n162), 526; Roger Brownsword, *Rights, Regulation and the technological revolution* (Oxford University Press 2008)

<sup>201</sup> Pennings (n162), 526.

<sup>202</sup> Brownsword (n200),

<sup>203</sup> Eg financial factors.

effect.<sup>204</sup> The doctrine rests on a particular definition of good/bad effect, and relies heavily on maintaining a moral distinction between intention and foresight. These are matters that are heavily contested in the academic literature,<sup>205</sup> and difficult to justify at a practical level.

Duty based ethical theory also presents a challenge for these procedures. For example, deontological theory requires that no one should be treated merely as a means to an end. Doctors might claim a right to protect the life of the pregnant woman or fetus, but even if this was possible, they would be limited to immediately necessary and proportionate protection, and they would not be able to ground their actions on a threat against their own right to life. Similarly, the pregnant woman could only terminate, if life is immediately and substantially threatened by the pregnancy, and termination was the only realistic option to avert or materially reduce the risk of that outcome. Alternative duty-based articulations<sup>206</sup> are unlikely to assist unless the pregnant woman's life is at substantial risk. The relevance of rights based ethical theory will ultimately turn on the priority given to maternal autonomy and liberty.<sup>207</sup>

### 3.9 The connections between moral norms/ status and legal protection/ interests<sup>208</sup>

In this section, we consider the second of Boonin's questions, namely whether termination of pregnancy should be lawful.<sup>209</sup> We will put to one side any technical difference between legality and lawfulness. To address Boonin's question, we need to explore the connection between moral norms/status and legal protection/liability. A direct connection between morality and the law is rooted in natural law theories, whilst legal positivists take a separationist approach to the issue to varying degrees.<sup>210</sup>

Responding to criticism by Dworkin (who conceptualised legal rights as a species of moral rights), Hart claims that:

*“Legal rights and duties are the point at which the law with its coercive resources respectively protects individual freedom and restricts it or confers on individuals or denies to them the power to avail themselves of the law’s*

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<sup>204</sup> Beauchamp & Childress (n4), 165.

<sup>205</sup> Paula Foot, *Virtues and Vices and Other Essays in Moral Philosophy* (Blackwells 1978).

<sup>206</sup> Eg Dignitarianism (Beyleveld and Brownsword (n89)).

<sup>207</sup> Wale (n194).

<sup>208</sup> For discussion of the connection between moral status and moral protection, see Beauchamp & Childress (n4), chp 3.

<sup>209</sup> Boonin (n54), 4.

<sup>210</sup> Raymond Wacks, *Understanding Jurisprudence* (4<sup>th</sup> ed, OUP 2015), 126-131.

*coercive machinery. So whether the laws are morally good or bad, just or unjust, rights and duties demand attention as focal points in the operations of the law which are of supreme importance to human beings and independently of moral merits of the laws. It is therefore untrue that statements of legal rights and duties can only make sense in the real world if there is some moral ground for asserting their existence”.*<sup>211</sup>

However, there are dangers in adopting an entirely separatist stance because laws that are incompatible with moral norms are likely to be viewed as unjust by the communities on which they are imposed with consequences for acceptance and enforcement. From a practical perspective, we should also consider whether the law is the most appropriate vehicle for pursuing moral ‘ideals’ - as opposed to setting minimum standards – and, for prioritising community rather than individualist goals. We may also want to distinguish between the issue (public or private domain), type of law (criminal or civil) or the social goals of regulatory intervention. Divergence may not be acceptable in sensitive areas with far reaching ramifications for individuals within the community. In the context of end of life decision-making, Hoffmann LJ asserted:

*“This is not an area [in] which any difference can be allowed to exist between what is legally and morally right. The decision of the court should be able to carry conviction with the ordinary person as being based not merely on legal precedent but also upon acceptable ethical values”*<sup>212</sup>

Even in less significant cases, Hoffmann LJ claimed that law must still be decided with “regard to the general moral considerations”,<sup>213</sup> although his framing clearly affords the judiciary with a degree of discretion. This may not be problematic in our context because:

*“the law may have the elbow-room to frame its permissions more loosely than those of morality if the moral cost of abortion does not entail murder, but involves some less grave kind of wrong”*<sup>214</sup>

The acceptable gap between what is legal and ethical will be an issue to which we return.

So far, we have been assuming that it is possible to determine clear moral norms but how might the law respond where there is clear polarity within a community or sections thereof? One response might be to attempt to broker a consensus, although this will probably be easier, if the divergence is narrow or otherwise lacking sensitivity. This process may be facilitated by framing the dispute in a way that emphasises points of

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<sup>211</sup> Leslie Green, Joseph Raz and Penelope A. Bulloch, *HLA Hart’s ‘The Concept of Law’* (3rd ed, Oxford University Press 2012), 269.

<sup>212</sup> *Airedale NHS Trust v Bland* [1993] AC 789 (HL).

<sup>213</sup> *Ibid.*

<sup>214</sup> Greasley (n59), 4.

convergence rather than divergence.<sup>215</sup> Although divergent opinions “*must be accommodated within the law*”,<sup>216</sup> it may not be possible to achieve sufficient agreement on core moral issues or legal rules/ethical codes capable of resolving all moral conflict.<sup>217</sup> Law makers have to decide how to mediate between competing views and there is an inherent danger that one view is enforced or preferred over another.<sup>218</sup> In Great Britain, that accommodation has taken place by fudging the issue of entity status and by medicalising the lawful access and decision-making processes around termination of pregnancy.<sup>219</sup>

Further, not all aspects of a legal system necessarily have the same functions or objectives. The criminal and civil law have distinct roles and objectives; the former being concerned with punishment, retribution and deterrence; and the latter upon remedies for the wronged/ loss sufferers. Notwithstanding overlap, there are differing priorities, and we need to be cognisant of the most appropriate/ effective vehicles to impose liability or to secure protection for the stakeholders involved. The social goals, degree of likely harm, and the culpability of the individuals concerned, all feed into this discourse. Even if the embryo or fetus have no status as a ‘human person’, a State might still legitimately impose barriers to protect women, the possible future person and the wider societal interests associated with human reproduction. There may also be societal consequences for removing legal protection or barriers,<sup>220</sup> and ultimately, legal rules in areas of moral controversy are often the product of political resolution.<sup>221</sup> Scott makes this telling comment:

*“but as a matter of public policy it may be important to give the embryo some legal protection so as to accommodate to some degree differing moral perspectives on it. Further, that the law can protect the embryo (or fetus) to some degree even though it lacks moral and legal rights reminds us that the language of rights is not the only valid moral or legal currency”.*<sup>222</sup>

### 3.10 Conclusions

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<sup>215</sup> Eg, as per Dworkin (n3).

<sup>216</sup> Amel Alghrani, Rebecca Bennet and Suzanne Ost, *Bioethics, Medicine, and the Criminal Law, Volume I, The Criminal Law & Bioethical Conflict: Walking the Tightrope* (Cambridge University Press 2013), chp12.

<sup>217</sup> Beauchamp & Childress (n4).

<sup>218</sup> Margaret Brazier and Suzanne Ost, *Bioethics, Medicine, and the Criminal Law, Volume III, Medicine and Bioethics in the Theatre of the Criminal Process* (Cambridge University Press 2013).

<sup>219</sup> See Roger Brownsword and Jeffrey Wale, ‘Compromise Medicalisation’ in C. Stanton and others (eds), *Pioneering Health Care Law Essays: In honour of the work of Professor Margaret Brazier* (Routledge 2015)

<sup>220</sup> For example, *R v Morgentaler* [1998] 3 SCR 463 effectively decriminalised abortion in Canada but produced more legal battles and greater barriers for women seeking terminations in that State (Brazier & Ost (n218)).

<sup>221</sup> Brazier and Ost (n218). Cf Greasley (n59), Chp 9.

<sup>222</sup> Scott (n119),161.

There are clearly divergent positions on the appropriate moral responses to these medical procedures. This poses a challenge for law makers and legal actors especially when the ramifications are so personal, significant and varied. One principal difficulty for law makers, is striking an appropriate balance between flexibility and determinancy (eg in setting standards and resolving disputes) so as to influence and direct professional behaviours in this context. It also raises an interesting question about the extent to which personal values and beliefs should be accommodated in professional medical practice. These are matters that we will further examine in later chapters.

Our analysis reveals a significant overlap in the ethical considerations around the termination of singleton and multiple pregnancies, but the presence/ development of multiple unborn lives generate additional tensions, possible conflict and considerations for the key decision-makers. What we make of the multiple factor will be influenced by the value and weight we place on intrinsic/ extrinsic and consequentialist considerations. If your starting point, is that there are no significant interests at stake other than those of the pregnant woman, there will be limited moral divergence between the singleton and multiple procedures. However, if fetal interests are recognised and linked to the quality of future life, we have a number of specific ethical considerations in play.

What does this background mean for doctors wanting to do the right thing in relation to fetal reduction and selective termination? First, moral conflict, tension or ambiguity cannot be avoided entirely because the moral/ethical norms are neither stable, or agreed across society. Secondly, this context makes it very difficult for doctors, and healthcare professionals generally, to work in fetal medicine unless they have a permissive attitude to termination or otherwise feel able to exclude their personal views from daily professional practice. Thirdly, any legal framework necessarily involves a degree of compromise within a divergent moral framework. As such, doctors cannot avoid the consequences of working within the conditions of that compromise.<sup>223</sup> Fourthly, the societal conditions and moral responses to these procedures are potentially subject to change over time and this has consequences for rigid and inflexible professional or legal frameworks. This in turn puts pressure on the people that have to work in and around those frameworks.

In closing, we should make our own ethical position clear as this may become important in responding to the third research question. We are generally in favour of

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<sup>223</sup> Brownsword and Wale (n219)

multi-property and gradualist accounts of moral status. Implantation or formation of the primitive streak appears to be a logical, albeit slightly indeterminate point for the start of human life. We do not accept that the intrinsic conditions immediately before and after birth are the same; and therefore, acknowledge human birth as a significant moral event. Nonetheless, we do not exclude the relevance of extrinsic factors but agree that such considerations are an insufficient basis for establishing moral status in the absence of intrinsic features.

This still leaves us to resolve three major issues. First, does the implanted human embryo or fetus have any morally significant interests prior to birth and is this subject to variation during the pregnancy? Secondly, if we recognise relevant interests, how should we address and balance them against the interests of the pregnant woman? Thirdly, how should we address any conflict or tension between different embryo or fetal interests in any decision to terminate?

In answer to the first question, we are influenced by capacity considerations and the aggregation of characteristics. As such, we are willing to accept that fetal interests change and become relevant in the latter stages of the pregnancy. At the very least, we are persuaded of the case for moral protection changes post viability or the acquisition of sentience. This flows into the second question, which is dependent on whether we acknowledge that there is a conflict of interests arising from the termination of pregnancy. We are not persuaded that there is an inevitable clash of rights but acknowledge that the characterisation of feticide as an omission is problematic. In any event, we have no real hesitation that the woman's rights and interests should act as the trump in the pre viable/ sentient scenario. Thereafter, the position is less clear but if the continuation of the pregnancy is likely to cause serious harm or threat to the life of the woman, termination would appear to be a permissible outcome. In answer to the third question, if faced with a straight forward moral choice between no or some survivors, we are relatively untroubled by the consequential choice in favour of the latter. However, once we dilute the certainty of outcomes and remove the binary nature of the choice, we start to equivocate, at least in isolation to maternal interests. We are more certain about selection based on perceived quality of life arguments. Whilst, we accept that it might be permissible for parents to take these considerations into account, we do not accept that this should be converted into a moral obligation to terminate for anomaly / disability, whether significant or otherwise. Further, whilst consideration of fetal interests may be morally permissible, this should not convert any concern about anomaly or disability into a legal basis for termination. This is an issue that we will return to.

# Chapter 4 – Legal Frameworks (1)

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## 4.1 Introduction

This chapter maps out the general legal landscape, and in particular, the legal framework governing the termination of pregnancy, fetal reduction and selective termination. It also examines the legal treatment of in-utero/ ex-vivo human life and the wider human rights jurisprudence. Our central purpose is to examine how fetal reduction and selective termination decisions fit against the general backcloth of the law. We cannot get away from the broader legal framework, from its difficult parts or from the fact that there is a fair amount of law to draw upon. However, what we have strived to do, is to unpick the legal features, norms and issues that have particular relevance to these specific medical procedures. From there, we will hopefully have a clearer foundation to evaluate how the relevant legal norms align with professional norms and clinical practice.



## 4.2 Criminal Liability

### 4.2.1 Offences: England, Wales and Northern Ireland

The key abortion related offences are found in sections 58/ 59 of the Offences Against the Person Act 1861 (**OAPA 1861**), apply to England, Wales and Northern Ireland,<sup>1</sup> and have a maximum sentence on conviction of life imprisonment. Section 58 make it unlawful to administer certain substances, or to use instruments or other means with the intent to procure a miscarriage:

***“Administering drugs or using instruments to procure abortion***

*Every woman, being with child, who, with intent to procure her own miscarriage, shall unlawfully administer to herself any poison or other noxious thing, or shall unlawfully use any instrument or other means whatsoever with the like intent, and whosoever, with intent to procure the miscarriage of any woman, whether she be or be not with child, shall unlawfully administer to her or cause to be taken by her any poison or other noxious thing, or shall unlawfully use any instrument or other means whatsoever with the like intent, shall be guilty of felony, and being convicted thereof shall be liable ... to be kept in penal servitude for life.”*

The section 58 offence can be committed by the pregnant woman or a third party – the former can only commit the offence if ‘with child’ but there is no similar requirement for other principals. As we shall discover, the answer to what it means to be ‘with child’ is far from straightforward.

The actus reus of section 58 requires the unlawful administration of ‘poison or other noxious thing’ or the use of ‘any instrument or other means’ by the pregnant principal. Third party principals need to administer or ‘cause to be taken’ the poison or noxious thing, or to use an instrument or other means with intent. The requisite mens rea is ‘intent’ to procure a miscarriage. For third party principals, the prosecution must also prove that they believed that a pregnancy did exist – not that it did in fact exist – although mere suspicion of pregnancy will not suffice.<sup>2</sup>

Although section 58 is headed ‘to procure abortion’, this phrasing is absent in the textual wording which makes explicit reference to the term ‘miscarriage’. There is no explicit mention of in-utero fetal harm, and the focus of the mens rea element is on the

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<sup>1</sup> But not Scotland. These provisions no longer extend to the Republic of Ireland (Protection of Life During Pregnancy Act 2013, s5 (EIRE)).

<sup>2</sup> *R (John Smeaton on behalf of the Society for the Protection of Unborn Children) v Secretary of State for Health* [2002] EWHC 610 [234].

miscarriage of the pregnancy, rather than actual harm to the fetus or embryo. Miscarriage is not defined in the Act and it is unclear whether this term applies to the physical miscarriage of the whole pregnancy, or to one or more fetal life. There may be occasions where the bi-products of termination will not be physically expelled, and/or where there is a lack of intention to procure expulsion (eg in first trimester embryo reductions).<sup>3</sup> Grubb has suggested that:

*“The better view is, however, that the term “miscarriage” does not require expulsion of the contents of the womb but merely that some or all of the contents cease to be carried alive within it...In any event the argument overlooks the fact that ultimately, the withered and dead products of the fetus will be expelled at the time the remaining fetuses are delivered”<sup>4</sup>*

Munby J reviewed the legal authorities in *R (Smeaton)*<sup>5</sup> and ultimately agreed with Wright J in the earlier (unreported) case of *R v Dhingra*<sup>6/7</sup> (involving a doctor charged under section 58<sup>8</sup> for fitting an IUD prior to the implantation of a fertilised egg):

*“It turns, as it seems to me, upon the true construction in section 58 of the word “miscarriage”. Does it have the wider meaning of any external interference with the process of reproduction from the time of fertilization; or does it have the narrower meaning of the displacement from the woman’s womb, and subsequent loss of, an established pregnancy? It is this more restricted meaning that is used by the medical profession in modern times... I have come to the conclusion that I should adopt the narrower interpretation of this part of section 58, and hold that the word “miscarriage” in this context relates to the spontaneous expulsion of the products of pregnancy”<sup>9</sup>*

Grubb claims that the amendments to the Abortion Act 1967 (**AA 1967**) (as per section 37 of the Human Fertilisation and Embryology Act 1990 (**HFEA 1990**)) put the whole issue beyond doubt, because fetal reduction and selective termination in multiple pregnancy are now treated as ‘miscarriage’.<sup>10</sup> Indeed, the AA 1967 now directly and explicitly couples the termination of a ‘foetus’ with ‘miscarriage’.

Section 58 does not to apply during the process of birth. There has been historic debate over whether these provisions apply from fertilisation or implantation of the

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<sup>3</sup> See Alison Hall, ‘Selective Reduction of Pregnancy: A Legal Analysis’, (1996) 5 *Journal of Medical Ethics* 304.; Margaret Brazier, ‘Unfinished Feticide: a legal commentary’, (1990) *Journal of Medical Ethics* 16; Andrew Grubb, A., ‘The new law of abortion: clarification or ambiguity?’ (1991) *Crim L.R.* 659.

<sup>4</sup> Grubb (n3), 667.

<sup>5</sup> *R (Smeaton)* (n2), [231].

<sup>6</sup> (1991) (unreported).

<sup>7</sup> *R (Smeaton)* (n2) [243]-[255].

<sup>8</sup> OAPA 1861.

<sup>9</sup> *R (Smeaton)* (n2), [249].

<sup>10</sup> Abortion Act 1967 (as amended) s 5(2); Grubb (n3) 668.

egg.<sup>11</sup> Ultimately, Munby J decided that the term ‘miscarriage’ must be construed by ‘*what it means today*’ and the term now means the “*termination of an established pregnancy, and **there is no established pregnancy prior to implantation.***”<sup>12</sup> So, the criminal law conceives the start of a legal pregnancy as implantation - an interpretation that is consistent with the statutory provisions governing ex-vivo human life,<sup>13</sup> but problematic in a legal sense because the timing cannot be established with certainty. It also means that the criminal law only prohibits contraceptive mechanisms that interfere with the natural pregnancy processes post implantation.

What does the section 59 offence add if anything to the criminal framework?

***“Procuring drugs, etc., to cause abortion***

*Whosoever shall unlawfully supply or procure any poison or other noxious thing, or any instrument or thing whatsoever, knowing that the same is intended to be unlawfully used or employed with intent to procure the miscarriage of any woman, whether she be or be not with child, shall be guilty of a misdemeanor, and being convicted thereof shall be liable . . . to be kept in penal servitude . . .*

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The section title refers to abortion but again the text employs the term miscarriage. It is aimed at suppliers or procurers of substances/ instruments with knowledge of unlawful use or employment against ‘any woman’, irrespective of actual pregnancy. The principal must know that the ‘thing’ is intended to be used or employed unlawfully with intent to procure a miscarriage of any woman. This is clearly important to drug manufacturers and wholesalers who produce/ supply abortifacient products, and to manufacturers and suppliers of surgical equipment. Again, there is no clarity on the starting point for protection and knowledge is not defined but is likely to be construed as more than mere suspicion.<sup>15</sup>

Finally, we have the seminal case of *R v Bourne*,<sup>16</sup> involving a teenage girl (aged 15) who had been raped and subsequently fallen pregnant. The case is important to our understanding and interpretation of the criminal framework prior to the implementation of the AA 1967. Dr Bourne performed a termination of pregnancy on the girl without remuneration and was subsequently charged/ tried under section 58 OAPA 1861.

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<sup>11</sup> See for eg John Keown, ‘Miscarriage: a medico-legal analysis’, (1984) *Crim L Rev* 604.

<sup>12</sup> *R (Smeaton)* (n2), [17] [emphasis added].

<sup>13</sup> Human Fertilisation and Embryology Act 1990, s 2(3) states “*a woman is not to be treated as carrying a child until the embryo has become implanted*”.

<sup>14</sup> OAPA 1861, s 59. See *R v Gurpreet Kaur* [2015] (unreported) for a recent conviction:

(<<https://www.gov.uk/government/news/woman-sentenced-to-27-months-for-selling-abortion-pills-illegally>>access17 January 2019).

<sup>15</sup> As per Munby J in *R (Smeaton)* (n2).

<sup>16</sup> *R v Bourne* [1939] 1 KB 687 (HC)

Ultimately, he was found not guilty, but during the trial, Macnaghten J gave the infamous direction to the jury, qualifying section 58 with the meaning of section 1(1) of the Infant Life (Preservation) Act 1929 (**ILPA 1929**):

*“the burden rests on the Crown to satisfy you beyond reasonable doubt that the defendant did not procure the miscarriage of the girl in good faith for the purpose only of preserving her life. If the Crown fails to satisfy you of that, the defendant is entitled by the law of this land to a verdict of acquittal.”<sup>17</sup>*

Accordingly, section 58 should be construed so that there can be no conviction where the act - the administration or use - is performed in good faith for the sole purpose of preserving the life of the woman.<sup>18</sup> Further, Macnaghten J went on to direct the jury that this requirement “*ought to be construed in a reasonable sense*”<sup>19</sup> and made it clear that it was not restricted to cases where there was a risk of instant death:

*“if the doctor is of opinion, on reasonable grounds and with adequate knowledge, that the probable consequence of the continuance of the pregnancy will be to make the woman a physical or mental wreck, the jury are quite entitled to take the view that the doctor who, under those circumstances and in that honest belief, operates, is operating for the purpose of preserving the life of the mother”.*<sup>20</sup>

His interpretation of this section is therefore a broad one.

The Infant Life (Preservation) Act 1929 applies to England and Wales but not Scotland. The terms of this Act were materially replicated in Northern Ireland via the Criminal Justice Act (Northern Ireland) 1945. The original legislation was introduced because of a perceived loophole - section 58 did not offer any protection during the birth process, and domestic homicide law<sup>21</sup> requires the fetus to have acquired independent existence from the mother before applying.<sup>22</sup> It was therefore technically possible to kill a baby in the course of delivery without committing any criminal offence. The introduction to the Act states it is to “*amend the law with regard to the destruction of children at or before birth*” and has been used in relation to terminations of pregnancy and fetal killing at and before birth.<sup>23</sup> Section 1(1) provides:

### **“Punishment for child destruction**

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<sup>17</sup> Ibid., 691.

<sup>18</sup> According to Lord Mance this interpretation would extend to OAPA 1861, s 59 (*In the matter of an application by the Northern Ireland Human Rights Commission for Judicial Review (Northern Ireland)* [2018] UKSC 27, [77]).

<sup>19</sup> *Bourne* (n16), 693-694.

<sup>20</sup> Ibid., 694.

<sup>21</sup> In England, Wales and Northern Ireland.

<sup>22</sup> *Paton v Trustees of British Pregnancy Advisory Service* [1979] QB 276; *Attorney General's Reference (No 3 of 1994)* [1998] AC 245 (HL).

<sup>23</sup> For an example of the latter, see *The Guardian* (17 December 2015), <<https://www.theguardian.com/uk-news/2015/dec/17/man-convicted-of-killing-unborn-baby-by-kicking-pregnant-ex-girlfriend>> accessed 22 May 2017.

*Subject as hereinafter in this subsection provided, any person who, with intent to destroy the life of a child capable of being born alive, by any wilful act causes a child to die before it has an existence independent of its mother, shall be guilty of felony, to wit, of child destruction, and shall be liable on conviction thereof on indictment to penal servitude for life: Provided that no person shall be found guilty of an offence under this section unless it is proved that the act which caused the death of the child was not done in good faith for the purpose only of preserving the life of the mother.”*

The Act title focuses on “*infant life preservation*”, whereas section 1 is headed “*Punishment for child destruction*”. This couples protection with sanction and, unlike the OAPA 1861, explicitly directs its focus to a “*child capable of being born alive*”, a concept that appears to correlate with viability. The ILPA 1929 is silent about what “*capable of being born alive*” means, although section 1(2) does include a presumptive feature:

*“evidence that a woman had at any material time been pregnant for a period of twenty-eight weeks or more shall be primâ facie proof that she was at that time pregnant of a child capable of being born alive.”*

This provision assists the prosecution and forces defendants to adduce evidence on viability in the latter stages of pregnancy. However, the provision does not provide any assistance in calculating the starting point for protection, or any minimum duration for the pregnancy. In *C v S*, the claimant (the defendant’s former partner) argued that the ILPA 1929 applied to a pregnancy of 21 weeks duration.<sup>24</sup> The claimant unsuccessfully attempted to obtain injunctive relief to prevent a termination although, in any event, the defendant carried the child to term and gave the baby to the claimant after birth. In the Court of Appeal, Sir John Donaldson MR said:

*“We have no evidence of the state of the foetus being carried by the first defendant, but if it has reached the normal stage of development and so is incapable ever of breathing, it is not in our judgment “a child capable of being born alive” within the meaning of the Act and accordingly the termination of this pregnancy would not constitute an offence under the Infant Life (Preservation) Act 1929”<sup>25</sup>*

In *Rance & Rance & Others v Mid Downs Health Authority*, the doctors had failed to pick up an abnormality at the ultrasound scan in the 26 or 27<sup>th</sup> week of the Claimant’s pregnancy.<sup>26</sup> The child was subsequently born with abnormalities and the parents sued the health authority claiming that they were effectively denied the option of a lawful abortion by virtue of this omission. The health authority argued that by the

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<sup>24</sup> *C v S* [1988] QB 135 (CA).

<sup>25</sup> *Ibid.*, 151 H.

<sup>26</sup> *Rance & another v Mid Downs Health Authority* [1991] 1 QB 587 (HC).

26/27th week of pregnancy, the child was capable of being born alive and so any termination would have been unlawful under the 1929 Act at that time. Brooke J accepted this view and the claim was dismissed on the following basis:

*“In my judgment the meaning of the words "born alive" are clear, and the meaning of the words "capable of being born alive" are also clear... is each born alive if, after birth, it exists as a live child, that is to say, breathing and living by reason of its breathing through its own lungs alone, without deriving any of its living or power of living by or through any connection with its mother. For the purposes of this judgment I do not have to consider the case of life before breathing, which was referred to in Rex v. Brain, 6 C. & P. 349. Once the foetus has reached a state of development in the womb that it is capable, if born, of possessing those attributes, it is capable of being born alive within the meaning of the Act of 1929”<sup>27</sup>*

He explicitly rejected any suggestion that section 5(1) of the AA 1967 changed or modified the meaning of the ILPA 1929.<sup>28</sup>

Before the AA 1967 was amended<sup>29</sup>, the ILPA 1929 imposed a possible time restraint for lawful terminations once viability was achieved. Further, *C v S* made it clear that the 28 week time limit was only presumptive, and a pregnancies under 28 weeks could still fall under the protection of the ILPA 1929 if the fetus was ‘*capable of being born alive*’.<sup>30</sup> However, a time limit has now been imposed for the principal ground for termination by the AA 1967.<sup>31</sup> Grubb claims that Parliament may have inadvertently extended the time limit for legal terminations by the subsequent amendment to section 5(1) AA 1967 because now, even if a fetus is capable of being born alive, a termination will be lawful providing the doctors comply with their obligations under the AA 1967. However, the ILPA 1929 still covers situations which is not otherwise authorised by the AA 1967.<sup>32</sup> The imposition of a time limit via the AA 1967<sup>33</sup> has the effect of fixing (at least for S1(1)(a)) what would otherwise be a variable time limit dependent on available technology, knowledge and competence. Given that 90% of the terminations undertaken in England and Wales occur below 13 weeks, most singleton procedures are unaffected by these time restrictions in any event.<sup>34</sup>

The ILPA offence requires an ‘*intent to destroy the life of a child capable of being born*

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<sup>27</sup> *Ibid.*, 621 A.

<sup>28</sup> *Ibid.*, 621 F/G.

<sup>29</sup> By the HFEA 1990, s37.

<sup>30</sup> See also Grubb (n3), 664; Rance (n26).

<sup>31</sup> S1(1) (a).

<sup>32</sup> Grubb (n3), 664.

<sup>33</sup> S 1(1)(a).

<sup>34</sup> Department of Health & Social Care (DHSC), *Abortion Statistics, England & Wales, 2017* (DHSC Revised December 2018), para 2.24.

*alive*' and a *'wilful act'* causing death. The term *'wilful'* is likely to require a deliberate rather than a careless act, although the phrase adds little given the requirement of intent.<sup>35</sup> It is unclear whether an intention to cause some harm to the fetus would suffice although foresight of death as a virtual certainty of an act is likely to suffice.<sup>36</sup> Poor drafting also extends into the caveat in section 1(1) with the repeat use of negative terms: *'no person'*, *'unless'* and *'not done'*. What that section appears to be saying is that there can be no conviction if the act that causes the death of the *'child'* was undertaken in good faith and with the sole purpose of preserving the life of the mother.

There are also distinct common law provisions governing criminal offences against the person that result in death. In England, Wales and Northern Ireland, criminal homicide liability can only arise if a child dies after having obtained independent existence from the mother. Without independent existence, there is no *'reasonable creature in being'* for the purposes of the crime of murder - should the entity die before or during birth, there can be no conviction. In *Attorney General's Reference (No3 of 1994)*,<sup>37</sup> a pregnant woman was stabbed in the abdomen causing her baby to be born prematurely and the child subsequently died from the consequences of that prematurity. The House of Lords affirmed that the defendant could not be convicted of murder and there was no basis for extending the doctrine of transferred malice to a case where there had been no intention to injure the fetus. However, the defendant was convicted of unlawful act manslaughter – it was enough that the defendant had perpetrated an unlawful act that was objectively dangerous to a *'person'*, and (for the court's purposes) it did not matter that the unlawful act had been done prior to birth.

This should be contrasted with the subsequent Court of Appeal decision in *CP (A Child) v Criminal Injuries Compensation*.<sup>38</sup> This case concerned a child that had developed fetal alcohol spectrum disorder as result of maternal alcohol consumption during pregnancy. The legal issue was whether the child could claim under the Criminal Injuries Compensation Scheme as a victim of a crime. CP argued that her mother had committed an offence under section 23 of the Offences against the Person Act 1861 - namely that she had unlawfully administered to *"any other person any poison or other destructive or noxious thing"*, and had inflicted grievous bodily harm as a result. There was no dispute that the mother had administered the relevant *"thing"*

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<sup>35</sup> Michael Allen, *Textbook on Criminal Law* (11th ed, Oxford University Press 2011), 90-91.

<sup>36</sup> *R v Nedrick* [1986] 1 WLR 1025

<sup>37</sup> *Attorney General's Reference (No3 of 1994)* (n22).

<sup>38</sup> *CP (A Child) v CIC* [2014] EWCA Civ 1554



(excessive alcohol), or that CP had sustained the necessary degree of harm. What was in issue was whether CP was “*any other person under the Act*”. The Court of Appeal determined that CP did not satisfy the criteria and ruled against CP’s alternative argument that equated her situation with the common law offence of unlawful act manslaughter. This argument relied on the premise that a fetus becomes a person when born. However, the problem for CP was that the unlawful act<sup>39</sup> required the administration and the infliction of harm to be on “*a person*” - infliction of harm on an embryo or fetus would not suffice. CP’s attempt to circumvent this problem - by arguing that some harm was caused after birth - was also rejected because the fetal alcohol spectrum disorder had been factually caused before her birth. Any post-birth suffering was treated as a consequence of the harm suffered in the womb.<sup>40</sup> So a child once born, cannot claim they are a victim of crime as result of any injuries sustained during pregnancy and has no entitlement to criminal injuries compensation.<sup>41</sup> This means that a pregnant woman can lawfully cause some harm to her developing child (subject to civil liability<sup>42</sup>) but cannot otherwise terminate her pregnancy without lawful authority.<sup>43</sup>

### **Offences: England and Wales only**

The Births and Deaths Registration Act 1953<sup>44</sup> imposes post death registration requirements with criminal sanctions in England and Wales<sup>45</sup> for ‘*still born*’ children defined as:

*“a child which has issued forth from its mother after the twenty-fourth week of pregnancy and which did not at any time after being completely expelled from its mother breathe or show any other signs of life, and the expression “still-birth” shall be construed accordingly”<sup>46</sup>*

This statutory provision has three distinct requirements: (1) a child has issued forth from its mother; (2) after the 24<sup>th</sup> week of pregnancy and (3) at no time after expulsion did the child breathe or show any signs of life. The statute uses the language of ‘child’ rather than ‘fetus’ and is consonant with the workings of the ILPA 1929. The registration requirements do not apply to an unexpelled entity, or to one that has been

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<sup>39</sup> The conduct element of the section 23 offence.

<sup>40</sup> Jeffrey Wale, ‘Drinking can harm a foetus, but court finds girl born with disorder wasn’t victim of crime’, (2014b) *The Conversation*, <<https://theconversation.com/drinking-can-harm-a-foetus-but-court-finds-girl-born-with-disorder-wasnt-victim-of-crime-35119>> accessed 16 January 2015.

<sup>41</sup> Cf, civil liability under the Congenital Disabilities (Civil Liability) Act 1976.

<sup>42</sup> An exception applies to women driving when pregnant as per Congenital Disabilities (Civil Liability) Act 1976, s2.

<sup>43</sup> Margaret Brazier and Suzanne Ost, *Bioethics, medicine, and the criminal law, Volume III, Medicine and bioethics in the theatre of the criminal process* (Cambridge University Press 2013).

<sup>44</sup> As amended.

<sup>45</sup> ss 35-38.

<sup>46</sup> s 41.



completely expelled at/before the 24<sup>th</sup> week. The statute is also silent whether the expulsion needs to be a natural event although a broad construction is taken in practice. Although, there are no specific registration requirements where still birth expulsion occurs at or before the 24<sup>th</sup> week of pregnancy, regulatory guidance from the Human Tissue Authority still governs the handling and disposal of fetal and pregnancy remains.<sup>47</sup>

Whilst there are some synergies with the AA 1967, this is another example of the patchy legal framework addressing the legal status of the embryo/fetus. These provisions have specific implications for fetal reductions carried out in the later stages of pregnancy. The requirements for registration and burial permits (even when fetal products cannot be identified) are contentious. There have been various calls for legislative amendment, including registration based on the timing of fetal death rather than expulsion, and for registration at/ before 24 weeks of pregnancy.<sup>48</sup>

### **Offences: Scotland**

In Scotland, procuring a woman's miscarriage has long been a common law criminal offence.<sup>49</sup> Lawful abortions were possible before 1967, and there was some uncertainty whether it was necessary to include Scotland within the ambit of the AA 1967. Ultimately that Act was applied to Scotland although the Bourne scenario was unlikely to have provoked litigation because of the specific need for 'evil intent' in this jurisdiction.<sup>50</sup> Further, attempted abortion was only an offence if it could be proved the woman was actually pregnant because:

*"The victim of the crime of abortion or attempted abortion in Scots Law was the potential child, so that if there was no potential child there was no crime"*<sup>51</sup>

This position should be contrasted with sections 58/59 OAPA 1861 where the legal sanction is applied against third parties irrespective of whether the woman is pregnant. Whilst the protective provisions of the ILPA 1929 do not apply in Scotland, the death registration requirements are replicated via the Registration of Births, Deaths and Marriages (Scotland) Act 1965 (as amended).<sup>52</sup>

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<sup>47</sup> Human Tissue Authority, *Guidance on the disposal of pregnancy remains following pregnancy loss or termination* (HTA March 2015).

<sup>48</sup> K S. Joseph and others, 'Rationalising Definitions and Procedures for Optimising Clinical Care and Public Health in Fetal Death and Stillbirth' (2015) 125(4) *Obstetrics & Gynaecology* 784. See also Civil Partnerships, Marriages and Deaths (Registration Etc.) Act 2019, ss 3-4.

<sup>49</sup> Gayle Davis and Richard Davidson, 'A fifth freedom' or 'hideous atheistic expediency? The Medical Community and Abortion Law Reform in Scotland, c 1960-1975', (2006) 50 *Medical History* 29, 31-32.

<sup>50</sup> John Mason and Graeme Laurie, *Mason & McCall Smith's 'Law & Medical Ethics* (OUP 2013), 335.

<sup>51</sup> Davis and Davidson (n49), 32.

<sup>52</sup> s 56

## Summary

It is apparent that fetal reduction and selective termination are subject to the general criminal law framework. Our analysis reveals that there is a patchwork quilt of criminal offences making up the ‘*law relating to abortion*’,<sup>53</sup> obfuscated by inconsistent approaches to legal protection and statutory terminology. Although non-literal approaches to statutory interpretation have helped, there are ongoing tensions created by the failure to update and consolidate the different pockets of legislation.

### 4.2.2 Defences

We now move on to examine the wider defence framework in more detail.

#### Defences: Northern Ireland

The AA 1967 does not apply in Northern Ireland but the material provisions of the ILPA 1929 are replicated by section 25 of the Criminal Justice Act (Northern Ireland) 1945. The law in Northern Ireland is summarised in the appellate decision in *Family Planning Association of Northern Ireland v Minister for Health & Social Services & Public Safety*:

*“Operations in Northern Ireland for the termination of pregnancies are unlawful unless performed in good faith for the purpose of preserving the life of the mother;  
·The ‘life’ of the mother in this context has been interpreted by the courts as including her physical and mental health;”*<sup>54</sup>

This settled and restrictive position was challenged by the Northern Ireland Human Rights Commission for Judicial Review claiming that the law was incompatible with Article 3 (the prohibition of torture and inhuman or degrading treatment), Article 8 (right to respect for private and family life) and Article 14 (prohibition of discrimination) of the European Convention on Human Rights (the NIHRC case). Their challenge was limited to the legal prohibition of terminations of pregnancy (a) involving fetal abnormality, and (b) arising from sexual crime and (c) from incest. The challenge partially succeeded in the High Court – a declaration of incompatibility for pregnancies resulting from sexual crime or involving fatal fetal abnormality was made for a breach of Article 8 (but not Articles 3 and 14).<sup>55</sup> However, the challenge subsequently failed in

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<sup>53</sup> Abortion Act 1967, ss 1(1) and 6.

<sup>54</sup> [2004] NICA 37 [12] (Shiel LJ).

<sup>55</sup> *The Northern Ireland Human Rights Commission’s Application* [2015] NIQB 96.

the Northern Ireland Court of Appeal.<sup>56</sup> Although the court accepted that the Commission had standing to bring the claim, these matters were ultimately an issue for the Northern Ireland Assembly to decide. However, the Northern Ireland Assembly has not supported a change to the law<sup>57</sup> and has been unable to consider the matter again since it ceased legislative activities in January 2017.

Executive guidance to healthcare professionals has continued to be restrictive,<sup>58</sup> but the 2016 version now makes it clear that it is lawful to give advice on the lawful use of abortion services outside of Northern Ireland.<sup>59</sup> In *R (on the application of A and B)*, King J rejected a challenge claiming free NHS abortion services for Northern Ireland nationals not ordinarily resident in England.<sup>60</sup> This judgment was subsequently upheld by the UK Supreme Court,<sup>61</sup> although in a subsequent U turn, the UK Government confirmed that they would be making public funding available for Northern Ireland residents accessing termination services in England.<sup>62</sup>

This takes us onto the NIHRC appeal in the UK Supreme Court.<sup>63</sup> It proved critical that the appeal/ action had been brought in the name of the Commission rather than named victims. The Northern Ireland Court of Appeal had forwarded a reference from the Attorney General of Northern Ireland challenging whether the Commission had standing to bring the proceedings and to seek a declaration of incompatibility under section 4 of the Human Rights Act 1998. The Supreme Court ultimately decided there was no legal standing, and the Commission's appeal was dismissed by a majority of 4<sup>64</sup> to 3 on this issue. However, the Court did go on to express obiter views on the law in Northern Ireland that may be important when individual victim claims are issued. The specific divisions within the Supreme Court were as follows:

- A 4/3 majority<sup>65</sup> considered that the law in Northern Ireland is disproportionate and incompatible with Article 8 in relation to the prohibition for pregnancy resulting from rape and incest.

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<sup>56</sup> *The Northern Ireland Human Rights Commission's Application* [2017] NICA 42.

<sup>57</sup> The last relevant Assembly vote was on the 10 February 2016.

<sup>58</sup> DHSSPS *March 2016 Guidance*, para 1.2,

<<https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/guidance-termination-pregnancy.pdf>>accessed 22 May 2017.

<sup>59</sup> *Ibid.*, para 5.13.

<sup>60</sup> *R (on the application of A and B) v Secretary of State for Health* [2014] EWHC 1364 (Admin)

<sup>61</sup> *R (on the application of A and B) v Secretary of State for Health* [2017] UKSC 41

<sup>62</sup> See BBC – Northern Ireland women to get free abortions in England (29 June 2017), <<http://www.bbc.co.uk/news/uk-politics-40438390>>accessed 20 June 2017.

<sup>63</sup> NIHRC (n18).

<sup>64</sup> Lord Mance, Lord Reed, Lady Black and Lord Lloyd-Jones.

<sup>65</sup> Lady Hale, Lord Mance, Lord Kerr and Lord Wilson.

- A 5/2 majority<sup>66</sup> considered that the law in Northern Ireland is disproportionate and incompatible with Article 8 in relation to the prohibition in cases of fatal fetal abnormality.<sup>67</sup> The Court found that legal prohibitions on serious fetal abnormality were not incompatible with Convention rights.
- A 4/3 majority<sup>68</sup> concluded that the current law, in abstract, is not incompatible with Article 3. The minority were split – Lord Kerr and Wilson took the view that the law was presently incompatible, and Lady Hale did not consider it necessary to decide the issue in light of her decision on Article 8.

Although the case may not have achieved the intended outcome, it does provide a platform for future challenges. Lord Mance made his position abundantly clear:

*“the present law clearly needs radical reconsideration. Those responsible for ensuring the compatibility of Northern Ireland law with the Convention rights will no doubt recognise and take account of these conclusions, at as early a time as possible, by considering whether and how to amend the law, in the light of the ongoing suffering being caused by it as well as the likelihood that a victim of the existing law would have standing to pursue similar proceedings to reach similar conclusions and to obtain a declaration of incompatibility in relation to the 1861 Act.”*<sup>69</sup>

The outcome of the constitutional referendum and the subsequent legal reforms in the Republic of Ireland will undoubtedly add pressure for legal change north of the Irish border.<sup>70</sup>

## Defences: England, Wales and Scotland

The Abortion Act 1967 (AA 1967) applies to England, Wales and Scotland. It came into force on the 27 April 1968, and was the product of a Private Members’ Bill introduced by Mr David Steel in June 1966.<sup>71</sup> Section 1(1) AA 1967 specifically provides a defence to any criminal offence under ‘*the law relating to abortion*’ and one interpretation is that it renders what would otherwise be unlawful into lawful conduct.<sup>72</sup> Section 6 clarifies that ‘*the law relating to abortion*’ means sections 58/59<sup>73</sup> and “any

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<sup>66</sup> Lady Hale, Lord Mance, Lord Kerr, Lord Wilson and Lady Black.

<sup>67</sup> The minority said it was not possible to conclude, in the abstract, that the current law is disproportionate or incompatible with Article 8 (Lord Reed, Lord Lloyd-Jones and Lady Black in relation to rape/ incest).

<sup>68</sup> Lord Mance, Lord Reed, Lady Black and Lord Lloyd-Jones.

<sup>69</sup> *NIHRC* (n18), [135].

<sup>70</sup> See BBC – Irish Abortion Referendum (26 May 2018), <<https://www.bbc.co.uk/news/world-europe-44256152>>accessed 7 June 2018; Health (Regulation of Termination of Pregnancy) Act 2018 (Act No. 31 of 2018) (EIRE).

<sup>71</sup> Taking over an earlier attempt to introduce legislation by Lord Silkin (Medical Termination of Pregnancy Bills HL (1965-1966))

<sup>72</sup> *Doogan and Wood v Greater Glasgow Health Board* [2014] UKSC 68

<sup>73</sup> OAPA 1861

*rule of law relating to the procurement of abortion*” (ie the ILPA 1929 and the separate criminal provisions in Scotland). In any event, section 5(1) AA 1967 was amended so that no offence is committed under the ILPA 1929 by a registered medical practitioner who terminates a pregnancy in accordance with the provisions of the AA 1967.<sup>74</sup>

The current version of section 5(2) AA 1967 provides:

*“For the purposes of the law relating to abortion, anything done with intent to procure a woman’s miscarriage (or, in the case of a woman carrying more than one foetus, her miscarriage of any foetus) is unlawfully done unless authorised by section 1 of this Act and, in the case of a woman carrying more than one foetus, anything done with intent to procure her miscarriage of any foetus is authorised by that section if–*

*(a) the ground for termination of the pregnancy specified in subsection (1)(d) of that section applies in relation to any foetus and the thing is done for the purpose of procuring the miscarriage of that foetus, or (b) any of the other grounds for termination of the pregnancy specified in that section applies”.*

The question is whether this section modifies what is unlawful conduct? The response by Munby J in *R (Smeaton)* was as follows:

*“Parliament when it originally enacted the 1967 Act did so, as section 6 shows, expressly by reference to sections 58 and 59 of the 1861 Act. Section 5(2) of the 1967 Act, read in conjunction with section 6, provides avowedly for the 1967 Act to define that which is (un)lawful for the purposes of the 1861 Act. The 1861 Act and the 1967 Act operate as a statutory code in relation to the procuring of abortions or miscarriages – the two words being used synonymously – the 1967 Act defining that which is lawful and the 1861 Act that which is criminal.”<sup>75</sup>.*

In *R v Smith*,<sup>76</sup> Scarman LJ placed emphasis on the Act’s conversion of the unlawful into the lawful but Lord Edmund Davies (dissenting) in *Royal College of Nursing of the UK v Department of Health and Social Security* (‘RCN’ case) claimed that the AA 1967 had ‘both restricted and amplified the existing abortion law’.<sup>77</sup> In the subsequent *Doogan* case, the focus was once again on the AA 1967 as a vehicle for converting the unlawful to the lawful, rather than as a concurrent means of defining criminality.<sup>78</sup> Lady Hale stated:

*“Hence, as the House of Lords decided in the Royal College of Nursing Case, what is authorised by the Act is the whole course of medical treatment bringing about the ending of the pregnancy. By virtue of section 5(2), any other conduct which is prohibited by sections 58 and 59 of the Offences against the Persons*

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<sup>74</sup> As per HFEA 1990, s 37.

<sup>75</sup> *Smeaton* (n2), [358]-[361].

<sup>76</sup> *R v Smith (John)* [1974] 1 All ER 376, 378.

<sup>77</sup> *Royal College of Nursing of the UK v Department of Health and Social Security* [1981] AC 800 (HL), 830f.

<sup>78</sup> *Doogan* (n72), [33]-[34] & [38].

*Act 1861 in England and Wales or by any rule of law in Scotland remains a criminal offence.*<sup>79</sup>

The problem with this interpretation is that it makes the erroneous assumption that the law - and what was unlawful - was in a state of clarity in 1967. Indeed, the preamble to the 1967 Act highlights that the legislation was enacted to '*clarify*' existing law and there is abundant evidence in Hansard of the ambiguous state of the criminal law at the time of enactment.<sup>80</sup> This discussion also begs the question why Parliament did not simply start from scratch and produce a single statute.

The 1967 Act explicitly provides a defence to a 'pregnancy' terminated by a registered medical practitioner and applies to the "*whole course of medical treatment bringing about the termination of the pregnancy*".<sup>81</sup> It covers medical and surgical means of termination - for the former, the Act will cover steps from the administration of drugs up to the ending of the pregnancy, and possibly those situations requiring immediate aftercare.<sup>82</sup> Protection will extend to other healthcare professionals acting under the immediate direction and control of the registered medical practitioner in connection with the medical treatment authorised by the Act.<sup>83</sup> It does not offer legal protection to more remote participants in the termination process,<sup>84</sup> although that is probably unnecessary in light of the criminal framework that has been analysed.<sup>85</sup> It remains unclear whether nurses acting under the control of registered medical practitioners have the same legal protection under the ILPA 1929. Section 5(1) AA 1967 now states that no offence under the ILPA 1929:

*"shall be committed by a registered medical practitioner who terminates a pregnancy in accordance with the provisions of the Act".*

Montgomery argues that this protection may extend to nurses,<sup>86</sup> and it seems logical that "*terminates a pregnancy*" in the ILPA 1929 should be construed consistently with the decision in the *RCN* case. This interpretation is reinforced by the relevant Departmental guidance which makes no distinction between the protection afforded in

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<sup>79</sup> *Doogan* (n72), [33].

<sup>80</sup> Jeffrey Wale, 'Commentary: Greater Glasgow Health Board v Doogan', UK Health Care Law, (2015a) <<https://ukhealthcarelaw.wordpress.com/2015/01/20/commentary-greater-glasgow-health-board-v-doogan-another-2014-uksc-68/>> accessed 20 January 2015; Mary Neal, 'The Scope of the Conscience-Based Exemption in Section 4(1) of the Abortion Act 1967: *Doogan and Wood v NHS Greater Glasgow Health Board* [2013] CSIH 36', (2014) 22(3) *Med L Rev* 409.

<sup>81</sup> *RCN* (n77); *Doogan* (n72), [33]-[34].

<sup>82</sup> *Doogan* (n72), [34].

<sup>83</sup> *RCN* (n77); Department of Health, *Guidance in relation to requirements of the Abortion Act 1967*, (DOH 2014a); Royal College of Nursing (RCN), *Termination of Pregnancy: An RCN nursing framework* (RCN 2017); Sally Sheldon and Joanne Fletcher, 'Vacuum aspiration for induced abortion could be safely and legally performed by nurses and midwives', (2017) *J Fam Reprod Health Care* 1.

<sup>84</sup> *Doogan* (n72) [38]

<sup>85</sup> We will address remoteness in participation in later sections.

<sup>86</sup> Jonathan Montgomery, *Health Care Law* (Oxford University Press 2003)

respect of either Act.<sup>87</sup>

Section 1 AA 1967 is headed “*Medical Termination of Pregnancy*” but has been applied to medical and surgical methods of termination.<sup>88</sup> The statutory language refers to ‘*pregnancy*’ rather than ‘*fetal life*’ and the inconsistent use of terminology (termination, terminated and treatment) has caused many problems for judicial interpretation. The amended section 5(2) makes it clear that for the purposes of the “*law relating to abortion*”, anything done with intent to procure a “*miscarriage of any foetus*” is unlawful unless authorised by section 1, extending coverage to multiple pregnancy.<sup>89</sup> Section 5(2) does not address whether there needs to be an intention to do an act which results in the expulsion of fetal product,<sup>90</sup> but where a miscarriage is foreseen as a virtual certainty of an act, that can be used as evidence to infer the requisite intention for liability under section 58 OAPA 1861.<sup>91</sup> Again, the AA 1967 does not specifically define the term ‘miscarriage’.

The AA 1967 is understandably silent about acts done with the intention to procure fetal harm short of death/miscarriage because of the connections with the OAPA 1861. However, does the AA 1967 offer protection if there is an intention to procure a miscarriage but the termination fails with or without consequential fetal harm? Lord Diplock considered there would be legal protection under the 1967 Act:

*“Furthermore if “termination” or “terminated” meant only the event of miscarriage and not the whole treatment undertaken with that object in mind, lack of success which apparently occurs in one or two per cent of cases, would make all who had taken part in the unsuccessful treatment guilty of an offence under section 58 or 59 of the Offences Against the Person Act 1861. This cannot have been the intention of Parliament.”<sup>92</sup>*

However, Lord Edmund-Davies (dissenting in the same case) claimed that there would be no freestanding criminal liability under the OAPA 1861 in these circumstances, irrespective of the AA 1967.

Section 1(1) makes it clear that ‘a person’ will not be guilty of an offence under the law relating to abortion, when a pregnancy is terminated by a registered medical practitioner “*if two registered medical practitioners are of the opinion, formed in good*

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<sup>87</sup> DOH 2014a (n83), para 29.

<sup>88</sup> RCN (n77).

<sup>89</sup> As per HFEA 1990, s37(5); AA 1967. Note – AA 1967, s5(2)(a) and (b) extends the reach of AA 1967, s1.

<sup>90</sup> Is it an intention to procure fetal death suffice?

<sup>91</sup> *R v Nedrick* (n36).

<sup>92</sup> RCN (n77), 828a (Lord Diplock).

*faith*” that at least one of the lawful grounds for termination is made out.<sup>93</sup> Although the statutory provision is silent on the point, the Departmental Guidance for completing the HSA1 certificate (which needs to be completed, signed and dated by both medical practitioners pursuant to the Abortion Regulations 1991) requires a statement that “at least one and the same ground for abortion in section 1(1) of the 1967 Act exists”.<sup>94</sup> A subsequent guidance note has confirmed this position.<sup>95</sup>

The section 1 ground does not have to factually exist - it is enough that two medical practitioners form their belief in good faith that such a ground exists:

*“The Act...has introduced the safeguard of two opinions: but, if they are formed in good faith by the time the operation is undertaken, the abortion is lawful. Thus a great social responsibility is firmly placed by the law upon the shoulders of the medical profession...”*<sup>96</sup>

Although Scarman LJ thought there was an important residual role for the court when addressing the bona fides of medical assessment, a more restrictive view was articulated in the case of *Paton*:

*“Not only would it be a bold and brave judge (I think Mr Rankin used that expression) who would seek to interfere with the discretion of doctors acting under the Abortion Act 1967, but I think he would really be a foolish judge who would try to do any such thing, unless, possibly, there is clear bad faith and an obvious attempt to perpetrate a criminal offence.”*<sup>97</sup>

In any event, Keir Starmer QC (as Director of Public Prosecutions (DPP)) highlighted the practical hurdles of prosecuting doctors on the platform of inadequate risk assessment.<sup>98</sup> One immediate obstacle is that the statutory HSA1 form does not explicitly require the doctor to examine or even see the patient before making their assessment under the AA 1967.<sup>99</sup> In his published reasons for not prosecuting two doctors for inadequate risk assessment, the DPP conceded:

*“The prosecution would have to be in a position to prove beyond reasonable doubt, that the assessments carried out by the doctors was carried out in bad faith or carried out in such a way that fell below a standard which any reasonable doctor would consider adequate. In the absence of any considered medical guidance it is extremely difficult for the prosecution to undertake this exercise. Equally, it would be very difficult for a jury to assess what may or may*

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<sup>93</sup> AA 1967.

<sup>94</sup> Department of Health, *Guidance on HSA1 & HSA2* (DOH 2013), 1

<sup>95</sup> DOH 2014a (n83), para 11.

<sup>96</sup> *R v Smith* (n76), 378f - 381e (Scarman LJ) (emphasis added).

<sup>97</sup> *Paton* (n22),282b.

<sup>98</sup> Keir Starmer, Letter to Dominic Grieve, Attorney General dated 7 October 2013.

<sup>99</sup> See Abortion Regulations 1991, s 3 and sch 1.



*not be an “adequate” assessment by the doctor.”*<sup>100</sup>

Successful prosecutions against doctors are very rare because of the difficulty in lifting the veil of discretion afforded to medical professionals in this context. *R v Smith* is a rare example of a successful prosecution against a doctor – the conviction occurring because (1) the medical record evidence in the case; (2) the defence of ‘inevitable’ abortion appears to have been disbelieved by the jury.<sup>101</sup> The veil of protection is further extended by the wide discretion afforded to doctors by section 1(2) AA 1967 for lawful terminations under sections 1(1) (a) and (b).<sup>102</sup>

The Department of Health sought to address concerns about medical accountability in their 2014 guidance note - pre-signing the HSA1 form, or signing without adequate patient information, will be indicative of non-compliance with the AA 1967.<sup>103</sup> The guidance also recommends that registered medical practitioners should be prepared to justify ‘*how they considered information specific to the woman when forming their opinion*’ and requires a record of that assessment.<sup>104</sup> The prosecution may be able to use non-compliance to infer or supply evidence of ‘bad faith’, although this is technically Executive rather than medical guidance. It remains to be seen whether this guidance will have any real impact on professional conduct or prosecutorial outcomes.

### **Lawful grounds**

The lawful grounds for termination in section 1(1) of the AA 1967<sup>105</sup> can be broadly classified as medical,<sup>106</sup> fetal abnormality and emergency grounds. In relation to the medical classification, Grubb subdivides section 1 (1) (a) into ‘maternal medical’ and ‘familial medical’ grounds.<sup>107</sup> Rather confusingly, the mandatory HSA4 return uses a different lettering system to the Act which is replicated in the national reporting of abortion statistics:

**A** - Section 1(1) (c)

**B** - Section 1(1) (b)

**C** - Section 1(1) (a) (limited to consideration of the pregnant woman).

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<sup>100</sup> Starmer (n98). Nb the Attorney General subsequently stopped a private prosecution against these doctors.

<sup>101</sup> *R v Smith* (n76).

<sup>102</sup> For discussion of the breadth of discretion afforded to medical gatekeepers, see Sally Sheldon and others, ‘The Abortion Act (1967): a biography’ (2019) 39(1) *Legal Studies* 18.

<sup>103</sup> DOH 2014a (n83), para 10.

<sup>104</sup> DOH 2014a (n83), para 14.

<sup>105</sup> As amended by the HFEA 1990, s37.

<sup>106</sup> AA 1967, ss 1(1) (a) to (c).

<sup>107</sup> Grubb (n3), 660.

**D** - Section 1(1) (a) (limited to consideration of any existing children of the family).

**E** - Section 1(1) (d).

**F** – Section 1(4) (risk to the the life of the pregnant woman).

**G** – Section 1(4) (to prevent grave permanent injury to the physical or mental health of the pregnant woman).

In 2017, approximately 98% of all abortions in England and Wales were certified on ground C, 1% on ground D, 2% on ground E with a small balance distributed to the other grounds.<sup>108</sup> These lettering classifications will be used for subsequent analysis:

### **Grounds C and D (Section 1 (1) (a))**

*“That the pregnancy has not exceeded its twenty-fourth week and that the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family”.*

Only this ground is subject to a specific time limit - the pregnancy must not have exceeded its 24<sup>th</sup> week. The latest Departmental guidance makes it clear that all treatment related to the termination must be completed by 23 weeks and 6 days.<sup>109</sup> In fact, only 0.1% of terminations were actually undertaken at 24 weeks or over in 2017.<sup>110</sup> Unhelpfully, the Act does not specify a method for calculating the start of the pregnancy but Grubb suggests 4 possibilities: the first day of the woman’s last period, the date of conception, the date of implantation or the first day of the woman’s missed period.<sup>111</sup> He points to the:

*“attraction of the symmetry of interpreting the Abortion Act so that the defence to the offence in section 58 operates from the point in time when that crime could first be committed ie at implantation”<sup>112</sup>*

We know that implantation is already used as a starting point for statutory protection under the HFEA 1990,<sup>113</sup> but in reality, the timing issue will be determined by accepted medical practice and Departmental Guidance (ie the first day of the woman’s last

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<sup>108</sup> *Abortion Statistics* (n34) para 2.14 (due to rounding these figures do not add up to 100%).

<sup>109</sup> Department of Health, *Detailed guidance note for completing the abortion notification form HSA4 for abortions performed in England and Wales* (DOH 2013a) **but** now clarified by Department of Health and Social Care, *Clarification of time limit for termination of pregnancy performed under Grounds C and D of the Abortion Act 1967* (DHSC 23 July 2018) and Department of Health and Social Care, *Further clarification of time limit for termination of pregnancy performed under Grounds C and D of the Abortion Act 1967* (DHSC 28 March 2019).

<sup>110</sup> *Abortion Statistics* (n34), para 2.26.

<sup>111</sup> Grubb (n3), 665.

<sup>112</sup> Grubb (n3), 666.

<sup>113</sup> S 2(3); see also *R (Smeaton)* (n2).

menstrual period). The original version of the HSA4 form<sup>114</sup> required an estimate for the length of gestation but the current English/ Welsh version<sup>115</sup> only requires doctors to state the number of completed weeks.<sup>116</sup>

Section 1 (1) (a) and 1 (1) (c) require a comparative risk assessment to be made - whether the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated. The latest Departmental guidance on assessing and recording risk provides some assistance.<sup>117</sup> Although there is no requirement for an examination of the pregnant woman pre-certification, prior examination/meeting (whether in person or by technological means) by at least one of the certifying doctors is considered good practice.<sup>118</sup> The relevant risk must be of injury to the physical or mental health of the pregnant woman or any existing children of the family. Section 1(2) states that “*account may be taken of the pregnant woman’s actual or reasonably foreseeable environment*”, affording wide discretion to the certifying doctors and adding weight to the ‘social ground’ descriptor often associated with this provision.<sup>119</sup>

In many cases, the physical health risks to the woman of continuing a pregnancy necessarily outweigh the minimal risk entailed in the modern termination procedure. Indeed, some evidence suggests that termination in the first trimester is nearly always safer than continuing pregnancy to term,<sup>120</sup> and the inclusion of mental health as a risk factor makes it easier to tip the balance in favour of termination.<sup>121</sup> Arguably this ground creates termination on demand - the threshold being so low that it is easily made out subject to the 24 week limit.<sup>122</sup> However, doctors must still certify in good faith that the ground “*applies to this individual and not solely on the basis of abstract statistics*”.<sup>123/124</sup>

What the doctors cannot consider under section 1 (1) (a), are the specific risks to the health of the fetus/ embryo, because they are not treated as existing children of the

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<sup>114</sup> Abortion Regulations 1991, sch 2.

<sup>115</sup> Revised September 2006.

<sup>116</sup> See the Abortion (Amendment) (England) Regulations 2002 and the Abortion (Amendment) (Wales) Regulations 2002/8

<sup>117</sup> DOH 2014a (n83), para 12-15.

<sup>118</sup> DOH 2014a (n83), para 6.

<sup>119</sup> Montgomery 2003 (n86)

<sup>120</sup> *Abortion Statistics* (n34): no maternal deaths were reported following termination in 2017 (para 2.42).

<sup>121</sup> Grubb (n3), 660. Indeed, the 2017 Abortion statistics show that the vast majority of abortions using ground C relate to the mental health factor (n34, para 2.15).

<sup>122</sup> Emily Jackson, ‘Abortion, Autonomy and Prenatal Diagnosis’, (2000) 29 *Social Legal Studies* 470; Emily Jackson, ‘The legality of abortion for fetal sex’, <[http://www.reproductivereview.org/images/uploads/Britains\\_abortion\\_law.pdf](http://www.reproductivereview.org/images/uploads/Britains_abortion_law.pdf)> accessed 24 May 2018.

<sup>123</sup> Grubb (n3), 661.

<sup>124</sup> See also BMA’s *The Law and Ethics of Abortion* (BMA 2014 updated October 2018), 6-7; DOH 2014a (n83), para 11.

family. This is an important point in multiple pregnancy when concern for fetal mortality/morbidity may be a central consideration,<sup>125</sup> although Herring claims that the risk of the fetuses being lost in multiple pregnancy nearly always involves some risk of harm to the woman.<sup>126</sup> No explicit provision is made for the health of the paternal parent (or male donor in assisted conception), although there might be scope for indirect consideration of their interests via section 1(2) AA 1967 for grounds B, C and D.

### **Ground A (section 1 (1) (c))**

*“That the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated”*

A comparative risk assessment is also required by section 1(1) (c) - this time the comparative exercise is between the risk to the life of the pregnant woman of continuance and the risk of termination. There is no time limit but section 1(1) (a) is more likely to be used by doctors up to the 24<sup>th</sup> week; and this provision does not have the benefit of section 1(2). Importantly, sections 1(1) (a) and (c) do not specify the degree of divergent risk required – all that is needed is an assessment that the relevant risk arising from continuance of the pregnancy is greater than the risk if the pregnancy were terminated.

### **Ground B (Section 1 (1) (b))**

*“That the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman”*

Section 1(1) (b) does not require a comparative risk assessment to be made between continuance and termination - the requirement is simply that the termination must be necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman. It is unclear whether a small risk of grave permanent injury would be sufficient, but it has been suggested that the term ‘necessary’ requires foresight of such harm as a practical certainty.<sup>127</sup> Grubb doubts whether a termination will be ‘necessary’ if it:

*“does not involve a lower risk of permanent injury to the mother’s health than would exist if the pregnancy continued”.*<sup>128</sup>

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<sup>125</sup> Claire-Marie Legendre and others, ‘Differences between selective termination of pregnancy and fetal reduction in multiple pregnancy: a narrative review’ (2013) (26(6) *Reproductive Bio-Medicine Online (Elsevier Science)* 542, 547-8.

<sup>126</sup> Jonathan Herring, *Medical Law and Ethics* (7<sup>th</sup> ed, OUP 2018), 310.

<sup>127</sup> Marc Stauch and Kay Wheat, *Text, cases and materials on medical law & ethics* (4<sup>th</sup> edition, Routledge 2012), 383.

<sup>128</sup> Grubb (n3), 662.

The text speaks to prevention not the reduction of injury,<sup>129</sup> and this may be relevant to fetal reductions in multiple pregnancy where the latter may be more applicable. Although there is no time limit, section 1(2) does apply. 'Grave' is not defined but is likely to be construed as 'serious'. The requirement of permanent injury is not required by the other medical grounds, and the thresholds for grounds A/B are clearly higher than for grounds C/D.

### **Ground E (S 1(1) (d))**

*"That there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped"*<sup>130</sup>

This is a highly contentious ground that has no time constraint and is often used in fetal reduction and selective termination in multiple pregnancy in Great Britain. Whilst, this is the only ground that directly refers to the health, state or interests of the unborn entity, it is arguable whether the primary purpose is for the benefit of the unborn entity,<sup>131</sup> the future child or the pregnant woman that would have to care for the child if it were born alive.<sup>132</sup> 'Substantial risk' is not defined but plainly does not require a certainty. A medical practitioner may have to defend his certification but in practice challenges are very rare. The phrase '*would suffer from such physical or mental abnormalities*' is essentially a medical question. Grubb queries whether a HIV positive baby would suffer from 'physical abnormalities' - given the likelihood that it would be asymptomatic at birth<sup>133</sup>- before concluding that the HIV infection could be construed as a physical abnormality.<sup>134</sup> He also raises another important issue - would that child suffer from abnormalities so '*as to be seriously handicapped*'? Clearly, the subsection links abnormality with a certain degree of handicap/ disability, and the mere presence (or substantial risk) of an abnormality is insufficient without any link to disability. Consequently, there is uncertainty whether the subsection covers the situation where the risk involves an asymptomatic child with a definite<sup>135</sup> or possible future risk of handicap.<sup>136</sup>

Although the strict legislative wording requires a high degree of risk (substantial) and high magnitude of outcome ('seriously handicapped'), the actual medical emphasis

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<sup>129</sup> Hall (n3), 307.

<sup>130</sup> Now contained in AA 1967, s 1(1)(d)

<sup>131</sup> As per Stephenson LJ in *McKay v Essex AHA* [1982] QB 1166 (CA), 1179H.

<sup>132</sup> Jane E S. Fortin, 'Legal Protection for the Unborn Child', (1988) 51 *MLR* 54, 72; Sally Sheldon and Stephen Wilkinson, "Termination of Pregnancy for Reason of Foetal Disability: Are There Grounds for a Special Exception in Law?", (2001) 9 *Med L. Rev* 85.

<sup>133</sup> Grubb (n3), 662-663.

<sup>134</sup> Grubb (n3), 663.

<sup>135</sup> Eg Huntington's Chorea.

<sup>136</sup> Eg HIV positive.

may be on severity rather than certainty of prognosis.<sup>137</sup> In places, the relevant Royal College guidance equates ‘substantial risk’ with ‘likely’,<sup>138</sup> and associates the degree of risk ‘with the seriousness and consequences of the likely disability’.<sup>139</sup> Indeed, Sheelagh McGuinness claims this section of the AA 1967 may be ‘operating beyond any plausible legitimate interpretation of the ground’,<sup>140</sup> and highlights the presumptive effect that it may have on parental choices following prenatal screening.<sup>141</sup> The suggestion here is that professional and practice norms are out of step with the legal normative framework.

These issues were brought into sharp focus by the judicial review litigation in *Jepson*.<sup>142</sup> Reverend Joanna Jepson challenged a police decision not to investigate the certification of a termination for a bilateral cleft lip and palate at 28 weeks gestation. Following initial court permission, the judicial review proceedings were suspended pending a police investigation. Subsequently, the CPS declined to prosecute the doctors and the judicial review proceedings were not pursued any further. Although the doctors involved were never prosecuted, Reverend Jepson had, to some extent, made her point to the medical profession - lawful abortions on the ground E ought to be restricted to cases of serious not trivial disability. However, defining the scope of what is ‘serious’ remains unresolved. The case also highlights the scrutinising effect of the statutory notification provisions,<sup>143</sup> because Jepson was able to access material data on the disability ground.<sup>144</sup>

Interpretative issues arise partly from a medical reluctance to produce a definitive list of conditions capable of meeting the requirements of section 1(1)(d). The Royal College of Obstetricians and Gynaecologists (RCOG) argue that:

*“It would be unrealistic to produce a definitive list of conditions that constitute serious handicap. Precise definition is impractical for two reasons. Firstly, sufficiently advanced diagnostic techniques capable of accurately defining abnormalities or of predicting the seriousness of outcomes are not currently available. Secondly, the consequences of an abnormality are difficult to predict, not only for the fetus in terms of viability or residual disability but also in relation to the impact in childhood as well as on the family into which the child would be*

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<sup>137</sup> Helen Statham, Wendy Solomou and Jasper B. Green, J, ‘Late termination of pregnancy: law, policy and decision making in four English fetal medicine units’, (2006) 113(12) *BJOG: An International Journal of Obstetrics and Gynaecology* 1402, 1406.

<sup>138</sup> Royal College of Obstetricians and Gynaecologists (RCOG), *Termination of pregnancy for fetal abnormality* (RCOG 2010b), 10.

<sup>139</sup> *Ibid.*, 10.

<sup>140</sup> Sheelagh McGuinness, ‘Law, Reproduction, and Disability: Fatally ‘Handicapped’?’, (2013) 21 *Med L. Rev* 213, 227.

<sup>141</sup> *Ibid.*, 213.

<sup>142</sup> *Jepson v The Chief Constable of West Mercia Police Constabulary* [2003] EWHC 3318.

<sup>143</sup> As per Abortion Regulations 1991 (as amended).

<sup>144</sup> The decision in *Department of Health v Information Commissioner* [2011] EWHC 1430 has ensured ongoing public access to ground E abortion statistics.

*born*".<sup>145</sup>

This view has been supported by some academic research<sup>146</sup> and by the House of Commons, Science and Technology Committee.<sup>147</sup> However, a subsequent Parliamentary Inquiry into Abortion on the Grounds of Disability (although rejecting a list approach) recognised the potential for “*differences between doctors on which disabilities fall within the scope of the law*” and recommended a review of legal application beyond viability.<sup>148</sup> This reinforces the perspective of a legislative provision which is unpredictable and uncertain in scope.

Interpretative issues also arise from the outdated term '*handicap*' and the role played by medical practitioners in defining their own legal defence. Jepson claimed that '*seriously handicapped*' should be understood by reference to the remediability of that condition, having suffered childhood disability that had been successfully treated.<sup>149</sup> Rosamund Scott highlights that it is the medical profession that determines the degree of medical input that the future child is likely to require; and questions whether disability should be seen as a solely medical or social concept.<sup>150</sup> The medical approach sees disability situated within the individual as a medical condition; whereas social framing conceives disability as social prejudice and discrimination. The UK Parliamentary Inquiry recommended that consideration should be given to removing what some perceive as discrimination against persons with disability.<sup>151</sup>

The medical/social distinction also has implications for Jepson's argument about the remedial nature of the condition or disability. Do we look at those conditions that cannot be medically corrected or restrict serious handicap to those conditions that cannot be 'alleviated' by other social means?<sup>152</sup> Scott claims that if you view disability using the medical model, the term '*seriously handicapped*' has a much wider meaning than a social interpretation that takes into account the possibility of alleviation by medical and social means. Some conditions will result in significant problems by themselves but, for others, social factors may be relevant, and ultimately Scott prefers a combined model of interpretation.<sup>153</sup>

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<sup>145</sup> RCOG 2010b (n138) 9-10.

<sup>146</sup> Staham, Solomou & Green (n137), 1407-8.

<sup>147</sup> House of Commons, *Scientific Developments Relating to the Abortion Act 1967* (Twelfth report of session 2006/07), 31.

<sup>148</sup> *Parliamentary Inquiry into Abortion on the Grounds of Disability* (2013), 4/19

<sup>149</sup> Rosamund Scott, 'Interpreting the Disability Ground of the Abortion Act' (2005) 64(2) *Cambridge Law Journal* 388, 393.

<sup>150</sup> *Ibid.*, 393.

<sup>151</sup> (n148), 49.

<sup>152</sup> Scott (n149), 394.

<sup>153</sup> Scott (n149), 395.

RCOG define 'seriously handicapped' as a physical or mental disability which would "cause significant suffering or long-term impairment of their ability to function in society".<sup>154</sup> They identify several factors that should be considered during the assessment process:

- The potential for effective treatment in-utero or after birth,
- The probable degree of self-awareness and ability to communicate with others,
- The suffering that would be experienced,<sup>155</sup>
- The probability of being able to live alone and to be self-supportive as an adult.
- The extent to which actions performed by individuals without disability that are essential for health would have to be provided by others.<sup>156</sup>

What is unclear, is whether doctors should consider the pregnant woman's own perception of abnormality/disability, and the extent to which her wishes (and those of her partner) should be taken into account in the determination of severity.<sup>157</sup> Whilst RCOG acknowledges that the woman's right to decline termination must be fully supported,<sup>158</sup> it is the medical profession who ultimately control the assessment and communication process. Statham et al. found some variation amongst healthcare professionals concerning the relevance of the woman's view on disability, but with third trimester requests, the focus appeared to be on the legality of the procedure rather than supporting patient autonomy.<sup>159</sup> This finding is corroborated by our own research interviews.

There is an obvious link between ground E and antenatal screening/ testing. As technology advances it become possible to diagnose a wider range of conditions with different degrees of certainty. It also raises a number of issues including the legitimacy and accuracy of testing, and the communication of information/ scan imagery to parents.<sup>160</sup> Again, the UK Parliamentary Inquiry into the disability ground highlighted the importance of the information sharing/ counselling/ support phases<sup>161</sup> and

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<sup>154</sup> RCOG 2010b (n138) 8.

<sup>155</sup> The first three points are explicitly supported by the BMA 2014 (updated October 2018) (n124), 6.

<sup>156</sup> RCOG 2010b (n138), 9.

<sup>157</sup> Scott (n149), 397. See also Rosamund Scott, 'The Uncertain Scope of Reproductive Autonomy in Preimplantation Genetic Diagnosis and Selective Abortion', (2005) 13 *Med L. Rev* 29.

<sup>158</sup> RCOG 2010b (n138), 26.

<sup>159</sup> Statham, Solomou & Green (n137), 1406.

<sup>160</sup> See O. Graham, S. Ankrett and S R. Killick, 'Viewing ultrasound scan images prior to termination of pregnancy: Choice for women or conflict for ultrasonographers?' (2010) 30(5) *Journal of Obstetrics & Gynaecology* 484; Scott Woodcock, 'Abortion counselling and the informed consent dilemma', (2011) 25 *Bioethics* 495; Scott (n150), 412.

<sup>161</sup> (n148).



subsequent Departmental guidance has sought to address some of these issues.<sup>162/163</sup> Of course, doctors can sidestep the difficulties associated with ground E by relying on grounds C/D up to 24 weeks;<sup>164</sup> a practice supported by RCOG;<sup>165</sup> and frequently exercised in practice.<sup>166</sup> Although, ground E provides an important avenue in a few late diagnosis cases, there have been continuing parliamentary attempts to remove this subsection.<sup>167</sup>

### **Emergency - Grounds F and G (Section 1(4) AA 1967)**

*“Subsection (3) of this section, and so much of subsection (1) as relates to the opinion of two registered medical practitioners, shall not apply to the termination of a pregnancy by a registered medical practitioner in a case where he is of the opinion, formed in good faith, that the termination is immediately necessary to save the life or to prevent grave permanent injury to the physical or mental health of the pregnant woman.”*

These grounds require that the procedure must be ‘*immediately necessary*’ to save the life or prevent grave permanent injury to the pregnant woman but is otherwise a replicant of sections 1(1) (b) and (c) without comparative risk assessment. In these circumstances, the strictures of certification by two doctors and place of treatment are relaxed.

### **Treatment – methods, place and participants**

The main surgical method used in fetal reduction/ selective termination of multiple pregnancy is feticide. The principal surgical methods for singleton termination are vacuum aspiration, dilation and evacuation, and feticide with evacuation in later pregnancies.<sup>168</sup> The principal medical method of termination in the UK involves either the administration of mifepristone<sup>169</sup> in combination with the drug misoprostol or the sole use of misoprostol. With the combined option, mifepristone is administered first, followed by misoprostol (usually) a few days later. Medical methods now dominate

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<sup>162</sup> Department of Health, *A Framework for Sexual Health Improvement in England* (DOH 2013e), 35-37; Department for Health, *Procedures for the Approval of Independent Sector Places for the Termination of Pregnancy* (DOH 2014b).

<sup>163</sup> For discussion of non-invasive prenatal testing, see Nuffield Council on Bioethics, *Non-invasive Prenatal Testing: Ethical Issues* (NCOB 2017); Roger Brownsword and Jeff Wale, ‘Testing Times Ahead: Non-Invasive Prenatal Testing and the Kind of Community We Want to Be’, (2018) 81(4) *MLR* 646.

<sup>164</sup> Scott (n149), 391. See also Scott (n157).

<sup>165</sup> RCOG 2010b (n138), 8.

<sup>166</sup> See for eg, *Abortion Statistics* (n34).

<sup>167</sup> Abortion (Disability Equality) HL Bill 16 (2016-17).

<sup>168</sup> The 2017 abortion statistics identify vacuum aspiration as the predominant surgical procedure (n34), para 2.38.

<sup>169</sup> Drug name mifegyne/ RU486.

singleton terminations,<sup>170</sup> and the restriction of surgical termination in some private clinics in 2016, is likely to increase the uptake of medical methods in the future.<sup>171</sup> This shift in practice has access implications for late stage terminations although there may be consequential gains for patient safety by restricting surgical interventions to specialist centres.

Section 1(3) AA 1967 provides that “*any treatment for the termination of pregnancy must be carried out in*” a designated NHS hospital or other approved place, save in emergency cases. Section 1(3)A extends ministerial power in relation to the approval of place and treatment specification, where that treatment consists primarily of medicinal methods.<sup>172</sup> These sections have been scrutinised in relation to substantive nursing engagement in the medical termination process. The term ‘*treatment*’ also appears in section 4 but not in sections 1(1) or 5(1) of the AA 1967. Lord Roskill was prepared to treat ‘*termination of pregnancy*’ and ‘*treatment for termination of pregnancy*’ as virtually synonymous in the context of whether nurses were acting lawfully when administering abortifacient (Prostaglandin) drugs to pregnant women in the *RCN* case.<sup>173</sup> That decision establishes that nurses acting under the direction and control of registered medical practitioners have legal protection when administering abortifacient drugs:

*“the doctor need not do everything with his own hands; the requirements of the subsection are satisfied when the treatment for termination of a pregnancy is one prescribed by a registered medical practitioner carried out in accordance with his directions and of which a registered medical practitioner remains in charge throughout”*<sup>174</sup>

The decision in *British Pregnancy Advisory Service (BPAS) v Secretary of State for Health*<sup>175</sup> establishes that ‘*treatment for the termination of pregnancy*<sup>176</sup>’ is not limited to the actual prescription of abortifacient substances like mifepristone. Accordingly, abortifacient drugs need to be administered in an ‘approved place’ although it is then permissible for the woman to leave and for the physical termination to take place at home. From October 2017, women in Scotland were allowed (but not obliged) to take the second dose (misoprostol) at home as part of their termination treatment, subject to

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<sup>170</sup> Abortion Statistics (n34).

<sup>171</sup> Abortion Statistics (n34), para 2.34.

<sup>172</sup> AA 1967.

<sup>173</sup> (n77)

<sup>174</sup> (n77), 828H-829A (Lord Diplock).

<sup>175</sup> [2011] EWHC 235.

<sup>176</sup> As per AA 1967, s 1(3).

requirements concerning their health and home circumstances. These arrangements were subsequently extended into England and Wales in 2018.<sup>177</sup>

All providers of abortion services must be registered with the Care Quality Commission (CQC)<sup>178</sup> and meet essential standards of quality and safety as per the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. Regulation 20 of the Care Quality Commission (Registration) Regulations 2009 imposes additional obligations on independent providers of terminations of pregnancy in England, and regulatory sanctions and penalties may be imposed for non-compliance.<sup>179</sup> The Department of Health issued new procedures for independent sector provision in May 2014,<sup>180</sup> and these emphasise timely access to services, a choice of method for the pregnant woman at all stages of gestation and the on-going offer of qualified counselling services.

### **Conscientious objection<sup>181</sup>**

That brings us on neatly to section 4 AA 1967 and the right to conscientiously object to participation in abortion. The statutory provision is phrased in negative terms: “*no person shall be under any duty... to participate in any treatment authorised by this Act*”,<sup>182</sup> and does not apply where treatment is “*necessary to save the life or to prevent grave permanent injury to the physical or mental health of a pregnant woman*”.<sup>183</sup> There is no requirement of immediate necessity, and section 4 does not apply to terminations authorised by sections 1(1) (b), (c) or 1(4) AA 1967.

Close reading of the two key legal cases - *Janaway* and *Doogan*<sup>184</sup> - highlight the significant problems caused by poor and inconsistent drafting in the AA 1967. *Janaway* concerned a GP receptionist who refused to type appointment letters for terminations. She claimed section 4 protection following dismissal, but the House of

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<sup>177</sup> See Gov.UK (25 August 2018), <<https://www.gov.uk/government/news/government-confirms-plans-to-approve-the-home-use-of-early-abortion-pills>> accessed 14 December 2018; Department of Health & Social Care, *The Abortion Act 1967 - Approval of a Class of Places 27 December 2018* (DHSC)

<sup>178</sup> Health & Social Care Act 2008

<sup>179</sup> See for eg, CQC action against Marie Stopes International, <[https://www.cqc.org.uk/sites/default/files/new\\_reports/AAAG6589.pdf](https://www.cqc.org.uk/sites/default/files/new_reports/AAAG6589.pdf)> accessed 22 March 2019.

<sup>180</sup> DOH 2014b (n162); Department of Health, *Changes to the procedures for the approval of Independent Sector Places for Terminations of Pregnancy: Responses to Proposals in Consultation* (DOH 2014c).

<sup>181</sup> This section is adapted from: Jeffrey Wale, ‘Commentary: Greater Glasgow Health Board (Appellant) v Doogan & Another (Respondents) [2014] UKSC 68’, (2015), <<https://ukhealthcarelaw.files.wordpress.com/2015/01/commentary-greater-glasgow-health-board.pdf>> accessed 18 June 2018.

<sup>182</sup> AA 1967, s 4(1)

<sup>183</sup> AA 1967, s 4(2)

<sup>184</sup> *R v Salford AHA Ex P Janaway* [1989] AC 537; *Doogan* (n72)

Lords dismissed her judicial review application. This case establishes that protection does not extend to remote participants in the termination process outside of the hospital context. In *Doogan*, the court was concerned with the hospital context, and specifically two labour ward co-ordinators working within an NHS hospital. Their role entailed tasks including the admission of patients, the allocation of staff and the supervision/ support of other midwives. They objected to undertaking these tasks in connection with patients undergoing terminations of pregnancy and mounted a judicial review challenge against the handling of their grievance on the issue. The appeal worked its way through to the Supreme Court which eventually found in favour of the Health Board. The court found that the only question to be decided was the meaning of the words ‘*to participate in any treatment authorised by this Act to which he has a conscientious objection*’.<sup>185</sup> The previous House of Lords judgment in *Janaway* had not specifically considered what those words meant in the context of hospital treatment.<sup>186</sup>

The court in *Doogan* found that human rights’ issues (for example, the right to refuse the performance of employment duties as a manifestation of religious belief) gave rise to difficult questions relating to an employer’s aims/ means that are context specific; and did not assist the interpretation of section 4.<sup>187</sup> Instead, they found that issues of discrimination under the Equality Act 2010 (including reasonable adjustment claims) were more appropriately addressed in employment tribunal proceedings.<sup>188</sup> As there was no available evidence, the court would not address any consequential arguments relating to any particular statutory interpretation, including the risk to abortion access.<sup>189</sup>

The court found that the policy or purpose of the AA 1967 was to broaden the grounds for lawful terminations; to ensure patient safety via proper skill and hygienic conditions; and to avoid the mischief of back street abortions. According to Lady Hale, there was also a policy to provide the service within the NHS and approved clinics in the private and voluntary sectors.<sup>190</sup>

Ultimately, the court found that sections 1 and 4 should be read together – the termination of pregnancy in section 1 must be the treatment referred to in section 4.<sup>191</sup> The RCN case established that what is authorised by the AA 1967 is the “*whole course*

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<sup>185</sup> *Doogan* (n72), [11].

<sup>186</sup> *Ibid.*, [11].

<sup>187</sup> *Ibid.*, [23].

<sup>188</sup> *Ibid.*, [24].

<sup>189</sup> *Ibid.*, [25]-[27].

<sup>190</sup> *Ibid.*, [27].

<sup>191</sup> *Ibid.*, [28].

of medical treatment bringing about the ending of the pregnancy”.<sup>192</sup> It follows that section 4 (and the right to object on the basis of that section) applies to the whole course of medical treatment bringing about the termination of the pregnancy. In medical terminations, it begins with the administration of the drugs and normally concludes with the ending of the pregnancy by expulsion of the fetus etc. It includes medical and nursing care connected to the process of labour/giving birth and the disposal of any tissue bi products. Lady Hale acknowledges there may be aftercare required as a process of birth but section 4 would not extend to ordinary nursing and pastoral care of a patient who has just given birth because “*it was not unlawful before the 1967 Act and thus not made lawful by it*”.<sup>193</sup> Doctors signing the statutory HSA1 forms are not covered by section 4(1) – the forms are a necessary precondition but are not part of the treatment process. Lord Keith in *Janaway* had suggested this interpretation could extend to the forming of opinions by doctors as required by section 1,<sup>194</sup> and although Lady Hale is not explicit, she appears to agree with this view.

In conclusion, the court found that a narrow meaning to the words ‘*to participate in*’ was more likely to have been in the contemplation of Parliament when the Act was passed.<sup>195</sup> This interpretation restricts the words in section 4 to those ‘actually taking part’ in a ‘hands-on capacity’ and relates to those acts made lawful by section 1.<sup>196</sup> Consequently, ancillary, administrative and managerial tasks associated with those tasks are outside the acts made lawful by section 1, and the tasks carried out by the ward co-ordinators were closer to the latter types of roles. The court made it clear that any conscientious objector is under an obligation to refer a patient/case/task to a professional who does not share that objection.<sup>197</sup> The case is notable because the Court’s narrow interpretative stance does not sit comfortably with previous broader interpretations of the Act. It also neatly side steps much of the historic background leading to the implementation of the AA 1967.<sup>198</sup> We will come back to conscientious objection in terminations of pregnancy in chapter 6.

## **Certification and notification provisions<sup>199</sup>**

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<sup>192</sup> *Ibid.*, [33].

<sup>193</sup> *Ibid.*, [34].

<sup>194</sup> *Janaway* (n184).

<sup>195</sup> Cf with the broad statutory construction in the *RCN* case (n77).

<sup>196</sup> *Doogan* (n72), [37] - [38].

<sup>197</sup> *Ibid.*, [40].

<sup>198</sup> For discussion, see *Wale* (n181).

<sup>199</sup> AA 1967, s 2.

The certification and notification provisions in the AA 1967 provide some degree of external scrutiny, and deliberate failure to comply with these provisions and their accompanying regulations may result in conviction for a summary criminal offence.<sup>200</sup> Any medical practitioner authorising termination must certify their section 1 opinion in prescribed form and the doctor undertaking the termination must give external notice (again in prescribed form) to the relevant medical officer.<sup>201</sup>

**Certification** of section 1 opinions is made using an HSA 1 or 2 paper form. HSA 1 (Certificate A in Scotland) is used for section 1(1) terminations and HSA 2 (Certificate B in Scotland) for emergency terminations. Both forms should be kept locally by the medical practitioners for 3 years.<sup>202</sup> These forms must be signed and dated by both practitioners before the termination is performed,<sup>203</sup> and the Abortion Regulations 1991 state that the certificate of opinion should be given for section 1(1) terminations “*before the commencement of the treatment for the termination of the pregnancy to which it relates*”<sup>204</sup> and for section 1(4) terminations “*not later than 24 hours after such termination*”.<sup>205</sup>

**Notification** of the termination procedure is made via the HSA4 form and can be completed/ submitted online or in paper format. In England and Wales, the HSA4 form must be submitted to the relevant Chief Medical Officer (CMO) for every completed termination within 14 days of the procedure.<sup>206</sup> In Scotland, the equivalent form must be sent to the Chief Medical Officer within 7 days. The registered medical practitioner who performed the termination is the person legally responsible for giving notice to the CMO,<sup>207</sup> and the HSA4 form must record the original number of fetuses/embryos and the number preserved in multiple pregnancies. The Departmental guidance notes for completing the paper HSA4 form indicates that all forms relating to selective termination are scrutinised by a medical practitioner and more information can be requested on these cases.<sup>208</sup>

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<sup>200</sup> AA 1967, s 2(3).

<sup>201</sup> See the Abortion Regulations 1991, Abortion (Amendment) (England) Regulations 2002, Abortion (Amendment) (Wales) Regulations 2002/8 and DOH 2014a (n83). The 2002 Regulations changed the prescribed forms.

<sup>202</sup> DOH 2014a (n83), para 11.

<sup>203</sup> DOH 2013 (n94), 2; DOH 2014a (n83), para 11.

<sup>204</sup> S 3(2)

<sup>205</sup> S 3(3)

<sup>206</sup> DOH 2014a (n83), para 26-27.

<sup>207</sup> DOH 2014a (n83), para 28.

<sup>208</sup> Department of Health, *Detailed guidance note for completing the abortion notification form HSA4 for abortions performed in England and Wales* (DOH 2013a).

The Care Quality Commission (CQC) undertook a series of unannounced inspections on abortion providers in 2012. 14 NHS hospitals were found to be pre-signing the HSA 1 forms, and although subsequent CQC inspections found no additional evidence of pre-signing, the Department of Health has subsequently confirmed that this practice is unacceptable.<sup>209</sup> A Departmental/RCOG data matching exercise comparing the Department's records and the National Down's Syndrome Cytogenetic Register (NDSCR) highlighted a number of discrepancies in relation to ground E notifications.<sup>210</sup> RCOG found no:

*“evidence or impression that there was wilful failure to comply with the law, but rather a lack of understanding of the statutory requirements, which in turn produced a lack of organisation and accountability”.*<sup>211</sup>

Although a number of explanations are offered for these discrepancies (including the alternative use of Ground C), a deferential approach appears to have been taken to investigation<sup>212</sup> and the subsequent Departmental response.<sup>213</sup> Notwithstanding the lack of evidence on 'guilty mind',<sup>214</sup> it is of concern that some doctors may have been unaware of their statutory obligations and that the Executive placed reliance on a representative body in this context.<sup>215</sup> Clearly, the certificate and notification provisions are an inadequate protective mechanism without independent/robust investigation and enforcement.

For completeness, we should mention the blanket duty to report any information a person may have about the commission of an offence in Northern Ireland.<sup>216</sup> This duty requires doctors in Northern Ireland to report unlawful terminations or any reasonable suspicion thereof.

## Consent

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<sup>209</sup> Department of Health, *Matching Department of Health Abortion Notifications & Data from the National Down's Syndrome Cytogenetic Register & recommendations for improving notification compliance* (DOH 2014d).; DOH 2014a (n83), para 17.

<sup>210</sup> DOH 2014d (n209)

<sup>211</sup> DOH 2014d (n209), 11.

<sup>212</sup> Using RCOG for the fact-finding rather than the police.

<sup>213</sup> Issuing guidance and not prosecuting.

<sup>214</sup> As per s AA 1967, s2(3).

<sup>215</sup> DOH 2014d (n209), 11.

<sup>216</sup> Criminal Law Act (Northern Ireland) 1967, s5.

Medical and surgical methods of termination need valid maternal consent although additional legal foundation may be required depending on the nature of the intervention.<sup>217</sup> Although, maternal consent is not an explicit requirement of the legal defence under section 1 AA 1967, RCOG states that “*wherever possible, women should be offered the choice of method*”,<sup>218</sup> and the BMA emphasises the need for competent and voluntary decisions made on the basis of “*sufficient, accurate information*”.<sup>219</sup> In terms of paternal consent, the BMA says:

*“a woman’s partner has no legal right to demand or refuse a termination. However, it is good practice to encourage women to discuss the decision with their partner”*<sup>220</sup>

In terms of the obligation to disclose information, this will turn on the specific legal context<sup>221</sup> and we will consider recent developments in the law in chapter 6. If we set aside the legal issues for one moment, pre-procedure counselling remains a delicate and polarising subject matter because even truthful information “*can have a detrimental impact on the decision making of patients considering abortion*”.<sup>222</sup> Domestic attempts to mandate counselling prior to termination have failed,<sup>223</sup> and the Executive has persistently rejected this requirement for independent providers,<sup>224</sup> albeit with caveats relating to the provision of “*impartial and accurate information*”.<sup>225</sup> For some, the AA 1967 entrenches the rights of doctors and offers a system of medical control over fertility,<sup>226</sup> whilst for others, it facilitates termination on demand until the 24<sup>th</sup> week of pregnancy.<sup>227</sup>

## Safeguards and medical monopoly

On paper, the AA 1967 created a medical monopoly - the medical profession largely control access and, to some extent, the decision to terminate - although the practical

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<sup>217</sup> See *Collins v Wilcock* [1984] 3 All ER 374 (CA); *R v Brown* [1993] 2 All ER 75 (HL).

<sup>218</sup> RCOG 2010b (n138), 27. See also NICE, *Termination of Pregnancy – NICE Guideline – Draft for Consultation* (NICE April 2019), 36-37.

<sup>219</sup> BMA 2014 (Updated October 2018) (n124), 15.

<sup>220</sup> *Ibid.*, 17.

<sup>221</sup> Jonathan Herring and others, ‘Elbow Room for Best Practice? Montgomery, Patients Values, and Balanced Decision-Making in Person-Centred Clinical Care’ (2017) 25(4) *Med L. Rev* 582.

<sup>222</sup> Woodcock (n160).

<sup>223</sup> For example, the failed attempt by Nadine Dorries MP to amend the Health and Social Care Bill in 2011. See also, NICE (n218), 25.

<sup>224</sup> DOH 2014b (n162), 12.

<sup>225</sup> DOH 2014a (n83), 11.

<sup>226</sup> Sally Sheldon, *Beyond Control: Medical Power & Abortion Law* (Pluto1997), 42.

<sup>227</sup> Herring 2018 (n126), 320-323.



realities of this gatekeeping role may have shifted over time.<sup>228</sup> To be lawful the procedure must be carried out, or at least implemented by doctors with the assistance of nursing staff. In the case of fetal reductions/ selective terminations, the procedure must take place on NHS hospital premises or other approved place, and regulations are in place to ensure appropriate/ safe standards of treatment. Certification is required from a second medical practitioner (save in emergency), opinions must be their own and external notification is required. Only pregnant (or formerly pregnant) women can easily and realistically challenge the legality of a procedure or have the legal standing to do so.<sup>229</sup> Reverend Jepson's attempt to force the hand of the prosecuting authorities ultimately failed, as did attempts to prosecute doctors for inadequate risk assessment. Similarly, attempts by genetic fathers to secure injunctive relief against planned terminations have failed.<sup>230</sup> Jonathan Montgomery frames the AA 1967:

*“as enshrining a set of positions on the lens through which it is thought by Parliament to be appropriate to consider a decision to terminate a pregnancy; that is, what constitutes a legally acceptable ground for an abortion. This is partly constructed by reference to clinical issues about risk and prognosis, and partly by reference to social judgements; for example, about which injuries are ‘grave’, what constitutes an ‘abnormality’, and the ‘seriousness’ of ‘handicap’. These frame the choices that are to be made available to women, setting boundaries of acceptability. Although they do not define these boundaries, medical professionals are their guardians. Clinical discretion, exercised in good faith, links the political settlement reached by Parliament with the decisions in individual cases.”<sup>231</sup>*

What is of specific concern, is whether the legal lens by which Parliament framed fetal reductions and selective terminations synchronises with the exercise of professional discretion in this context. This is something that we will return to shortly.

## Interpretation

Our analysis demonstrates that the legislative framework is patchy, lacking clarity, in places badly drafted and hard to access and understand. There is evidence of inconsistent statutory interpretation<sup>232</sup> and multiple sources are needed to access the

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<sup>228</sup> Montgomery 2003 (n86); Sheldon et al. (n102). For discussion of the media portrayal of medical power in this context, see Ellie J. Lee, 'Constructing abortion as a social problem: "Sex selection" and the British abortion debate.' (2017) 27(1) *Feminism and Psychology* 15.

<sup>229</sup> Grubb (n3), 661.

<sup>230</sup> Paton (n22); C v S (n24).

<sup>231</sup> Jonathan Montgomery, 'Conscientious Objection: Personal & Professional Ethics in the Public Square', (2015) 23(2) *Med L. Rev* 200, 209-210.

<sup>232</sup> Cf *RCN* (n77) and *Doogan* (n72).

relevant legal rules. Whilst it could be argued that the UK has failed to provide effective means for assessing the scope of lawful activities,<sup>233</sup> legislative change seems unlikely in the short term. Future judicial challenges may come from technological disruption, pressure for home-based terminations, rights-based attacks in the European Court of Human Rights<sup>234</sup>, or substantive abuse by stakeholders. In the meantime, the courts are left to interpret this messy patchwork and whilst clarity and consistency ought to be a priority,<sup>235</sup> social and political considerations continue to impede the overarching determinacy of the law. Despite these reservations, the AA 1967 works reasonably well in practice and medical delivery affords most patients the type of access not immediately apparent from the legal fiction.

#### 4.2.3 Fetal reduction/ selective termination and the criminal framework

Both fetal reduction and selective termination involve surgical intervention - the main method is feticide via inter cardiac injection of potassium chloride<sup>236</sup> or occasionally Lignocaine. In 2017, there were 111 recorded procedures in England and Wales and 84% were performed using ground E.<sup>237</sup> The courts have not drawn a clear distinction between the procedures, for example, in *Doogan* the term '*selective abortion*' is used to describe:

*"Where a woman is carrying more than one foetus, either in order to abort a foetus which may be seriously handicapped or because the reduction in the number of fetuses she is carrying is justified on one of the other grounds"*<sup>238</sup>

Although Lady Hale also refers to "*selective reduction in the number of fetuses*",<sup>239</sup> she makes no terminological distinction between the ending of anomalous or healthy fetal life. Her approach is consistent with the BMA's guidance to their members.<sup>240</sup>

There is no evidence that either procedure was expressly contemplated when the OAPA 1861 or AA 1967 were enacted, but there was growing concern about the

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<sup>233</sup> See *A, B, C v Ireland* [2010] ECHR 2032. However, cf the views of Rosamund Scott, 'Risks, Reasons and Rights: The European Convention on Human Rights and English Abortion Law', (2016) 24(1) *Med L. Rev* 1.

<sup>234</sup> See *Tysiack v Poland* [2007] 45 EHRR 42; Scott (n233)

<sup>235</sup> Brazier 1990 (n3); Grubb (n3).

<sup>236</sup> In 2012, 74 out of 82 cases in England & Wales were by this method.

<sup>237</sup> *Abortion Statistics* (n34), para 2.44.

<sup>238</sup> *Doogan* (n72), [6].

<sup>239</sup> *Ibid.*, [8].

<sup>240</sup> BMA 2014 (n124). Relevant RCOG guidance expressly excludes the topic of embryo reduction from its remit (RCOG, *Multiple pregnancy: the management of twin and triplet pregnancies in the antenatal period* (NICE Clinical Guidance) (RCOG 2011a)).

legality of selective termination and fetal reduction by the time that Parliament debated the 1990 amendments.<sup>241</sup> There was some uncertainty whether the prosecution could demonstrate an intention to procure a ‘miscarriage’ in early reductions without immediate expulsion of body parts.<sup>242</sup> Others were concerned that there might not be protection under the AA 1967 if there was an incomplete termination of the pregnancy.<sup>243</sup> The HFEA 1990 sought to address these concerns and implemented amendments to section 5(2) AA 1967. This section now makes it clear that anything done with intent to procure a miscarriage of any fetus in a multiple pregnancy will be unlawful unless authorised by that section. Although, Grubb agrees that the section is effective at bringing both procedures within the ambit of the AA 1967,<sup>244</sup> Alison Hall is less confident:

*“Section 37(5) of the 1990 act confirms that an abortion of one of a number of fetuses is legal if it complies with the amended Abortion Act – but the amended Abortion Act only offers protection where, in the words of section 1(1) “a pregnancy is terminated”. There has been considerable debate about whether the condition of pregnancy is specific to each individual fetus. If pregnancy means “the state of being with child” or “the state of the uterus in being pregnant” then the technique will fall outside the amended Abortion Act and can never be other than a criminal act.”<sup>245</sup>*

However, Grubb’s interpretation appears to be more realistic, attentive to the statutory language used and in keeping with parliamentary intention.

The amended section 5(2)(a) does address our working definition of selective termination.<sup>246</sup> A medical practitioner can only act lawfully if the thing done with intent is for the purpose of procuring a miscarriage of a fetus that meets the ground E criteria in section 1 (1)(d) AA 1967. Section 5(2) (b) authorises fetal reduction provided any of the other section 1(1) grounds can be made out but there is no requirement for any specific fetus to be targeted. Grubb says this makes sense because:

*“no one fetus can be singled out as the threat to the mother; rather it is the cumulative effect of their presence which creates the risk to her.”<sup>247</sup>*

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<sup>241</sup> HFEA 1990, s37. See also David Price, ‘Selective reduction and feticide: the parameters of abortion’ (1988) *Crim. L.R.* 199; Brazier 1990 (n3).

<sup>242</sup> Price (n241) 3; Hall (n3), 306.

<sup>243</sup> Price (n241); Brazier 1990 (n3) 68; Grubb (n3), 667-668.

<sup>244</sup> Grubb (n3), 668.

<sup>245</sup> Hall (n3), 306.

<sup>246</sup> Legendre et al.(n125).

<sup>247</sup> Grubb (n3), 668.

However, these changes do not address the elevated risks posed by the multiple pregnancy to the fetuses themselves.<sup>248</sup> Statistically, multiples have a higher probability of adverse maternal/ fetal outcomes than singleton pregnancies<sup>249</sup> but the fetal outcomes are not a lawful ground for termination. Fetuses are not '*existing children of the family*'<sup>250</sup> and the Act makes no provision for addressing competing interests within the womb. Further, it is unlikely that general elevated risks of prematurity/ abnormality automatically equate with a substantial risk of serious handicap in any specific entity in low order multiple pregnancies.

Hall highlights that section 1(1)(b) AA 1967 speaks of prevention not reduction of risk – when used, the reduction must be assessed as necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman.<sup>251</sup> A fetal reduction may reduce but not completely obviate the risk to the woman if a multiple pregnancy is maintained.<sup>252</sup> Hall argues that a comparative exercise must be made between continuing with different types of multiple pregnancy although this requirement is not expressly provided for in the relevant subsection. However, in most cases, treating doctors will be able to validly certify fetal reductions under the alternate social ground<sup>253</sup> - a practice clearly envisaged in associated BMA guidance.<sup>254</sup> Arguably, section 5 (2) (b) AA 1967 also covers the alternative definition of selective termination<sup>255</sup> providing the medical or emergency grounds can otherwise be made out.

### 4.3 Civil Liability

#### Civil liability for in-utero harm

In England, Wales and Northern Ireland, civil liability is governed by the Congenital Disabilities (Civil Liability) Act 1976 (CDCLA). This Act holds tortfeasors liable for pre-natal injuries but crystallises the cause of action on the birth of the child. The embryo/fetus derives no rights pending birth and there is no civil cause of action for death in-utero.<sup>256</sup> Fortin points out that:

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<sup>248</sup> Hall (n3), 306.

<sup>249</sup> Alan Cameron, *Fetal medicine for the MRCOG and beyond* (2<sup>nd</sup> ed, RCOG Press 2011).

<sup>250</sup> AA 1967, s 1(1)(a); Brazier 1990 (n3), 69.

<sup>251</sup> Hall (n3), 307.

<sup>252</sup> Eg a reduction from quads to triplets.

<sup>253</sup> AA 1967, s 1(1)(a). There is corroborating evidence of this practice from our research interviews.

<sup>254</sup> BMA 2014 (updated October 2018) (n124), 8.

<sup>255</sup> Ie. Fetal pathologies that do not meet the criteria in AA 1967, s 1(1)(d) but which could be prejudicial to the development of the other healthy fetus(es) (Legendre et al. (n125), 543).

<sup>256</sup> Jane E S. Fortin, 'Legal Protection for the Unborn Child' (1988) 51 *MLR* 77.

*“The 1976 Act also avoids the illogicality of maintaining that the tortfeasor owes a duty of care to a legal non-entity, the unborn child. Instead, a formula of derivative liability is used whereby a third person is only liable to a child born disabled if he had been ‘liable in tort to the parent or would, if sued in due time, have been so’.”*<sup>257</sup>

Although the fetus has no general cause of action against the mother, the Act does impose a limited duty of care in relation to the driving of a motor vehicle.<sup>258</sup> Overall, the civil law is largely coherent with the criminal law jurisprudence in this context.<sup>259</sup> The common law remains relevant for events prior to the enactment of the CDCLA - a child who has suffered pre-natal injuries because of a negligent act occurring during the pregnancy, has a cause of action at birth and can recover in respect of damage suffered since the birth as a result of the pre-natal injuries.<sup>260</sup> There is no statutory equivalent of the CDCLA in Scotland.

### **Civil liability for wrongful conception/ birth/ life**

Essentially these claims maintain that but for the defendant’s negligence, the child would not have been conceived or born at all.<sup>261</sup> Although the domestic common law has resisted wrongful life claims by the child (the *McKay* exclusion),<sup>262</sup> there are some compensatory avenues open to the parents of the child in relation to wrongful conception/ birth cases.<sup>263</sup> In *Parkinson*<sup>264</sup> the court was willing to compensate for the special costs associated with bringing up a disabled child following a negligently performed sterilisation (wrongful conception). The emphasis here was on compensating the parents for the extra costs associated with the disability, rather than providing the child with damages for the disability. One important statutory exception to the *McKay* exclusion provides a born child (with disability arising from licensed fertility treatment) with a remedy against the person whose negligence caused the disability.<sup>265</sup>

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<sup>257</sup> Ibid. See CDCLA 1976, s 1(3).

<sup>258</sup> CDCLA 1976, s2.

<sup>259</sup> See *CP* (n38), [47] and [66] - [67] (CA).

<sup>260</sup> See Dillon LJ in *Burton v Islington HA* [1993] QB 204 (CA).

<sup>261</sup> For the distinction, see Samuel Walker, ‘Applying the actual/potential person distinction to reproductive torts’, (2014) 14(1-2) *Medical Law International* 3.

<sup>262</sup> *McKay v Essex Area Health Authority* [1982] QB 1166 (HL).

<sup>263</sup> *McFarlane v Tayside Health Board* [1999] 4 All ER 961 (HL); *Rees v Darlington Memorial Hospital NHS Trust* [2004] 1 AC 309 (HL).

<sup>264</sup> *Parkinson v St James and Seacroft University Hospital NHS Trust* [2002] QB 266 (CA).

<sup>265</sup> See CDCLA, s1A; Stauch & Wheat 2012 (n127), 411.

## Criminal Injuries Compensation Authority (CICA)

We have already examined the ruling in *CP (A Child)*<sup>266</sup> that a child with fetal alcohol spectrum disorder was not a victim of crime. In any event, the CICA rules have been amended to exclude those children damaged by alcohol in the womb from the ambit of 'victim of crime'.<sup>267</sup>

### 4.4 The 'in-utero' embryo/ fetus

The Scottish approach to in-utero fetal status has already been highlighted.<sup>268</sup> Sir George Baker P summarised the English Law approach in *Paton*:

*"The foetus cannot, in English law, in my view, have any right of its own at least until it is born and has a separate existence from the mother."*<sup>269</sup>

Similarly, in *Re MB (Medical Treatment)*, the Court of Appeal stated:

*"The foetus up to the moment of birth does not have any separate interests capable of being taken into account when a court has to consider an application for a declaration in respect of a caesarian section operation"*<sup>270</sup>

However, that does not mean that the fetus has no legal status and Lord Mance has recently suggested that the (aforementioned) statement in *MB* may be "too dogmatic".<sup>271</sup> In *Attorney General's Reference (No 3 of 1994)*, Lord Mustill rejected:

*"the reasoning which assumes that since (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"*<sup>272</sup>

Similarly, Lord Hope emphasised that:

*"an embryo is in reality a separate organism from the mother from the moment of its conception. This individuality is retained by it throughout its development until it achieves an independent existence on being born. So the foetus cannot be regarded as an integral part of the mother in the sense indicated by the*

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<sup>266</sup> *CP* (n38).

<sup>267</sup> Ministry of Justice (MOJ), *The Criminal Injuries Compensation Scheme 2012* (MOJ 2012), Annex B 4(1)(e).

<sup>268</sup> Chapter 4.2.

<sup>269</sup> *Paton* (n22), 989.

<sup>270</sup> [1997] EWCA Civ 3093.

<sup>271</sup> *NIHRC* (n18), [93].

<sup>272</sup> *AG Ref No3* (n22), 256-7.

*Court of Appeal, notwithstanding its dependence upon the mother for its survival until birth”*<sup>273</sup>

In *S*, Judge LJ concluded that a 36-week fetus ‘*is not nothing: if viable it is not lifeless and is certainly human*’.<sup>274</sup> However, an embryo or fetus cannot be made a ward of court,<sup>275</sup> nor can they bring legal proceedings until birth.

So, whilst the embryo or fetus is not seen as an integral part of the mother, neither is it an autonomous human person for the purposes of the law. European human rights jurisprudence has repeatedly side stepped the issue of status,<sup>276</sup> although fetal interests have been afforded a measure of protection by the domestic criminal law linked to development or viability.<sup>277</sup> Once a child is born it can bring a civil action for in-utero harm using the Congenital Disabilities (Civil Liability) Act 1976. A person can only be convicted of a criminal offence for causing in-utero harm that results in the death of a child once born.<sup>278</sup> The overall legal position is arguably incoherent but does offer a pragmatic solution in the absence of further consolidation and clarity.

There has been a general reluctance by the domestic judiciary to tackle ethical or moral issues head on. Sir George Baker P in *Paton* said:

*“In the discussion of human affairs and especially of abortion, controversy can rage over the moral rights, duties, interests, standards and religious views of the parties. Moral values are in issue. I am, in fact, concerned with none of these matters. I am concerned, and concerned only, with the law of England as it applies to this claim. My task is to apply the law free of emotion or predilection”*<sup>279</sup>

In *Bland v Airedale NHS Trust*,<sup>280</sup> Hoffmann LJ claimed that judicial decisions should be based upon “*acceptable ethical values*”, whilst asserting that he “*would expect medical ethics to be formed by the law rather than the reverse*”. However, in the House of Lords, Lord Browne-Wilkinson showed more reluctance and questioned whether complex moral issues would be better resolved by Parliament.<sup>281</sup> More recently, Munby J stated:

*“It is no part of my function as I conceive it to determine the point at which life begins. In the view I have taken of the 1861 Act there is no need for me to do so. It is, as it seems to me, undesirable that I should do so. Even were I to attempt to do so, the effect of my decision would be limited. In the nature of things all I could do would be to determine as a matter of law an issue which*

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<sup>273</sup> *Ibid.*, 267F.

<sup>274</sup> *St George’s Healthcare NHS Trust v S* [1999] Fam 26, 45f.

<sup>275</sup> *Re F (In Utero)* [1988] Fam 122

<sup>276</sup> See *Paton v UK* [1981] 3 EHRR 408; *Vo v France* [2004] 2 FCR 577 and *A, B, C v Ireland* [2010] ECHR 2032.

<sup>277</sup> AA 1967, s 1(1)(a); ILPA 1929, s 1.

<sup>278</sup> *AG Ref no3* (n22).

<sup>279</sup> *Paton* (n22), 278c-d.

<sup>280</sup> *Bland v Airedale NHS Trust* [1993] AC 789 (HL), 825G.

<sup>281</sup> *Ibid.*, 878C.

*has much wider ramifications and which in other contexts may well have to be determined by reference to quite different criteria*<sup>282</sup>

The reluctance of the judiciary to engage in this realm is an important regulatory consideration when gaps or uncertainty are created or left open by the legislature.

#### 4.5 The 'ex-vivo' embryo

The HFEA 1990 paved the way for the creation and storage of ex-vivo embryos for both reproductive and research purposes; and made it possible to undertake research on spare embryos produced in consequence of assisted reproduction treatment (ART) and those created specifically for research. Understandably, this Act aligns the start of pregnancy with the in-vivo environment,<sup>283</sup> and avoids any interpretation that could link the concept with the free-standing creation of embryo life independent of context. Legal pregnancy is therefore restricted to the implanted embryo, and the effect of the HFEA 1990 is to create an entirely separate regulatory regime for the ex-vivo embryo. The Warnock Committee<sup>284</sup> eventually concluded that the embryo was a separate entity with a 'special status' albeit one that has never been adequately defined.<sup>285</sup> The majority concluded that the ex-vivo embryo warranted some degree of legal protection,<sup>286</sup> but the subsequent legislation (HFEA 1990) left open some gaps around the treatment of human gametes<sup>287</sup> and pre-implantation fertilised eggs. The European Tissues and Cells Directive<sup>288</sup> aimed to address the former and was subsequently implemented by the Human Fertilisation and Embryology Act 2008<sup>289</sup> and Human Fertilisation & Embryology (Quality & Safety) Regulations 2007.<sup>290</sup> Importantly, these provisions no longer restrict the creation of human embryonic life to fertilisation.<sup>291</sup>

The associated regulatory regime works through a combination of prohibition and authorised conduct subject to licences issued by the Human Fertilisation and Embryology Authority (the **Authority**). A human embryo cannot be stored for more

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<sup>282</sup> *R (Smeaton) (n2)*, [54].

<sup>283</sup> HFEA 1990, s 2(3).

<sup>284</sup> Warnock Committee Report, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (HMSO Reprint 1988).

<sup>285</sup> *Ibid.*, para 11.17/18 at 63-64.

<sup>286</sup> *Ibid.*

<sup>287</sup> Both in-vivo and ex-vivo.

<sup>288</sup> Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004, Setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells.

<sup>289</sup> HFEA 2008.

<sup>290</sup> See also HFEA *Code of Practice* (8<sup>th</sup> and 9<sup>th</sup> editions HFEA).

<sup>291</sup> Section 1(2) HFEA 2008



than 14 days after mixing of gametes,<sup>292</sup> preventing use of the embryo following formation of the 'primitive streak'.<sup>293</sup> The storage or use of an embryo under any circumstances which is prohibited is made unlawful unless otherwise licenced by the Authority.<sup>294</sup> It is unlawful to alter the genetic structure of any cell while it is part of an embryo,<sup>295</sup> and this restriction includes the alteration of DNA, subject to some exceptions permissible under licence.<sup>296</sup> The consent of the gamete provider to the continued storage or use of any resulting embryo is an absolute requirement, and the '*bright-line*' for consent is placed at the point of embryo transfer. This means that until the embryo is transferred, the gamete provider has an unqualified right to withdraw that consent. If the consent has been withdrawn, the licence holder has no other option but to destroy the embryo, and the statutory framework does not permit any discretion.<sup>297</sup>

The Authority makes decisions and grants licences for embryo creation, research and treatment; and in respect of research uses a 'principles' or defined purposes framework.<sup>298</sup> Licences for IVF treatment should not be granted unless account has been taken of the welfare of any child that may be born as a result of the treatment or any child affected by the birth.<sup>299</sup> Unlike the AA 1967, we have a clear statutory expression of purpose in section 13(5) HFEA 1990, namely the welfare of the possible future child and any child affected by the birth.

In summary, the creation, treatment, research and storage of the ex-vivo embryo is subject to some level of restriction and control; the law offers some degree of protection for that entity without granting or recognising any express legal rights or interests. One oddity is that ex-vivo embryos appear to have greater legal protection than the in-vivo counterparts prior to implantation.

## 4.6 Human rights

The operation of the Human Rights Act 1998 and the public funding of UK termination services<sup>300</sup> necessitates analysis of jurisprudence concerning the European Convention

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<sup>292</sup> HFEA 1990, s 4A (3).

<sup>293</sup> At this point we can definitively identify the number of embryos. See Warnock (n284), 6.6.

<sup>294</sup> HFEA 1990, s 4(2).

<sup>295</sup> HFEA 1990, Sch 2, para 1.4.

<sup>296</sup> HFEA 1990, s 3ZA (5); see also Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015.

<sup>297</sup> Sonia Harris, 'Regulating Reproduction: Frozen Embryos, Consent, Welfare & the Equality Myth' at 50, Chp 3 in Ronan Deazley & Stephen Smith (eds), *The Legal, Medical, and Cultural Regulation of the Body: Transformation and Transgression*, (Ashgate Publishing, 2009). Cf *ARB v IVF Hammersmith Ltd* [2018] EWCA Civ 2803

<sup>298</sup> HFEA 1990, sch 2, para 3A

<sup>299</sup> HFEA 1990, s 13(5)

<sup>300</sup> DHSC *Abortion Statistics* (n34), para 2.11. In 2017, 98% of abortions were funded by the NHS.

on Human Rights (ECHR).<sup>301</sup> At the outset, we should make it clear that the European Court of Human Rights (ECtHR) and Commission have repeatedly side stepped the issue of embryo or fetal status. In *Paton v UK*, the Commission avoided an absolutist interpretation of Article 2 (right to life) because:

*“The 'life' of the foetus is intimately connected with, and cannot be regarded in isolation from, the life of the pregnant woman. If Article 2 were held to cover the foetus and its protection under this Article were, in the absence of any express limitation, seen as absolute, an abortion would have to be considered as prohibited even where the continuance of the pregnancy would involve a serious risk to the life of the pregnant woman. This would mean that the 'unborn life' of the foetus would be regarded as being of a higher value than the life of the pregnant woman.”*<sup>302</sup>

Ultimately, the Commission concluded that it was not being called upon to decide whether Article 2 covered the fetus, or whether it should recognise a 'right to life' with implied limitations. In any event, the Commission found that the termination in that case was covered by an implied limitation protecting the life and health of the woman at that stage of gestation.

In *Vo v France* (a case involving 3rd party harm to a fetus),<sup>303</sup> the Court decided it was for each individual member state to determine the appropriate degree of legal protection for the fetus using a wide margin of appreciation. The perceived absence of consensus appears to have proved decisive in granting States a wide margin of appreciation.<sup>304</sup> Scott points out that the facts of the case are important because of the subsequent reliance on this precedent by the ECtHR.<sup>305</sup> *Vo* was not about any conflict of fetal/ maternal rights or any moral/ legal balance; and the interests of the mother and baby were aligned against the 3<sup>rd</sup> party doctor that had negligently caused the fetal harm. Put simply, Scott claims that *Vo* should not be used as a benchmark for deciding cases where maternal/ fetal conflict arises, and in contexts that otherwise create difficulties for the recognition of rights and interests.<sup>306</sup> Potential fetal rights (under Article 2) and actual maternal rights (under Article 8) are interconnected in abortion cases because they cannot be exercised independently due to the physical connection between woman and unborn entity.<sup>307</sup>

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<sup>301</sup> 1950 (Council of Europe)

<sup>302</sup> [1981] 3 EHRR 408, [19].

<sup>303</sup> *Vo* (n276).

<sup>304</sup> Rosamund Scott, 'Reproductive Health: Morals, Margins and Rights', (2018) 81(3) *MLR* 422, 431.

<sup>305</sup> *Ibid.*, 430-431.

<sup>306</sup> *Ibid.*, 431-435.

<sup>307</sup> *Ibid.*, 434.

In *Tysiact v Poland*,<sup>308</sup> the applicant succeeded in her Article 8 challenge after having been denied the opportunity for a lawful termination on health grounds. The court decided that the State had failed to provide the applicant with an effective mechanism for determining her entitlement to a therapeutic termination. In *A, B, C v Ireland*,<sup>309</sup> the court whilst noting that:

*“not every regulation of the termination of pregnancy constitutes an interference with the right to respect for the private life of the mother”*

found that the prohibition on terminations<sup>310</sup> amounted to an interference with the first and second applicants’ right to respect for their private lives (Article 8). The central question was whether there had been an unjustified interference with their Article 8 rights and the court answered that question in the negative. However, for the third applicant, the issue was (as per *Tysiact*) whether the State had provided effective means for determining the entitlement to a lawful termination. The court concluded that the Irish State had failed to comply with their positive obligation to secure effective respect for the applicant’s private life – there was no accessible and effective procedure for establishing the qualification for lawful termination.

Further successful actions were brought against Poland for their access provisions in *RR v Poland*<sup>311</sup> and by a victim of sexual crime in *P and S v Poland*.<sup>312</sup> In these cases, the court ruled that there had been breaches of Articles 8 and 3 (inhuman and degrading treatment). These cases demonstrate that when access mechanisms are highly restrictive or unclear; and/or where the State fails to support a person adequately, it is possible to bring a successful human rights action. However, Fenwick has described the ECtHR’s approach as highly deferential and avoidant of substantive issues like reproductive health, dignity and autonomy.<sup>313</sup> He claims that the court is framing these cases as one of effective delivery of healthcare rather than substantive determination of the “*nationally struck balance between fetal and maternal interests*”.<sup>314</sup> Scott also notes the continuing failure by the ECtHR to give legal recognition to patient autonomy or to fully develop the importance of psychological integrity in cases concerning termination.<sup>315</sup> She claims that the flawed use of a wide margin of

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<sup>308</sup> *Tysiact v Poland* [2007] 45 EHRR42.

<sup>309</sup> [2010] ECHR 2032.

<sup>310</sup> Sought for reasons of health and well-being.

<sup>311</sup> [2011] 53 EHRR 31.

<sup>312</sup> *P & S v Poland* [2012] App No 57375/08.

<sup>313</sup> Daniel Fenwick, “Abortion jurisprudence” at Strasbourg: Deferential, avoidant and normatively neutral’, (2014) 34(2) *Legal Studies* 214.

<sup>314</sup> *Ibid.*, 239.

<sup>315</sup> Scott (n304),446-447.

appreciation cannot be justified in cases of direct maternal/ fetal conflict,<sup>316</sup> and is critical of judicial responses to ‘moral’ attacks by those who have “*no need for a given reproductive intervention – and thus no interest in choosing it*”.<sup>317</sup> Scott also argues elsewhere, that the requirements of section 1(1)(a) AA 1967 may be incompatible with Article 8 ECHR because criminalisation is unnecessary and offers unnecessary hurdles for pregnant women in the majority of first trimester cases where the risk of continuing the pregnancy is higher than the risk of termination.<sup>318</sup>

Before closing, we return to the **NIHRC case**,<sup>319</sup> which involved challenges under Articles 3, 8 and 14 ECHR to the Northern Ireland prohibition on termination for fetal abnormality and of pregnancies resulting from sexual crime or incest. Although, the challenge failed due to a lack of standing, the Supreme Courts’ views on compatibility are worthy of consideration.<sup>320</sup> Whilst the unborn entity was not considered a rights holder under the ECHR,<sup>321</sup> the majority agreed that the current domestic law pursues a legitimate aim, namely “*the moral interest in protecting the life, health and welfare of the unborn child*”.<sup>322</sup> According to Lady Hale, there is also a similar community interest relating to pregnant women.<sup>323</sup> The core issue became whether the interference with a woman’s qualified Article 8 rights is necessary in a democratic society in a way that strikes a fair balance between maternal rights and fetal interests. The majority agreed that the interference was unnecessary and unjustified in relation to all three categories but distinguished fatal fetal abnormality (an unnecessary interference) from serious fetal abnormality (a necessary interference based on equality grounds and associated international obligations).<sup>324</sup> Arguably, the concentration on fetal anomaly shifts emphasis away from maternal bodily autonomy to the status of the unborn entity. However, the majority fixed on the maternal obligation to carry to term thereby maintaining focus on the protection of bodily autonomy:<sup>325</sup>

*“Where the unborn child cannot survive, in contrast to the other categories of pregnancy with which we are concerned, there is no life outside the womb to protect. In those circumstances, even if allowance is made for the intrinsic value of the life of the foetus, the moral and ethical views of society cannot, it seems to me, be sufficient to outweigh the intrusion upon the autonomy of the pregnant*

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<sup>316</sup> *Ibid.*, 451.

<sup>317</sup> *Ibid.*, 424.

<sup>318</sup> Rosamund Scott, ‘Risks, Reasons and Rights: The European Convention on Human Rights and English Abortion Law’, (2016) 24(1) *Med L. Rev* 1.

<sup>319</sup> NIHRC (n18). Cf also *R (on the application of A and B) v Secretary of State for Health* (n61).

<sup>320</sup> See the summary in this chapter at pages 82-84.

<sup>321</sup> NIHRC (n18), [21], [24], [94] and [305]-[306].

<sup>322</sup> *Ibid.*, [21], [105] and [278]

<sup>323</sup> *Ibid.*, [21].

<sup>324</sup> *Ibid.*, [31], [133] and [331].

<sup>325</sup> *Ibid.* [28], [133], [326], [368] and [371].

*woman, and her suffering, if she is obliged to carry to term a pregnancy which she does not wish to continue.*<sup>326</sup>

The majority took a different position in relation to Article 3, reflecting the fact that this is an absolute rather than a qualified right and due to the need to test the severity of the (mis)treatment in a fact specific rather than abstract environment.

## 4.7 Conclusions

The overarching impression is of a jurisdictionally complex, and occasionally opaque legal environment that healthcare professionals must navigate at their own risk. At face value, the termination framework pays scant regard to maternal rights and reproductive choice. However, others have been more generous describing the AA 1967 as a “*benign fiction*”<sup>327</sup> because reproductive services are delivered in spite of this framework, and women in Great Britain are generally afforded access to publicly funded terminations. There is some evidence of evolutionary development following the implementation of the AA 1967, a process that can be explained by the use of vague (or flexible) legal rules, the generous exercise of professional discretion, clinical/ technological advances, changes in societal opinion, the decline of religious norms or a combination of these factors.<sup>328</sup> Either way, we have a general legal framework that accommodates most scenarios, but which also offers a degree of flexibility for the more difficult case.

Domestic and international law has fudged the question of legal personhood for the unborn entity and created a framework that offers a half way house – one which neither recognises unqualified maternal rights or open-ended legal protection for the unborn entity. This static compromise is likely to be challenged by disruptive societal and technological changes<sup>329</sup> and may be reaching the end of its legitimate and workable life span.

We should recognise that legal frameworks have the capacity to shape relationships - between patients, healthcare professionals and the healthcare system – and

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<sup>326</sup> Ibid., [371] (Lady Black).

<sup>327</sup> Herring (n126), 320.

<sup>328</sup> Roger Brownsword and Jeffrey Wale, ‘Compromise medicalisation’, in C. Stanton and others (eds), *Pioneering Health Care Law Essays: In honour of the work of Professor Margaret Brazier* (Routledge 2015); Sheldon et al. (n102), 33.

<sup>329</sup> David R. Lawrence and Margaret Brazier, ‘Legally Human? ‘Novel Beings’ and English Law’, (2018) 26(2) *Med L. Rev* 309.

sometimes in unexpected ways.<sup>330</sup> Sally Sheldon makes this telling observation about the impact of medical power and control on women in abortion care:

*“first at the level of a technical control of the means of avoiding reproduction, secondly at the level of decisional control-policing who should (and who should not) be allowed the possibility of an abortion, thirdly at the level of paternalistic control (where the benevolent doctor will enforce her views through ‘persuasion’), and lastly at the level of a normalising control exercised in the medical interview over women seeking abortion.”<sup>331</sup>*

These features should not be discounted when evaluating the impact of this legal framework on patient encounters.

Whilst fetal reduction and selective termination are governed by the general legal framework, they generally fall into the category of the difficult case. These procedures involve problematic choices for clinicians and prospective parents requiring specialist surgical intervention in fetal medicine (tertiary) centres.<sup>332</sup> Choices are often being made at a later stage than singleton terminations and involve complex assessments of competing medical risk. Decisions may also be made against a background of IVF treatment and a longstanding desire for children.

There are also two major problems with the general legal norms as they apply to these procedures. First, these procedures often engage or are justified by ground E – a problematic legal provision that in practice may stretch the boundaries of reasonable statutory interpretation. This ground<sup>333</sup> arguably requires doctors to go beyond their field of expertise and make social judgements about the ‘seriousness’ of ‘handicap’.<sup>334</sup> The legal text contains some outdated terminology and is open to (mis) interpretation and disagreement over meaning and scope. There is also some evidence of discordance between the legal and professional norms in this context.

Secondly, fetal reductions may involve decision-making considerations which the general law does not authorise. In high order multiples, the rationale for reduction may be pregnancy preservation or pregnancy maximisation. Whilst the law recognises inherent risks to the pregnant woman, it does not explicitly authorise the weighing of general fetal interests or provide for pregnancy preservation. This puts pressure on the interpretation of the lawful grounds for termination – most notably C and E<sup>335</sup> - and the resulting space between professional and legal norms. Indeed, the current legal framework makes divergent professional/ practice norms more likely in multiple

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<sup>330</sup> Sheldon et al. (n102).

<sup>331</sup> Sheldon (n226), 73.

<sup>332</sup> Cf the medical methods dominating singleton terminations in the UK.

<sup>333</sup> AA 1967, s 1(1)(d).

<sup>334</sup> Jonathan Montgomery (n231).

<sup>335</sup> AA 1967, s 1(1)(a) and (d) respectively.

pregnancies and has the capacity to place significant pressure on key decision-makers at a critical juncture.

## Chapter 5 – Legal Frameworks (2)

Contents:

- 5.1 Introduction
- 5.2 Legal regulation using the concept of pregnancy.
- 5.3 Regulatory options - termination of pregnancy.
- 5.4 Legal regulation of healthcare professionals and providers.
- 5.5 Compelling medical treatment.
- 5.6 Conclusions

### 5.1 Introduction

In this chapter, we develop our analysis of the legal normative frameworks and start with an examination of legal regulation using the concept of pregnancy. Here, our focus is on how pregnancy is used by the law, and regulation more generally “as a *distinctive marker according to which pre-and post-events are defined and analyzed*”.<sup>1</sup>

In the preceding chapter, we established (albeit with some equivocation around precision) that a legal pregnancy starts from implantation of the fertilised human egg and ends following birth and complete expulsion from the woman. Specifically, we now address how the concept of pregnancy has been used in legal regulation and examine whether pregnancy (and decision-making by the pregnant woman about her pregnancy) should be the sole or primary criterion for regulating pre and post implantation activities.<sup>2</sup>

We then move on to outline some possible reform options before closing with an examination of the broader legal frameworks governing healthcare professionals, healthcare providers and the delivery of medical treatment. We have two central aims in this chapter. First, to examine whether and what changes might be made to the existing legal norms to better accommodate terminations of pregnancy, and specifically fetal reductions and selective terminations. Secondly, to gain a clearer picture of the broader legal framework regulating doctors, and more generally healthcare professionals and service providers. This will provide a foundation for addressing the

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<sup>1</sup> Judith Daar, ‘The outdated pregnancy: Rethinking traditional markers in reproductions’, (2014) 35(4) *Journal of Legal Medicine* 505, 507.

<sup>2</sup> *Ibid.*, 509.



wider options for regulating medical decision-making and assist the development of responses to the third research question.

## 5.2 Legal regulation using the concept of pregnancy

The possibility of ex-vivo existence necessitates consideration of entity status and the appropriate degree of legal protection that ought to be afforded to the independent embryo.<sup>3</sup> Disconnected physically from the pregnant woman, the embryo exists as an independent entity, albeit one where there are widely divergent views over its nature and moral status. In the case of a pre-implanted but in-vivo embryo, there is no legal pregnancy even though the embryo is developing within an internal environment. Offering freestanding legal protection or status to that entity could create issues for medication or other devices designed to interfere with the implantation process and initiate wider implications for female autonomy and gender equality.<sup>4</sup>

The environmental context of the embryo is central - pregnancy embodies a physical state of existence ('being with child') and a direct relationship between the growing entity and the pregnant woman. The implanted embryo cannot be easily protected without some potential or actual violation of the pregnant woman's autonomy.<sup>5</sup> Conversely, any interests that the ex-vivo embryo may possess, or that can be ascribed to it, can be asserted and enforced independently without direct physical impact on the woman. The physical separation of the ex-vivo embryo from the parental donors cannot be ignored, although there might be good societal interests independent of physical location that demand some consistency of approach. Genetic, gender or racial profiling might be typical cases where a unified approach to legal regulation is warranted, although, we would still need to address matters relating to development and the degree of invasion/ harm to the entities involved.<sup>6</sup> The parental role in the creation of the entity is a further consideration although this does not establish a neat 'bright line' and may only separate the in-vitro embryo created for research from those

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<sup>3</sup> Amel Alghrani and Margaret Brazier, 'What Is It? Whose is It? Re-Positioning the Fetus in the context of Research', (2011) *Cambridge Law Journal* (1) 51.

<sup>4</sup> Sonia Harris, 'Regulating Reproduction: Frozen Embryos, Consent, Welfare & the Equality Myth', chp 3 in Ronan Deazley and Stephen Smith (eds), *The Legal, Medical, and Cultural Regulation of the Body: Transformation and Transgression*, (Ashgate Publishing, 2009).

<sup>5</sup> Margaret Brazier and Suzanne Ost, *Bioethics, medicine, and the criminal law, Volume III, Medicine and bioethics in the theatre of the criminal process* (Cambridge University Press 2013).

<sup>6</sup> Eg, Rosamund Scott, 'Choosing between Possible Lives: Legal and Ethical Issues in Preimplantation Genetic Diagnosis', (2006) 26(1) *OJLS* 153.

created for reproductive purposes.<sup>7</sup> There are also practical differences between selective termination/ fetal reduction and embryo research that may justify different approaches to paternal consent, especially relating to the withdrawal of reproductive permission.<sup>8</sup>

The role of the law and the legitimacy of State interference in reproductive choice also needs to be addressed. Whilst the criminal law may have a limited role in the regulation of reproductive choice,<sup>9</sup> few States have allowed unfettered access to abortion or unqualified freedom in embryo research.<sup>10</sup> States might want to protect pregnant women and gamete providers from potential harm although this may not legitimise interference in Millian terms. The criminal law may have a legitimate role to play in the wider protection of genetic characteristics and unsanctioned interferences with the human genetic code; or perhaps in avoiding the commodification of the creation process.<sup>11</sup> States may have a role to facilitate and secure particular variations in reproductive autonomy;<sup>12</sup> decriminalised frameworks may still require legitimisation,<sup>13</sup> and the absence of restrictive regulation is not a guarantee of reproductive access or choice.

This takes us on to examine whether termination procedures should be regulated solely by reference to the pregnancy, the pregnant woman, or by direct legal protection of the unborn entity or through a combined approach. This has very real implications for fetal reduction and selective termination, when distinct entity interests are possibly in play. UK law ceded exclusivity to the legal concept of pregnancy when it amended the Abortion Act in 1990. Whilst the original anomaly ground included reference to “*if the child were born*”,<sup>14</sup> the 1990 amendments extended protection to the gestational pregnancy of any “*foetus*”,<sup>15</sup> and added the requirement that the anomaly ground should apply to procuring the “*miscarriage of that foetus*”.<sup>16</sup> Although the ILPA 1929 offered a measure of independent protection for the unborn entity from viability, the 1990 amendments extended qualified and divergent protection from implantation based

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<sup>7</sup> For a discussion on the ethical distinctions between the in-vitro embryo created for research and reproductive purposes see Katrien Devolder, *The ethics of embryonic stem cell research* (OUP 2015). See also David R. Lawrence and Margaret Brazier, ‘Legally Human? ‘Novel Beings’ and English Law’, (2018) 26(2) *Med L. Rev* 309.

<sup>8</sup> Alghrani and Brazier (n3).

<sup>9</sup> Kerry Petersen, ‘Classifying Abortion as a Health Matter: The Case for De-Criminalising Abortion Laws in Australia’, chp 22 in Sheila McLean, *First Do No Harm: Law, Ethics and Healthcare* (Ashgate 2006)). See for eg, the Abortion Bill 2018-19 (HC Bill 276).

<sup>10</sup> Canada is a rare example of a State where abortion has been decriminalised.

<sup>11</sup> Heather Widdows, ‘Persons and their parts: new reproductive technologies and risks of commodification’, chp 4, (79-86) in Ronan Deazley and Stephen Smith (eds), *The Legal, Medical, and Cultural Regulation of the Body: Transformation and Transgression* (Ashgate 2009).

<sup>12</sup> Erin Nelson, *Policy and Reproductive Autonomy* (Hart 2013).

<sup>13</sup> Mary Neal, ‘Locating lawful abortion on the spectrum of proper medical treatment’, in S. Fovargue and A. Mullock (eds), *The Legitimacy of Medical Treatment: What role for the medical exception?* (Routledge 2015).

<sup>14</sup> Abortion Act 1967 (original version), s1(1)(b).

<sup>15</sup> AA 1967, s 5(2).

<sup>16</sup> AA 1967 (as amended), s 5(2)(a). The reference to the term “foetus” in AA 1967 (original version), s5(1) is also acknowledged.

on gestational time limits. The anomalous fetus now has less explicit legal protection than a healthy post 24-week fetus<sup>17</sup> - a conceptual variation driven by considerations external to the infringement of maternal bodily autonomy. Although fetal status might be interconnected with the exercise of maternal autonomy, legal variation exists because of intrinsic changes in the physical status of the unborn entity.

Regulation using the concept of pregnancy has some practical advantages because it acknowledges the interconnected relationship between the pregnant woman and her developing fetus. The concept promotes the values of the pregnancy over individual entity interests and diverts our attention away from heavily contested definitional/ status issues. It shifts the focus onto decisions made by the pregnant woman about her pregnancy, and would, for example, facilitate the drafting of rules authorising fetal reduction for the protection of the wider pregnancy. We create difficulties when we try to justify or base legal rules on the kind of entity the embryo/ fetus is or may become, or otherwise introduce considerations external to the pregnancy. These may be legitimate considerations for parental decision-making (whose autonomy interests might be invoked upon discovery of serious anomaly) but challenge the coherence of regulation based on the concept of pregnancy.<sup>18</sup> So, if the law permits selective termination based on individual anomaly or impact on “*children of the family*”,<sup>19</sup> it necessarily engages a decision-making criterion other than the pregnancy or the pregnant woman.<sup>20</sup> Of course, the birth of a disabled, premature or unwanted child may have an adverse impact on the woman, but by allowing the ‘entity’ or external factors to play any role in the decision-making or regulatory process, we have ceded exclusivity from the concept of pregnancy. Conflicting or ambiguous public narratives are important here.<sup>21</sup> Although coherence could be achieved by making the wishes of the pregnant woman the sole legal criterion for lawful termination, it is unclear whether there is broad societal support for unrestricted third trimester terminations.<sup>22</sup> Open ended entitlement may also prove problematic for healthcare professionals unwilling or unable to respond to unrestricted patient demand. Whilst we accept that a balance needs to be struck, we would be reluctant to endorse a legal framework supporting unqualified or unrestricted patient autonomy. One possible solution is the use of a time limit that is not qualified by considerations other than the pregnancy/ pregnant woman.

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<sup>17</sup> As AA 1967, S1(1)(a) is no longer available as a ground of termination.

<sup>18</sup> For discussion on the possible engagement of parental interests in such cases, see Rosamund Scott, ‘Interpreting the Disability Ground of the Abortion Act’ (2005) 64(2) *Cambridge Law Journal* 388.

<sup>19</sup> AA 1967, s 1(1) (a).

<sup>20</sup> For example, when the decision to terminate is made to avoid or reduce the risk of fetal prematurity.

<sup>21</sup> Jeffrey Wale, ‘Don’t forget the legal framework: the public provision of non-invasive prenatal testing in England and Wales’ (2015) *Medical Law International* 203.

<sup>22</sup> *UK Parliamentary Inquiry into Abortion on the Grounds of Disability* (HMSO 2013).

This background creates a potential dilemma for supporters of a more liberal termination framework and for parents facing difficult decisions in the late stages of pregnancy. The current arrangements involve a compromise<sup>23</sup> but attempts to improve the coherence of the law (removing ground E) run the risk of restricting rather than extending maternal choice. This dilemma may intensify as clinical and technological advances direct increasing attention to entity status, further disrupting the interconnection between mother and unborn entity.<sup>24</sup> Having different regulatory regimes for ex/in-vivo environments is not necessarily incoherent,<sup>25</sup> but differentials may shine a spotlight on discrepancies within each framework. Some degree of coherence seems to be important for the overarching public narrative in cases of legal compromise.<sup>26</sup> Further, given the apparent societal polarity around the nature of fetal interests, we believe that the regulatory emphasis should be placed on the relational aspects of pregnancy whenever possible. In taking this position, we recognise that such positions will ultimately have to address advances disrupting the current relational aspects of pregnancy (eg ectogenesis).

### 5.3 Regulatory options - termination of pregnancy

In this section, we introduce some possible regulatory responses to the termination of pregnancy and attempt to pin down where we stand more explicitly. At the outset, we highlight two preliminary considerations. First, we should recognise the difference between an explicit right to terminate a pregnancy and a permissive liberty to do so.<sup>27</sup> The latter will not guarantee access to termination services - we know from experience that public funding has been so critical to securing access for women living in Northern Ireland. Although explicit maternal rights (or liberties) to terminate are frequently qualified, States do need to be clear about the precise circumstances when regulatory interference is warranted.<sup>28</sup> The US experience highlights the danger of uncertainty around overly qualified exceptions and the importance of the wider political framework

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<sup>23</sup> Roger Brownsword and Jeffrey Wale, 'Compromise medicalisation', in C. Stanton and others (eds), *Pioneering Health Care Law Essays: In honour of the work of Professor Margaret Brazier* (Routledge 2015); Jeffrey Wale, 'Commentary: Greater Glasgow Health Board v Doogan', UK Health Care Law, (2015a) <<https://ukhealthcarelaw.wordpress.com/2015/01/20/commentary-greater-glasgow-health-board-v-dooan-another-2014-uksc-68/>> accessed 20 January 2015.

<sup>24</sup> Samantha Halliday, *Autonomy and Pregnancy* (Routledge 2016); Daar (n1); Lawrence and Brazier (n7).

<sup>25</sup> For discussion, see Scott (n6); Roger Brownsword and Jeff Wale, 'Testing Times Ahead: Non-invasive Prenatal Testing and the Kind of Community We Want to Be', (2018) 81(4) *MLR* 646.

<sup>26</sup> See Wale (n21). For the balance to be struck between regulatory coherence and effectiveness, see Roger Brownsword, *Infosoc 2018: Informational Rights, Informational Wrongs, and Regulatory Responsibilities*, (Bournemouth University Working Papers in Law, No 1/201 2018), <<https://microsites.bournemouth.ac.uk/law-review/files/2018/03/Infosoc-2018-wps.pdf>> accessed 28 March 2019.

<sup>27</sup> Kate Greasely, *Arguments about Abortion: Personhood, Morality and Law* (Oxford University Press 2017), 205.

<sup>28</sup> Elizabeth Wicks, *The State and the Body: Legal Regulation of Bodily Autonomy* (Hart 2016), 48.

in securing abortion access.<sup>29</sup> Greasley also points out “*the optimal regulatory framework for securing the substantive abortion right will likely be jurisdiction-specific*”<sup>30</sup> although cross border threats should be anticipated in specific areas including medical methods of termination.

Secondly, there is the specific issue of how we accommodate fetal reduction and selective termination in any regulatory framework. Should we construct a bespoke model, or might it be better to accommodate within or otherwise adapt more general legal rules? The answer will be influenced by the breadth and specificity of the authorising grounds, and the extent to which the unborn entity is given specific recognition in the regulatory model. Our law currently adopts a hybrid (and ambiguous) entity approach combining general legal rules with specific modifications aimed at terminations in multiple pregnancy. We know that grounds C and E are the most important legal criteria in clinical practice for fetal reduction and selective termination. Accordingly, we are probably going to need to address how these grounds operate in practice and whether they need to be replaced, modified or supplemented.

### **Criminalise non-emergency terminations**

A criminal prohibition model was operated by the Republic of Ireland before 2019 although previous restrictions had been relaxed by the Protection of Life During Pregnancy Act 2013 allowing terminations for a real and substantial risk to the life of the pregnant woman. This criminal model arguably forced terminations underground, encouraged procedural tourism and presented serious issues for female equality and bodily autonomy. The Republic’s legal position has now liberalised considerably following the outcome of a constitutional referendum and the implementation of amending legislation.<sup>31</sup>

### **Amended existing criminal offences<sup>32</sup>**

Brazier and Ost say we should focus on the intrinsic value of all human life and protect the unborn entity absent conflicting interests.<sup>33</sup> They moot replacing the current legal framework with two new criminal offences - unlawful feticide before 24 weeks and child destruction from 24 weeks. Recent legislative efforts have also used the 24-week cut off as a foundation for amendment. For example, Diana Johnson’s Abortion Bill<sup>34</sup> attempts to repeal sections 59/60 OAPA 1861, modify section 58 so that it is restricted

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<sup>29</sup> Greasley (n27), 205-208.

<sup>30</sup> Greasley (n27), 208.

<sup>31</sup> Health (Regulation of Termination of Pregnancy) Act 2018 (Act No. 31 of 2018) (EIRE).

<sup>32</sup> Offences Against the Person Act 1861; Infant Life (Preservation) Act 1929.

<sup>33</sup> Brazier & Ost (n5).

<sup>34</sup> Clause 1, Abortion Bill 2018-19 (HC Bill 276).

to terminations after 24 weeks; and combines these changes with a new offence of non-consensual termination.<sup>35</sup> There is much to commend here although the model effectively decriminalises consensual termination up to 24 weeks and ducks the ground E coherency issue.

### **Amend the 'medical' model**

Whilst significant criticism has been directed at the medical model used in the AA 1967,<sup>36</sup> the medical profession has arguably played an important role in mediating between polarised extremes.<sup>37</sup> Although many continue to argue for formal statutory recognition of maternal rights,<sup>38</sup> there is potential danger in making doctors mere technicians acting on patient instructions without limits.<sup>39</sup> There might be scope to modify the need for dual certification without removing external scrutiny, although these modifications would not address concern that the medical gatekeepers are susceptible to practice change, internal opinion and represent a poor guarantee of access over the longer term.<sup>40</sup> These may be important considerations if abortion is decriminalised although periodic positive legislative review might mitigate some of these concerns.<sup>41</sup>

### **Modify oversight**

The publication of annual national statistics provides a measure of public scrutiny and oversight that is not apparent for other medical procedures. Although there is additional scrutiny of medical practice via the notification process,<sup>42</sup> there is some evidence of continuing professional abuse in terms of under and misreporting.<sup>43</sup> One response is a more robust and independent mechanism for investigating and enforcing regulatory failures – indeed, recent CQC and departmental responses have suggested that existing oversight mechanisms will be policed more robustly going forwards. Alternative options could target regulatory measures at institutional service providers, in combination or as an alternative to those directed at healthcare professionals. Additional scrutinisation measures might also be applied in the latter stages of pregnancy. Of course, reporting failures do not necessarily signify wholesale regulatory non-compliance, and educational/ system solutions directed at healthcare

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<sup>35</sup> Ibid., clause 2.

<sup>36</sup> Michael Thomson, 'Abortion Law and Professional Boundaries', (2013) 22(2) *Social and Legal Studies* 191; Sheena Meredith, *Policing pregnancy: The law and ethics of obstetric conflict* (Ashgate 2005); Sally Sheldon, *Beyond Control: Medical Power & Abortion Law* (Pluto 1997).

<sup>37</sup> Brazier & Ost (n5).

<sup>38</sup> Shelley Day Sclater and others, *Regulating Autonomy: Sex Reproduction & Family* (Hart 2009), chp 13.

<sup>39</sup> Brazier & Ost (n5).

<sup>40</sup> Greasley (n27), 204.

<sup>41</sup> Brownsword & Wale (n23).

<sup>42</sup> AA 1976, s2. See also Serious Crime Act 2015, s84.

<sup>43</sup> Department of Health, *Guidance in relation to requirements of the Abortion Act 1967*, (DOH 2014a); Jeffrey Wale, 'Mismatch in notifications reveal a worrying problem in our abortion statistics', *The Conversation* (2014), <<https://theconversation.com/mismatch-in-notifications-reveal-a-worrying-problem-in-our-abortion-statistics-28565>, >accessed 16 January 2015; Brownsword and Wale (n23).

providers/ professionals might be more effective at increasing notification compliance than punitive sanctions. 'Name and shame' mechanisms are also powerful media and commercial tools that can be used effectively against private service providers.

### **Time limits**

Another option is to impose a single time limit for all terminations save for emergency situations.<sup>44</sup> At present, there is no upper time limit on terminations based on fetal abnormality to cater for late diagnosis (following structural anomaly screening at 18-20 weeks) and delays arising from medical referrals.<sup>45</sup> Imposing a single inclusive time limit would leave a small number of difficult cases to resolve but could improve legislative coherence and avoid decision-making centred on criteria related to the unborn entity. Time limits may also prove helpful for clinicians in reconciling their personal and professional values - we should not discount adverse professional reaction to an unrestricted termination model. However, we should recognise that time limits force some women to resort to self help or unregulated options to end their pregnancy.<sup>46</sup> There would be a small but important impact on late selective terminations in multiple pregnancy. On reflection, we can see the merit of a general time limit, with a few exceptions based on maternal health or pregnancy impact striking the kind of balance articulated in the NIHRC case.<sup>47</sup>

### **Viability criterion**

There is scope to clarify or replace the viability criterion used in the ILPA 1929.<sup>48</sup> Alternatively, we could shift emphasis to sentience as a criterion of legal significance,<sup>49</sup> although this change is unlikely to make much of a difference in practice. However, ongoing clarification would support a legal model authorising unrestricted patient choice before viability/ sentience with qualified restriction thereafter to / during birth.<sup>50</sup> This would have the advantage of recognising the bodily autonomy of pregnant women during the early stages of pregnancy, acknowledging the changing status of the unborn entity and aligning with many gradualist accounts of moral status. Such an approach would facilitate the majority of fetal reductions, leaving a small batch of difficult cases to address.

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<sup>44</sup> Sjeff Gevers, 'Abortion legislation and the future of the 'counseling model'', (2006) 13(1) *European Journal of Health Law* 27.

<sup>45</sup> Eg, *UK Parliamentary Inquiry* (n22) and Lord Shinkwin's Abortion (Disability Equality) HL Bill 16 (2016-17).

<sup>46</sup> See for example, *R v Catt* [2013] EWCA Crim 1187.

<sup>47</sup> *In the matter of an application by the Northern Ireland Human Rights Commission for Judicial Review (Northern Ireland)* [2018] UKSC 27

<sup>48</sup> Nuffield Council of Bioethics, *Critical care decisions in fetal and neonatal medicine: ethical issues* (Nuffield Council on Bioethics 2006), 153.

<sup>49</sup> Kristin L. Savell, 'Life and death before birth: 4D ultrasound and the shifting frontiers of the abortion debate', (2007) 15(1) *Journal of Law & Medicine* 103.

<sup>50</sup> Wicks (n28), Chp 8. See also Brazier and Ost (n5).

## **Compulsory counselling<sup>51</sup>**

Some jurisdictions have introduced mandatory counselling or instruction sessions prior to termination. This approach is often pursued under the guise of enhancing informed consent and has proven popular in some countries (eg United States). The UK has consistently rejected this approach<sup>52</sup> because, even if well intentioned, mandatory counselling can act as an unnecessary hurdle to patient choice and access.<sup>53</sup> The key thing from our perspective is that patients have access to balanced and non-directive information about their options. This inevitably requires adequate time/space for proper dialogue and deliberation. It also requires an information exchange process that is sensitive to situational variations including patient knowledge and understanding.

## **Amended regulation of medical methods of termination**

Successful lobbying has enabled the lawful part administration of abortifacient medication at patient homes in England, Wales and Scotland. There may be some scope to extend this further, but the absence of on-site medical supervision might heighten the risk of harm to the women involved. This concern might be managed partly through technological solutions and added risk-based control measures aimed at high risk pregnancies and women. However, unsupervised home terminations might generate other issues for vulnerable women that would otherwise benefit from hospital support. The shift from surgical to medical methods of termination may also alter the dynamics of the relationship between pregnant women and healthcare professionals and this may not be an unqualified good.<sup>54</sup> Either way, this is unlikely to be a realistic option for fetal reduction or selective termination in the short term.

## **Decriminalise abortion**

There is a growing clamour for abortion to be classified as an ordinary health matter and decriminalised.<sup>55</sup> There are two direct arguments in favour of reform: (1) the unwelcome prosecution of women and healthcare professionals, and (2) the adverse public narrative communicated to pregnant women and prospective mothers by criminalisation. Picking up on the latter point, there is potential stigmatisation from the imposition of the criminal law, although the actual effect on patient access/ experience is not entirely clear. If decriminalisation occurs, it would leave these procedures to be

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<sup>51</sup> Gevers (n44).

<sup>52</sup> Eg, Nadine Dorries MP's failed amendments to the Health & Social Care Bill in 2011.

<sup>53</sup> Scott Woodcock, 'Abortion counselling and the informed consent dilemma', (2011) 25 *Bioethics* 495. See also NICE, *Termination of Pregnancy – NICE Guideline – Draft for Consultation* (NICE April 2019), 25.

<sup>54</sup> Carrie Purcell and others, 'The changing body work of abortion: A qualitative study of the experiences of health care professionals', (2016) *Sociology of Health and Illness* ISSN 0141-9889:1, 10-11.

<sup>55</sup> Peterson (n9); Sheldon (n36); Abortion (Decriminalisation): Ten Minute Rule Bill 2017 (HC Bill) (introduced by Diana Johnson MP).



regulated by general legal principles and professional regulatory rules; and would probably dispense with the need for dual certification. Decisions would need to be made about the broader role of healthcare professionals - if terminations are reduced to non-technical activities, the central role of medical decision-making would be relegated from the termination process.<sup>56</sup> However, fetal reduction/ selective termination procedures are very technical - making doctors mere technicians may have unexpected/ unwanted consequences on the patient relationship.<sup>57</sup> We would also need to decide whether decriminalisation should apply generally, or only to pregnant women and/or healthcare professionals acting in accordance with good medical practice and good faith. We would want to ensure that healthcare professionals acting outside of good medical practice were subject to any general criminal sanctions.

Some have recommended a shift in emphasis to reproductive responsibility, prompting a wider and more central role for educational and organisational policies instead of restrictive rules.<sup>58</sup> It is clear that good information systems can influence access and impact upon critical time limits. We also know from the Canadian experience that there may be unexpected consequences from deregulation, and there is no guarantee that decriminalisation will enhance patient access or maternal rights. Quick claims that using the criminal law risks increasing secrecy and jeopardising patient safety,<sup>59</sup> arguing that it might be more effective to target healthcare institutions rather than individual professionals.<sup>60</sup>

Accordingly, one possible regulatory solution could involve the continued imposition of criminal sanctions on institutional providers for breaches of care/ notification requirements; the decriminalisation of terminations carried out by registered healthcare professionals in accordance with good medical practice; and the maintenance of a general criminal prohibition in all other circumstances. The Human Medicines Regulations 2012 would continue to make it illegal to supply abortifacients without a medical prescription. Any reform would have to address how and whether to treat pregnant women as criminal principals.

However, there must be a risk that without a clear legal framework, pressure would be applied on healthcare professionals to offer termination procedures on demand. On balance, we would be reluctant to endorse blanket decriminalisation, although we can

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<sup>56</sup> Jose Miola, 'Making Decisions About Decision-Making: Conscience, Regulation, and the Law', (2015) 23(2) *Med L. Rev* 263.

<sup>57</sup> *Ibid.*; Jonathan Montgomery, 'Conscientious Objection: Personal & Professional Ethics in the Public Square', (2015) 23(2) *Med L. Rev* 200.

<sup>58</sup> Martin Richards, 'Which children can we choose: Boundaries of reproductive autonomy', chp 11 in S D. Sclater and others, *Regulating Autonomy: sex reproduction & family* (Hart 2009); Brazier & Ost (n5).

<sup>59</sup> Oliver Quick, *Regulating Patient Safety. The End of Professional Dominance?* (Cambridge University Press 2017), 108.

<sup>60</sup> *Ibid.*, chp 6.

see the merit of a more lightly regulated criminal framework covering consensual terminations before viability. This might reduce the gap between the legal and professional norms, and address many of the concerns about criminalisation in the vast majority of singleton and multiple terminations.

### **Separate legal regulation for multiple pregnancy**

The case has been made for separate legal regulation of terminations in multiple pregnancy.<sup>61</sup> Whilst, Great Britain has made some changes to reflect the specific circumstances of multiple pregnancy,<sup>62</sup> there is no provision for general embryo/ fetal interests to be considered. Nevertheless, there is evidence that terminations are being undertaken with the primary aim of pregnancy preservation or improving fetal outcomes (see chapter 9) and this divergence gives us cause to revisit the legal framework and medical practice. The main pressure for separating the legal frameworks is the increasing divergence between medical and surgical methods, although the issue is directly linked to the breadth and flexibility of the general termination framework.

### **Update/ consolidate the legal framework**

Much has changed since the termination framework was formulated.<sup>63</sup> medical terminations are ascendant in singleton pregnancies,<sup>64</sup> the balance between private/ public sector delivery has shifted and the institutional environments/ professional frameworks have changed significantly. In these circumstances, there appears to be a prima facie case for a revised unitary legal framework; and an opportunity to revisit criminal/ professional regulation and to reassess the balance between individual and organisational responsibility. Fetal reduction and selective termination warrant additional consideration given their divergence from the medical model used in most singleton procedures.

## **5.4 Legal regulation of healthcare professionals and providers**

This section sketches out the legal regulatory regime for healthcare professionals (HCP) and healthcare providers (HCPProv). We should start with a word of caution - this is a fluid and rapidly changing area, and despite some important developments

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<sup>61</sup> Judith F. Daar, 'Selective reduction of multiple pregnancy: lifeboat ethics in the womb', (1992) 25(4) *Davis L R* 773.

<sup>62</sup> Human Fertilisation & Embryology Act 1990, s37.

<sup>63</sup> OAPA 1861, ILPA 1929 and AA 1967

<sup>64</sup> 66% of all terminations were medically induced in 2017 (Department of Health & Social Care (DHSC), *Abortion Statistics, England & Wales, 2017* (DHSC Revised December 2018), para 2.35).

following the Francis Inquiry,<sup>65</sup> remains a dense, complicated and challenging statutory framework.<sup>66</sup> As fetal reduction and selective terminations are mainly elected surgical procedures undertaken within the NHS system, we will concentrate on the regulation of NHS providers in England and Wales. We will also differentiate between ‘**system**’ regulators (that regulate the NHS system/ bodies/ HCProv)<sup>67</sup> and ‘**professional**’ regulators (that regulate HCP).<sup>68</sup> In turn, professional regulators should be differentiated from representative professional bodies.<sup>69</sup>

### **System regulators<sup>70</sup>**

The current NHS system has its legal origins in the National Health Service Act 2006. ‘System regulation’ in the NHS has been in a state of flux, most notably following publication of the Francis Report on the Mid Staffordshire NHS Foundation Trust in 2013.<sup>71</sup> Although some of the legislative changes were already in place - for example, creation of the **Care Quality Commission (CQC)** and the internal NHS market<sup>72</sup> - further legal modifications were made after publication of the report. The most notable change has been the imposition of a statutory duty of candour on HCProv by the Care Act 2014.<sup>73</sup> In essence this mandates the supply of relevant information by the provider to the patient/ their family whenever an *“incident of a specified description affecting a person’s safety occurs in the course of the person being provided with a service”*.<sup>74</sup> The Act also makes it a criminal offence for providers to supply, publish or make available certain information that *“is false or misleading in a material respect”*, subject to a due diligence defence.<sup>75</sup>

The two main system regulators are the CQC (the Healthcare Inspectorate in Wales) and **NHS Improvement**. Sitting alongside these two system regulators are Public Health England,<sup>76</sup> NHS England and their equivalent organisations in Wales. The CQC’s role is to ensure the NHS meets national standards of quality and safety, and to promote health, safety and welfare of those using the system.<sup>77</sup> It attempts to deliver this objective through a registration and inspection process. The private healthcare sector is also subject to the CQC registration and inspection requirements in England.<sup>78</sup>

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<sup>65</sup> Robert Francis QC, *The Francis Report - Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (HC 947,2013)

<sup>66</sup> Professional Standards Authority (PSA), *Rethinking regulation* (PSA August 2015).

<sup>67</sup> Eg Care Quality Commission (CQC).

<sup>68</sup> Eg General Medical Council (GMC), Nursing and Midwifery Council (NMC).

<sup>69</sup> Eg British Medical Association (BMA), Royal College of Obstetricians & Gynaecologists (RCOG).

<sup>70</sup> There are also arms length regulators including the Human Fertilisation and Embryology Authority.  
<sup>71</sup> (n63).

<sup>72</sup> Health and Social Care Act 2012

<sup>73</sup> Part 2. Part 3 establishes Health Education England and the Health Research Authority.

<sup>74</sup> Care Act 2014, s 81.

<sup>75</sup> Care Act 2014, s 92.

<sup>76</sup> Created by the Health & Social Care Act 2012.

<sup>77</sup> Health and Social Care Act 2008(as amended), s 3.

<sup>78</sup> Health and Social Care Act 2008 (Regulated Activities) Regulations 2014.

The CQC use a risk-based approach to inspections and take information obtained between inspections into account. This mechanism can have ex ante and ex post effects – it may identify risks leading to improvements but may also identify harm/ fault after the event.

Monitor was originally created to protect and promote the interests of service users and to ensure that NHS services were effective and value for money.<sup>79</sup> Monitor was absorbed (with Patient Safety and the NHS Trust Development Agency) into NHS Improvement in 2016. This combined organisation is responsible for:

*“overseeing foundation trusts and NHS trusts, as well as independent providers that provide NHS-funded care. We offer the support these providers need to give patients consistently safe, high quality, compassionate care within local health systems that are financially sustainable. By holding providers to account and, where necessary, intervening, we help the NHS to meet its short-term challenges and secure its future.”<sup>80</sup>*

NHS improvement places emphasis on supporting HCProv (albeit with intervention powers if necessary) but also has a performance and financial management function in relation to foundation trusts and NHS trusts. Within this organisation there is the **Healthcare Safety Investigation Branch** that has the power to carry out some independent inspections and to support trusts in carrying out their own internal investigations. It remains to be seen to whether there will be any substantive overlap with the functions of the CQC.

The **National Institute for Health and Care Excellence (NICE)** provides guidance and quality standards for HCP and other health and social care professionals.<sup>81</sup> Section 233 of the Health and Social Care Act 2012 sets out its general duties:

*“(1) In exercising its functions NICE must have regard to—  
(a) the broad balance between the benefits and costs of the provision of health services or of social care in England,  
(b) the degree of need of persons for health services or social care in England, and  
(c) the desirability of promoting innovation in the provision of health services or of social care in England.”*

Technically NICE does not operate in Wales but there is a sharing arrangement with the Welsh Assembly that ensures that Wales benefits from any NICE guidelines and quality standards.<sup>82</sup>

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<sup>79</sup> Created by part 3 of the Health and Social Care Act 2012, s 62.

<sup>80</sup> NHS Improvement <<https://improvement.nhs.uk/about-us/who-we-are/>> accessed 19 June 2018.

<sup>81</sup> Health and Social Care Act 2012, part 8.

<sup>82</sup> NHS Wales <<http://www.wales.nhs.uk/sites3/page.cfm?orgid=465&pid=5396>> accessed 19 June 2018.

Finally, there is the **Parliamentary and Health Service Ombudsman** who makes final decisions on complaints that have not been resolved by the NHS in England, UK government departments and other public organisations.<sup>83</sup> The Ombudsman offers a free complaint handling service is free, operates independently and reports to a Parliamentary sub-committee. The Public Services Ombudsman for Wales offers a broadly equivalent service.<sup>84</sup>

### **Professional regulators**

There are currently 9 'professional' regulators<sup>85</sup> who are ultimately responsible for 32 healthcare professions within the UK. They focus on the regulation of individuals rather than systems or organisations, and according to the Law Commission, each regulatory body has the same overarching functions:

- (1) Setting the standards of behaviour, competence and education that professionals must meet;
- (2) Dealing with concerns from patients, the public and others about professionals who are unfit to practise because of poor health, misconduct or poor performance; and
- (3) Keeping registers of professionals who are fit to practise and setting the requirements for periodic re-registration (and in some cases revalidation) for each profession.<sup>86</sup>

Historically, there has been limited convergence between these bodies and repeat concern about inconsistency and fragmentation in the regulatory framework.<sup>87</sup> The Professional Regulators are now overseen and scrutinised by the **Professional Standards Authority for Health and Social Care (PSA)**<sup>88</sup> whose overarching objective is the protection of the public. The PSA is independent of the Executive, accountable to Parliament and has an oversight role for regulator performance (via annual performance reviews) and fitness to practice decisions and decisions not to investigate. In certain cases, the PSA may challenge fitness to practice decisions. It also shares good practice, generates important policy reports on the regulation of

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<sup>83</sup> Parliamentary and Health Service Ombudsman < <https://www.ombudsman.org.uk/> > accessed 20 June 2018.

<sup>84</sup> Public Service Ombudsman for Wales < <https://www.ombudsman.wales/making-a-complaint/> > accessed 20 June 2018.

<sup>85</sup> General Chiropractic Council; General Dental Council; General Medical Council; General Optical Council; General Osteopathic Council; General Pharmaceutical Council; Health and Care Professions Council; Nursing and Midwifery Council; Pharmaceutical Society of Northern Ireland.

<sup>86</sup> Law Commission, *Regulation of Health Care Professionals, Regulation of Social Care Professionals in England* (Law Comm No 345, 2014), 3 < [http://www.lawcom.gov.uk/wp-content/uploads/2015/03/lc345\\_regulation\\_of\\_healthcare\\_professionals.pdf](http://www.lawcom.gov.uk/wp-content/uploads/2015/03/lc345_regulation_of_healthcare_professionals.pdf) > accessed 26 January 2016.

<sup>87</sup> For discussion of the issues generated by duplicated professional regulation, see *R (On the application of Vesna Mandic-Bozic) v British Association for Counselling and Psychotherapy* [2016] EWHC 3134 (Admin).

<sup>88</sup> Created by the NHS Reform and Health Care Professions Act 2002 as the Council for the Regulation of Healthcare Professionals, then changed to the Council for Healthcare Regulatory Excellence, and subsequently rebadged as the PSA by the Health and Social Care Act 2012, s222.

healthcare and may respond to comments made against individual regulators. Quick argues that the PSA is:

*“an important alteration to the traditional structure for regulating healthcare professionals. The creation of an organisation that supervises the work of individual regulators reflects a growing distrust of those regulators and a greater emphasis on accountability, external scrutiny, public protection and consistency of decision making”.*<sup>89</sup>

The emphasis on protection and consistency are probably the most important functions of this organisation. In *Rethinking Regulation*, the PSA made this stark statement about the existing regulatory framework:

*“Health and care regulation is incoherent and expensive and there is little evidence for its effectiveness; if it was going to improve care it would have done so by now. It’s time to rethink regulation”.*<sup>90</sup>

Even before the Francis Public Inquiry report, the Government had consulted on the regulatory framework,<sup>91</sup> resulting in the publication of the Law Commission report on the *Regulation of Health Care Professionals* in 2014.<sup>92</sup> The key recommendations were:

1. A single, overarching objective of public protection should be placed on each regulator.
2. To introduce a single legal framework for the regulation of all health care professionals and for all social care professionals in England
3. Deliver greater consistency between regulators in certain key areas (eg composition and fitness to practice)
4. Otherwise provide more autonomy to the regulators (when in the public interest to do so) to deliver their functions subject to oversight by the PSA.

The Government published its response in 2015 and accepted the main thrust of these recommendations and made a promise to legislate.<sup>93</sup> At the time of writing, these legislative changes are still outstanding, and the outcome of the latest Departmental consultation is awaited.<sup>94</sup>

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<sup>89</sup> Quick 2017 (59),77.

<sup>90</sup> PSA, *Rethinking Regulation* (PSA 2015) < <http://www.professionalstandards.org.uk/docs/default-source/psa-library/rethinking-regulation.pdf?sfvrsn=2> >accessed 22 January 2016. See now PSA, *Right Touch Reform: A new framework for assurance of professions* (PSA 2017) < [https://www.professionalstandards.org.uk/docs/default-source/publications/thought-paper/right-touch-reform-2017.pdf?sfvrsn=2e517320\\_5](https://www.professionalstandards.org.uk/docs/default-source/publications/thought-paper/right-touch-reform-2017.pdf?sfvrsn=2e517320_5) >accessed 19 June 2018.

<sup>91</sup> DOH, White Paper, “Enabling Excellence” *Autonomy & Accountability for Health Care Workers, Social Workers and Social Care Workers* (DOH 2011).

<sup>92</sup> Law Com (n86).

<sup>93</sup> Department of Health (Dr Daniel Poulter), *Government Response to Law Commission Report No 345: Written Statement* (HCW 5235 CM 8995, 2015).

<sup>94</sup> Department of Health, *Promoting Professionalism, Reforming Regulation* (DOH 2017) <<https://www.gov.uk/government/consultations/promoting-professionalism-reforming-regulation>>accessed 19 June 2018.

As this research is primarily concerned with registered medical practitioners (doctors), we will summarise how the **General Medical Council (GMC)** regulates these professionals, with specific focus on the associated legal framework. Although the GMC was created in 1858,<sup>95</sup> the current legislative framework can be found in the Medical Act 1983 (as amended). It has modernised over recent years, particularly in response to adverse public inquiries<sup>96</sup> and now has some lay membership.<sup>97</sup> Its role is not to represent doctors but to ensure that public and healthcare users are protected. It does this through a system of professional registration, standard-setting guidelines,<sup>98</sup> and the prosecution of fitness to practice proceedings where appropriate.

The **Medical Practitioners Tribunal Service (MPTS)** was launched in 2012 with the aim of separating the investigation and prosecution of fitness to practice proceedings from their subsequent adjudication.<sup>99</sup> In 2015, further legislative changes were introduced to increase the degree of separation between the MPTS and the GMC, including putting the MPTS on a statutory footing.<sup>100</sup> However, the MPTS is still funded by the GMC and reports to their council (twice annually) as well as to Parliament (annually). The tribunals now consist of medical and lay members who are appointed following open competition. They require a legally qualified chair or a separate legal assessor who may give legal advice to the tribunal in relation to the proceedings.<sup>101</sup>

Medical practitioners are required to renew their licence and fitness to practice on a regular basis.<sup>102</sup> Under the Medical Act 1983,<sup>103</sup> a registered medical practitioner's fitness to practise may be found to be impaired by reason of one (or a combination) of the following criteria: misconduct, deficient performance, criminal conviction/ caution, adverse physical or mental health, inadequate English or a determination by another regulatory body. Upon referral, the GMC registrar can make an initial determination not to proceed or refer the case for further investigation or adjudication before the MPTS.<sup>104</sup> Following investigation, the case examiners may refer the case for adjudication before the MPTS or instead issue a letter of advice (for minor departures

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<sup>95</sup> Via the Medical Act 1858.

<sup>96</sup> See for eg, <[http://www.gmc-uk.org/Yearly\\_update\\_Francis\\_and\\_others\\_Nov15\\_final.pdf\\_63486491.pdf](http://www.gmc-uk.org/Yearly_update_Francis_and_others_Nov15_final.pdf_63486491.pdf)> accessed 17 July 2018.

<sup>97</sup> There are 6 lay and 6 medical members (January 2019).

<sup>98</sup> Most notably *Good Medical Practice* (GMC 2013, updated April 2014 & April 2019) < [https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-1215\\_pdf-51527435.pdf](https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-1215_pdf-51527435.pdf) > accessed 3 April 2019.

<sup>99</sup> See MPTS < <http://www.mpts-uk.org/> > accessed 24/ May 2017.

<sup>100</sup> The General Medical Council (Constitution of the Medical Practitioners Tribunal Service) Rules Order of Council 2015.

<sup>101</sup> The General Medical Council (Legal Assessors and Legally Qualified Persons) Rules Order of Council 2015.

<sup>102</sup> The GMC (Licence to Practice and Revalidation) Regulations Order of Council 2012 (No 2685); The General Medical Council (Fitness to Practise) (Amendment) Rules Order of Council 2014

<sup>103</sup> s35C (2).

<sup>104</sup> General Medical Council (Fitness to Practice) Rules Order of Council 2004 No 2608 (as amended).

from the *Good Medical Practice* guidelines<sup>105</sup> or minor cause for concern); issue a warning (for more significant departures not necessitating registration changes) or accept an undertaking from the practitioner concerned. Adjudication should be considered where there are registration changes and/or public protection issues are at stake; and the standard of proof has been reduced from the criminal to the civil standard in these cases.<sup>106</sup> Fitness to practice mechanisms operate ex post (ie after complaint/ adverse event) although early intervention may have ex ante effects (by preventing reoccurrence or more serious harm).

Following adjudication, the MPTS may impose conditions on registration; suspend or erase registration; issue warnings or accept undertakings from the medical practitioner. Appeals from MPTS decisions can be brought by the medical practitioner, the GMC or the PSA.<sup>107</sup> The GMC's standing to bring appeals is likely to be short lived and is considered duplicative of the powers already vested in the PSA.<sup>108</sup> It is noteworthy, that many disciplinary actions against doctors address conduct in the private sphere said to bring the medical profession into disrepute.<sup>109</sup> Some concern has been raised that this unnecessarily undermines the interests of individual doctors for the sake of protecting the wider interests of the medical profession.<sup>110</sup>

## 5.5 Compelling medical treatment

In this final section, we consider whether the law can be used to compel a doctor to act contrary to their professional judgement. The decision in *Re J*<sup>111</sup> makes it clear that ordinarily a court cannot order a doctor to act against their own professional judgement:

*"The... issue... is whether the court in the exercise of its inherent power to protect the interests of minors would ever require a medical practitioner or health authority acting by a medical practitioner to adopt a course of treatment which in the bona fide clinical judgment of the practitioner concerned is contra-indicated as not being in the best interests of the patient. I have to say that I cannot at present conceive of any circumstances in which [it] would be other than an abuse*

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<sup>105</sup> GMC (n434).

<sup>106</sup> Health & Social Care Act 2008, s 112.

<sup>107</sup> Health and Social Care Act 2008. See also John Martyn Chamberlain, 'Malpractice, Criminality, and Medical Regulation: Reforming the Role of the GMC in Fitness to Practice Panels', (2017) 25 (1) *Med L. Rev* 1.

<sup>108</sup> See the recommendations of Professor Sir Norman Williams in his rapid policy review of gross negligence manslaughter in healthcare (<<https://www.gov.uk/government/groups/professor-sir-norman-williams-review>> accessed 22 June 2016).

<sup>109</sup> Sarah Devaney, 'The Transmutation of Deference in Medicine: An Ethico-Legal Perspective', (2018) 26(2) *Med L. Rev* 202, 220-225.

<sup>110</sup> Quick 2017 (n59), 73. See also Devaney (109).

<sup>111</sup> *Re J (A Minor) (Child in Care: Medical Treatment)* (1993) Fam 15. See also *An NHS Trust and Others v Y* [2018] UKSC 46. [92] (Lady Black).



*of power as directly or indirectly requiring the practitioner to act contrary to the fundamental duty which he owes to his patient. This... is to treat the patient in accordance with his own best clinical judgment, notwithstanding that other practitioners who are not called upon to treat the patient may have formed a quite different judgment or that the court acting on expert evidence may disagree with him.”<sup>112</sup>*

Similarly, the Court of Appeal made the position abundantly clear in *R (Burke) v GMC*:

*“Autonomy and the right of self-determination do not entitle the patient to insist on receiving a particular medical treatment regardless of the nature of the treatment”.*<sup>113/114</sup>

Clinical judgement about the effectiveness or efficacy of a treatment or procedure remain central. However, doctors are still expected to explain their reasons for refusing a request and identify other reasonable options that might be available, including the possibility of a second opinion.<sup>115</sup> Jonathan Montgomery, offers one explanation why society might want to preserve professional discretion in the clinical encounter:

*“The normative legitimacy of this extensive respect for professional discretion lies principally in the belief that protecting this embodied tradition provides a reliable protection for patient interests. These are understood as being more than merely the expression of individual patient wishes. Some desires that patients might have are not respected by the law, such as requests for ineffective treatments, see *Burke v GMC* as discussed above. Consequently, the choices available to patients can properly be limited to those offered by professionals. For this reason, the legal construction of the relationship between patients and health professionals is one in which the conscience of professionals is generally privileged over that of patients.”<sup>116</sup>*

However, one area where doctors can be compelled to act against their better professional judgement involves the disclosure of ‘material’ information about the risks, benefits and reasonable alternatives to a clinical procedure. The decision in *Montgomery*<sup>117</sup> requires doctors to disclose this information - subject to a narrow therapeutic exception and a patient’s right of refusal.<sup>118</sup> Even when the therapeutic exception could apply, doctors may be reluctant to call upon and bear the burden of proving that exception if there is a risk of subsequent legal challenge. The impact of this court decision has been addressed by the research participants and will be examined in further detail in the next chapter.

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<sup>112</sup> *Re J* (n111) [Lord Donaldson] [26]-[27]. See also *Charlotte Wyatt* [2005] EWHC 2293 (Fam) [Sedley J] and *MB* [2006] EWHC 507 (Fam).

<sup>113</sup> *R (Burke) v GMC* [2005] 3 FCR 169, [31].

<sup>114</sup> This statement is consistent with draft GMC guidance (GMC, *Decision making and consent: Supporting patient choices about health and care, draft guidance for consultation* (GMC 2018), 5).

<sup>115</sup> *Ibid.*, para 42.

<sup>116</sup> Jonathan Montgomery, ‘Conscientious Objection: Personal & Professional Ethics in the Public Square’, (2015) 23(2) *Med L. Rev* 200, 209

<sup>117</sup> *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

<sup>118</sup> *Ibid.*, [85].

## 5.6 Conclusions

This chapter has examined the specific (termination of pregnancy) and general legal frameworks in which Maternal and Fetal Medicine consultants must operate. The former is a compromise solution which seeks (although probably fails) to accommodate a polarity of diverse views. In particular, we have identified an issue with the framing of ground E<sup>119</sup> and consequential impact for the certainty, clarity and coherency of the law.<sup>120</sup> This has a distortionary effect on those procedures that rely heavily on this legal ground, including fetal reductions and selective terminations in multiple pregnancy.<sup>121</sup> Importantly, ground E directs attention to and offers divergent protection founded on the intrinsic status of the unborn entity. In doing so, it reduces the significance of relational and autonomy considerations, and puts significant pressure on a professional normative framework that already show signs of divergence. We have suggested that relational considerations and maternal autonomy should be placed front and centre in the legal framework, albeit with some limits. We also question whether we ought to place the burden for social judgements about the value of different forms of human life on the shoulders of doctors. The medical control of terminations is oft criticised, although little is said about the burden that this role places on obstetricians and others in reproductive care, especially in areas of uncertainty. This is a point that we will develop in later chapters.

We have questioned how fetal reduction and selective termination should be accommodated in the legal framework. The answer cannot be finalised until we agree how the general rules for pregnancy termination should be framed. At this point, we argue that there is still a legitimate role for the criminal law albeit in a more limited form than the current framework. Finally, we have introduced the legal framework for professional and system regulation. The immediate impression is of an overly complex and fragmented system, and this has important ramifications for the professional regulation of these procedures.

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<sup>119</sup> AA 1967. S1(1)(d).

<sup>120</sup> For discussion of the arguments for/ against ground E, see Sally Sheldon and Stephen Wilkinson, "Termination of Pregnancy for Reason of Foetal Disability: Are There Grounds for a Special Exception in Law?", (2001) 9(2) *Med. L. Rev* 85.

<sup>121</sup> DHSC (n64), para 2.44.

# Chapter 6 – Personal, Professional and Cultural Frameworks

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## 6.1 Introduction

As previously indicated, this chapter is interconnected and complements our earlier discussion in chapter 3. Both chapters are concerned with the guidance that healthcare professionals might derive from the ethical frameworks and general ethical principles. Here the focus of the chapter is broader, examining the general principles of medical ethics and the role of professional ethical regulation and national public standards in healthcare. It also considers the role of workplace/ cultural norms, personal values and the specific complexities of medical decision-making in the context of our procedures. The chapter closes with an examination of the evolving relationship between patient autonomy and medical deference and the implications for future healthcare practice. Our overarching aim is to give a clearer sense of how personal, professional and practice norms might impact upon and guide decision-making in fetal reduction and selective termination.

## 6.2 Moral norms and status

Having attempted to unpick the status of the human embryo/ fetus in chapter 3, we return to examine moral norms in a broader societal, workplace and professional context. Beauchamp and Childress have described the ‘*common morality*’ - a set of universal norms that are learned and shared by all members of each human community<sup>1</sup> – embodying not only rules and obligations, but also moral character traits and virtues.<sup>2</sup> Bernard Gert claims that basic or common norms of morality cannot change or be invented over time.<sup>3</sup> However, Beauchamp and Childress argue that even basic moral norms are refined, if not created, with the scope of application changing over time as “(we) *handle social change through allowing exceptions to one or more stable norms*” in the common morality.<sup>4</sup> Critically any:

*“theory of the common morality that denies our capacity to criticize and even condemn traditions or communities whose viewpoints are morally unacceptable would be an ineffectual and indefensible theory”.*<sup>5</sup>

Fixed positions are difficult to maintain when there are strongly held and polarised moral views within society;<sup>6</sup> and termination of pregnancy and assisted death are two obvious examples. Conflicting moral stances can be fuelled by widely divergent religious, philosophical, political and cultural beliefs, although differences can occur because of variable application of common beliefs.

Divergent moral positions raise several questions. Should society<sup>7</sup> reject one moral approach or belief because that position commands less popular support; or should conflicting moral norms within a community (or parts thereof) demand equal or appropriate respect? If the latter, how might that respect manifest in practice? Should society be obligated to forge a compromise in these circumstances, creating a new societal norm, or might that compromise simply be a product of an existent societal norm? For example, it might be argued that the legal compromise delivered by the AA 1967 facilitated or created a shift in the normative (domestic) response to abortion.

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<sup>1</sup> Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (7th edition, Oxford University Press 2013), 3-4

<sup>2</sup> *Ibid.*, 3. They define a ‘moral virtue’ as a dispositional trait of character that is morally valuable and reliably present (at 310). For a qualified defence in the healthcare context, see Raanan Gillon, ‘Defending the four principles approach as a good basis for good medical practice and therefore for good medical ethics’, (2015) 41 *Journal of Medical Ethics* 111.

<sup>3</sup> Bernard Gert, *Morality: Its nature and justification* (OUP 2005) 114-115. Cf Beauchamp & Childress (n1), 413.

<sup>4</sup> Beauchamp & Childress (n1), 413.

<sup>5</sup> *Ibid.*, 415.

<sup>6</sup> See Beauchamp & Childress (n1), 23 for a discussion on what might happen where universal norms conflict.

<sup>7</sup> We recognise that the term ‘society’ can be used to refer to defined regional community areas or more universal contexts.

Alternatively, the Act might simply be the product of existent societal change. These are not matters that can fully be answered in this work, but we shall pick up relevant issues as we go along.<sup>8</sup>

Whilst there are undoubtedly some universal moral norms, disagreement about aspects of our moral life makes the gravitation towards group or fragmented moral norms within diverse communities much more likely. It is those group norms that have specific resonance in this research. At this point, we should remind ourselves of the possible connections between moral norms and legal rules:

*“Legal decisions often express communal moral norms and stimulate ethical reflection that over time alters those norms”<sup>9</sup>*

Whatever the jurisprudential view, tracking morality can provide societal benefit, ease tensions, aid compliance and ultimately, divergent moral views across communities need to be addressed, and hopefully accommodated within the law to some degree. This work endorses the view that what constitutes proper medical treatment in a normative and descriptive sense has fluctuated over time representing a complex interplay between the internal morality of medicine and the social context in which it operates.<sup>10</sup> This interplay arguably extends to the internal morality of individual healthcare professionals and their operative regulatory environment.

In the following sections, we shall attempt to unpack some of these ideas, with a view to identifying: (1) the ‘internal morality’ of contemporary western medicine;<sup>11</sup> (2) the general ethical framework in which contemporary medicine and healthcare professionals operate; 3) the role of individual, professional and cultural norms, with specific reference to fetal reduction/ selective termination; and 4) the relationship between individual autonomy and deference in contemporary healthcare.

### 6.3 Professional norms, personal values and decision-making

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<sup>8</sup> For discussion of compromise, see Roger Brownsword and Jeffrey Wale, ‘Compromise Medicalisation’, in C. Stanton and others(eds), *Pioneering Health Care Law Essays: In honour of the work of Professor Margaret Brazier* (Routledge 2015).

<sup>9</sup> Beauchamp and Childress (n1), 9; Martin Freeman argues that secularisation has left us increasingly dependent on the law as a ‘working source of morality’ (*Law and Bioethics* (Oxford University Press 2008), Chp 9).

<sup>10</sup> Lucy Frith, ‘What do we mean by proper medical treatment?’, Chp 3 in Sara Fovargue and Alexander Mullock (eds), *The Legitimacy of Medical Treatment: What role for the medical exception?* (Routledge 2015).

<sup>11</sup> See for eg, Stephen McAndrew, ‘Internal morality of medicine and physician autonomy’, (2019) *J Med Ethics* 1. doi:10.1136/medethics-2018-10506.

### 6.3.1 The role of professional norms

Professional norms have an important role to play in medicine and the healthcare professions – they relate to responsibility inside/ outside of a profession and can facilitate the delineation of the acceptable and proper from the unacceptable and improper. These norms can provide a yardstick to measure performance and enable action to be taken against members that persistently flout standards. Importantly, these norms provide a framework for the profession and its members to assert power within society. By setting boundaries of restricted interest, professional norms can serve to exclude others from participation or entry to that profession<sup>12</sup> and membership can (on occasion) offer protection against the reach of the criminal law. Finally, professional norms can provide a foundation to address issues affecting specific occupational groups, further fragmenting the normative framework(s). For example, subspecialisms within medicine can be affected by distinct dilemmas, leading to calls for discipline or issue centric guidance.

Professional norms can be represented in various forms, ranging from vague and aspirational ideals to formal codified standards demanding adherence from the members of that profession. The content and scope of these norms may be influenced directly by the profession, by specific disciplines within that profession,<sup>13</sup> by occupational culture and the wider societal context. When looking at professional ethical sources, we should also be careful to separate out the description of normative ideals ('what ought to happen') from normative standards imposing specific profession obligations,<sup>14</sup> because they have a layering effect, meaning that norms are working at different levels to varied ends and effects. In short, we need to be clear whether these documents are describing minimum standards requiring compliance, aspirational goals or a combination of both.

Jose Miola<sup>15</sup> divides the ethical discourse on professional medical norms (or professional medical ethics) into three distinct categories: (1) **Formal**, for example, the standards promulgated by statutory bodies like the General Medical Council (GMC); (2) **Semi-Formal**, for example, the guidance issued by representative bodies like the British Medical Association (BMA) and the Royal College of Obstetricians & Gynaecologists (RCOG) where they have no explicit disciplinary powers or statutory

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<sup>12</sup> That is particularly prevalent in learned professions that require a degree of specialist knowledge and skill.

<sup>13</sup> Sheelagh McGuinness and Michael Thomson, 'Medicine and Abortion Law: Complicating the Reforming Profession', (2015) 23(2) *Med L. Rev* 177, 197-198.

<sup>14</sup> Jose Miola, *Medical Ethics and Medical Law: A symbiotic relationship* (Hart 2007), 7.

<sup>15</sup> *Ibid.*, 6.

mandate; and (3) **Unofficial** discourse, from academics, pressure groups, charities and religious bodies. Miola claims that unofficial discourse has proved especially problematic because it has encouraged fragmentation, and has tended to be discursive, rather than directive in nature.<sup>16</sup> Of course, this analysis conceptualises professional norms as simple products of the professions,<sup>17</sup> although the medical “*profession must seek trust and make themselves deserving of trust*” by the public.<sup>18</sup> However, a more cynical view is that medical claims for trust are really about the profession seeking control. From this perspective, the assertion of therapeutic legitimacy via a model of good faith represents a professional desire for exclusivity, rather than a model for delivering effective patient rights.<sup>19</sup>

Iain Brassington claims that the terms ‘professional (medical) ethics’ and ‘morality (as used by Miola<sup>20</sup> and Hoffmann LJ<sup>21</sup>)’ are distinct concepts.<sup>22</sup> Whether professional ethics is a descriptive or normative term is up for debate,<sup>23</sup> but it is evident that the law and morality have some role to play in shaping professional ethical frameworks. There is some debate around whether there is an internal morality to medicine or medical practice,<sup>24</sup> but our view is that there is likely to be interplay between the internal and external concepts of morality in our specific research context.

### **Professional ethics as a mask for self-interest<sup>25</sup>**

The exclusionary effect of professionalism and professional rules can impact on other actors, including the members of discrete disciplines within a profession. Any lack of clarity around the boundaries or scope of professional rules is capable of creating jurisdictional friction - the absence of professional consensus over abortion has meant that the exclusionary effect has not been an entirely unified process in this context.<sup>26</sup> According to Michael Thomson, the medical profession created abortion as an ethical issue and subsequently placed themselves at the centre of the social response;<sup>27</sup> arguing that abortion law has remained the object of medical professionalism rather

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<sup>16</sup> *Ibid.*, 15.

<sup>17</sup> Iain Brassington, ‘On the Relationship between Medical Ethics and the Law’, (2018) 26(2) *Med L. Rev* 225.

<sup>18</sup> Frith (n10); See also Royal College of Physicians (RCP), *Doctors in Society – Medical professionalism in a changing world – Report of a working party* (RCP 2005).

<sup>19</sup> As per the AA 1967. See also McGuinness and Thomson (n13), 181.

<sup>20</sup> Miola (n14); Charles Foster and Jose Miola, ‘Who’s in charge? The relationship between Medical law, Medical ethics, and Medical Morality?’, (2015) 23(4) *Med L. Rev* 505.

<sup>21</sup> *Bland v Airedale NHS Trust* [1993] AC 789

<sup>22</sup> Brassington (n17); Bland (n21), 858.

<sup>23</sup> Brassington (n17).

<sup>24</sup> Cf R. M. Veatch, ‘The impossibility of a morality internal to medicine’, (2001) 26 *J Med Philos* 621 and McAndrew (n11).

<sup>25</sup> See, Iain Brassington ‘What’s the point of Professional Ethical Codes?’, (2017) *BMJ Blogs*, <<http://blogs.bmj.com/medical-ethics/2017/06/13>> accessed 14 June 2017.

<sup>26</sup> Constance Nathanson and Marshall Becker, ‘Professional Norms, Personal Attitudes, and Medical Practice: The Case of Abortion’, (1981) 22 *J of Health & Soc Beh* 198; McGuinness and Thomson (n13) 191.

<sup>27</sup> Michael Thomson, ‘Abortion Law and Professional Boundaries’ (2013) 22(2) *Social and Legal Studies* 191.

than its subject, with normative responses based on the changing objectives of each medical discipline.<sup>28</sup> Indeed, he conceptualises abortion as a boundary issue:

*“a key site where professional jurisdiction is asserted. A dynamic model of the processes of professionalisation, and an identification of the role of abortion in medicine’s professionalisation project, is essential in order to understand the contemporary social and legal reality of abortion.”<sup>29</sup>*

This suggests that the practice and professional norms as they relate to abortion offer an atypical framework but focal point for the wider practice of contemporary medicine.

## Medical norms

The seminal publication *Principles of Biomedical Ethics*<sup>30</sup> provides a good starting point for identifying and examining the core norms of contemporary western medicine. The authors identify four moral principles that have specific relevance to the medical profession. First, there is ‘*respect for autonomy*’ which has its roots in the libertarian philosophy of J S Mill.<sup>31</sup> In medical practice, this principle often has more to do with preventing unwanted infringements to the person, than it does in securing specific right(s) to medical treatment. Indeed, respect for autonomy can cut both ways in clinical practice and can be used to justify concurrent patient rights and the assertion of medical supremacy.<sup>32</sup> Of course, autonomy has more than one meaning, including the right to self determination and self governance,<sup>33</sup> and respect on any level may be impossible to achieve in any real practical sense in medical care.<sup>34</sup>

Secondly, the principle of ‘*non-maleficence*’ is a demand that doctors and healthcare professionals “*above all do no harm*”;<sup>35</sup> not doing something that has or may have an unjustifiable adverse effect on a person (ie refraining from acts or taking steps that might cause harm).<sup>36</sup> This principle requires clarity over the concept of harm - for example, a Millian account may provide exceptions for threats or conduct causing unjustifiable and rights violating harm on another.

Thirdly, the principle of ‘*beneficence*’ requires positive steps by the moral agent and concerns the moral obligation to act for the benefit of others. Benefit can be considered from an individual or utilitarian perspective encompassing the prevention/ removal of harm and/or the promotion of good. Discourse around the sanctity or

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<sup>28</sup> Ibid., 193-194.

<sup>29</sup> Ibid., 191.

<sup>30</sup> Beauchamp & Childress (n1).

<sup>31</sup> J S Mills, *On Liberty* (Penguin 1982).

<sup>32</sup> Charles Foster, *Choosing life, choosing death: The tyranny of autonomy in medical ethics and law* (Hart 2009).

<sup>33</sup> Jonathan Herring, *Medical Law and Ethics* (7<sup>th</sup> ed, Oxford University Press, 2018), 205-208.

<sup>34</sup> N. C. Manson and O. O’Neil, *Rethinking Informed Consent in Bioethics* (Cambridge University Press 2007).

<sup>35</sup> Herring (n33), 27.

<sup>36</sup> Cf McAndrew (n11): “*the internal morality of medicine prohibits any physician being forced to cause a pathology if in their medical judgement that is not justified*”.



inviolability of human life often appeals to this moral principle. Finally, we have the nebulous moral principle of ‘*justice*’ which also incorporates notions of fairness and equality. Associated medical discourse includes the social utility of treatments; the fair allocation of healthcare priorities and the appropriate rationing of scarce public resources.

The moral principles of beneficence and non-maleficence have ancient roots in the practice of medicine; the Hippocratic work of *Epidemics* proclaimed:

“As to disease, make a habit of two things - to help, or at least to do no harm”.<sup>37</sup>

However, autonomy and justice have become increasingly important principles in modern healthcare - the former being driven by societal focus on individual patient rights,<sup>38/39</sup> and the latter by expansionary state funded healthcare<sup>40</sup>. Although, some claim that professional autonomy affords greater benefit than harm to society,<sup>41</sup> there is the potential for conflict between patient autonomy and the principle of beneficence (often disparagingly labelled ‘paternalism’).<sup>42</sup> In the field of obstetrics, there are many examples of perceived conflict involving patient capacity, understanding and choice.<sup>43</sup> The UK abortion framework highlights the possible tension between patient autonomy and beneficence<sup>44</sup> with an absence of explicit maternal rights and a gatekeeping role for doctors using a duty of good faith and a list of indicative grounds.<sup>45</sup> However, it is possible that the perceived conflict between paternalistic medical practices and patient autonomy presents something of a false dichotomy - these moral principles do not always have to be seen in opposition.<sup>46</sup>

### 6.3.2 Medical decision-making: influences and constraints

Decisions to undertake or receive specific medical treatment, tests or interventions, typically engage a range of stakeholders including the patient, their family, the treating healthcare professional(s), the healthcare provider and any funder. We might also add

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<sup>37</sup> *Epidemics*, 1:11, in W H S Jones (ed) *Hippocrates*, vol 1, (Harvard University Press, 1923).

<sup>38</sup> Foster (n32).

<sup>39</sup> See the subsequent discussion on *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

<sup>40</sup> Eg the introduction of the NHS in the UK after the 2nd World War.

<sup>41</sup> McAndrew (n11).

<sup>42</sup> See for eg, E D. Pellegrino and D C. Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (OUP 1988); David Avitzour and others, ‘Nudging in the clinic: the ethical implications of differences in doctors’ and patients’ point of view’, (2018) *J Med Ethics* DOI: 10.1136/medethics-2018-104978.

<sup>43</sup> See for example, *Montgomery v Lanarkshire Health Board* [2015] UKSC 11; *Re S (Adult: Refusal of Medical Treatment)* [1993] Fam 123; *MB (An Adult: Medical Treatment)* [1997] 2 FLR 426; *St George's Health Care NHS Trust v S* [1999] Fam 26

<sup>44</sup> Most notably the Abortion Act 1967.

<sup>45</sup> *Ibid.*, s 1.

<sup>46</sup> March Stauch and Kay Wheat, *Text Cases and Materials on Medical law & Ethics* (5th Ed, Routledge 2015), 34.

society, or sections thereof, as an additional layer of possible participation.<sup>47</sup> Respect for bodily autonomy should dictate that medical decisions by the patient are made on free and informed basis, but this may not always be straightforward. It presupposes that real choices are available, that options have been presented in an informed and digestible form, and that the patient is free to act upon those options without impediment or restriction. Lady Hale claims that:

*“it is not possible to consider a particular medical procedure in isolation from its alternatives. Most decisions about medical care are not simple yes/no answers. There are choices to be made, arguments for and against each of the options to be considered, and sufficient information must be given so that this can be done”*<sup>48</sup>

In our context, we know that there is evidence that patients are not always provided with a real choice on the method of termination when ending pregnancy.<sup>49</sup>

The complexity of medicine provides healthcare professionals with a platform for asserting ‘exclusivity’, but many decisions/ interventions will fall into a category where that superior and restricted position is hard to justify.<sup>50</sup> McAndrew observes that “*some of the things that an obstetrician may do during labour and childbirth do not involve treating disease*”<sup>51</sup> and could be undertaken by a non-doctor. Of course, there will be some obstetric activities and decisions that warrant technical knowledge and expertise; and precautionary monitoring will be required for some pathologies that could not otherwise be undertaken by non-qualified persons.<sup>52</sup> Professional discretion may still be valuable if it provides a reliable mechanism for protecting patient interests, although discretion is liable to attack on the grounds of opacity and potential abuse.<sup>53</sup>

Foster and Miola also examine the regulatory constraints imposed on medical decision-making and divide medical decisions into three basic categories - those that are essentially legal, ethical or moral.<sup>54</sup> *Legal decisions* are those involving situations where the healthcare professional has limited or no choice because the law mandates a specific course of action.<sup>55</sup> For example, this would include the legal obligation to notify terminations to the Chief Medical Officer. With *ethical decisions*, the law leaves the profession to dictate how specific decisions are made using group rather than

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<sup>47</sup> Mark E. Cowen and Michael W. Kattan, *Encyclopaedia of Medical Decision Making* (Sage 2009).

<sup>48</sup> *Montgomery* (n43), [109].

<sup>49</sup> Jane Fisher and others, ‘Termination for fetal anomaly: Are women in England given a choice of method?’ (2015) 35(2) *Journals of Obs and Gynae* 168. For a wider discussion in the antenatal context, see Francesca Garrard and others, ‘Decisions, Choice and Shared Decision-Making in Antenatal Clinics: An Observational Study’, (2015) 98(9) *Patient Education & Counseling* 1106.

<sup>50</sup> Cf Lady Hale in *Montgomery* (n43), [114].

<sup>51</sup> McAndrew (n11).

<sup>52</sup> *Ibid.*

<sup>53</sup> Jonathan Montgomery, ‘Conscientious Objection: Personal and Professional Ethics in the Public Square’, (2015) 23(2) *Med L. Rev* 200.

<sup>54</sup> Foster and Miola (n20).

<sup>55</sup> *Ibid.*, 507.

individual values or norms. These group values are identified as '*professional medical ethics*', and should be contrasted with the more abstract discourse prevalent in '*philosophical medical ethics*'.<sup>56</sup> Finally, Foster and Miola define *moral decisions* as those choices uninhibited by anything other than the conscience and values of the individual decision-maker; although the emphasis is on furthering the interests of the decision-maker.<sup>57</sup> We shall park (for a moment) the idea that medical decisions can be neatly divided into exclusive categories even in areas of consensus, although observe that the distinction is not without practical difficulty.

Brassington argues that professional ethics have tended to develop with "*an eye on the law*"<sup>58</sup> without necessarily excluding the impact of other extrinsic influences.<sup>59</sup> Of course, the law may not always be sufficiently determinate to play any helpful role in the development of professional ethics.<sup>60</sup> In terms of the counter relationship, Brassington claims that what matters is "*whether and in what way to take on board professional guidance remains the prerogative of the law*".<sup>61</sup> Indeed, Foster and Miola query whether the law has abdicated too much responsibility to the medical profession and tended to be overly deferential in relation to 'ethical' decision-making.<sup>62</sup> They claim that the more 'ethical' and non-technical a medical decision is, the more the law ought to take control as the medical profession has no special claim to expertise in either ethics or ethical decision-making.<sup>63</sup> This has ramifications for non-technical decision-making, especially, if you believe that most important medical decisions fall into this category.<sup>64</sup> Lord Mustill, for example, saw no reason why "*the opinions of doctors should be decisive*"<sup>65</sup> in decisions to withdraw of life support. We have already observed that aspects of the AA 1967 invite partly social judgements – meaning that fetal reduction/ selective termination have the scope to fall into this category.

Although the professional centric *Bolam* decision<sup>66</sup> persists in some aspects of medical practice, the Supreme Court has now determined that doctors should no longer be the final arbiters of information disclosure in the case of *Montgomery v Lanarkshire Health Board*:

***"The doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments. The test***

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<sup>56</sup> See also Brassington (n17).

<sup>57</sup> (n20), 508-511.

<sup>58</sup> Brassington (n17), 7.

<sup>59</sup> *Ibid.*, 8.

<sup>60</sup> See participant E (chapter 9).

<sup>61</sup> Brassington (n17).

<sup>62</sup> See, for eg, *NHS Trust v Y* [2018] UKSC 46, [77] (Lady Black).

<sup>63</sup> (n20), 511.

<sup>64</sup> Indeed, Ian Kennedy argues that the majority of doctors' decisions are non-technical and are moral/ ethical (*The Unmasking of Medicine*, (George Allen & Unwin 1981), 78).

<sup>65</sup> Bland (n21), 895.

<sup>66</sup> *Bolam V Friern HMC* [1957] 2 All ER 118 as modified by *Bolitho v City & Hackney HA* [1992] PIQR p334.

*of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.*<sup>67</sup>

Whilst, the decision leaves open a therapeutic exception - allowing doctors to claim that disclosure would be detrimental to patient health - the court made it clear that this escape route should be construed narrowly.<sup>68</sup> The duty also goes beyond disclosure of information – there is a more demanding obligation to use reasonable care to ensure that the patient is aware of material risks, and reasonable treatment variants or alternatives. So instead of prioritising medical practices designed, in line with the principle of beneficence, the new priority in advising patients appears to be respect for their individual autonomy.<sup>69</sup> Is this view of *Montgomery* justified, and how far does the decision really advance the primacy of patient autonomy?<sup>70</sup>

The first issue is whether *Montgomery* is a sufficiently determinate legal decision to deliver any decisive change in medical practice? Many commentators have interpreted *Montgomery* as converting patients into autonomous consumers where medical decisions are no longer “a matter exclusively of medical expertise”.<sup>71</sup> However, Herring et al. claim that *Montgomery* promotes a model of consent based on “autonomy-through-partnership”, encouraging clinician/patient dialogue and person centred decision-making “driven primarily (although not exclusively) by the values of the patient concerned”.<sup>72</sup> They claim that the need to balance the ‘reasonable person’ (limb 1) and ‘particular patient’ (limb 2) aspects of the materiality test,<sup>73</sup> impose some limits on patient values in the decision-making process,<sup>74</sup> although *Montgomery* does not resolve the residual tension between these limbs.<sup>75</sup>

We make four general observations at this juncture. First, Herring/ Dunn et al. are suggesting that instead of giving primacy to respect for patient autonomy, the decision is more appropriately understood as a patient centric, rather than profession centric approach to information disclosure.<sup>76</sup> The second limb of *Montgomery* only requires disclosure if the doctor is reasonably aware that the patient accords significance to the

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<sup>67</sup> *Montgomery* (n43), [87] (emphasis added).

<sup>68</sup> *Ibid.*, [91]. There is provision for a patient's right of refusal [85] and exceptions in cases of necessity [88].

<sup>69</sup> Roger Brownsword and Jeff Wale, ‘The right to know and the right not to know revisited’ (Two Parts), (2017) 9 *Asian Bioethics Review* 3.

<sup>70</sup> For discussion, see Michael Dunn and others, ‘Between the Reasonable and the Particular: Deflating Autonomy in the Legal Regulation of Informed Consent to Medical Treatment’, (2019) 27(2) *Health Care Anal.* 110.

<sup>71</sup> Jonathan Herring and others, ‘Elbow Room for Best Practice? Montgomery, Patients' Values, and Balanced Decision-Making in Person-Centred Clinical Care’, (2017) 25(4) *Med L. Rev.* 582, 585-586.

<sup>72</sup> *Ibid.*, 589-590.

<sup>73</sup> *Montgomery* (n43), [87].

<sup>74</sup> Herring et al. (n71), 582-583; 602-603.

<sup>75</sup> *Ibid.*, 602-603.

<sup>76</sup> Dunn et al. (n70). See also Albert Lee, ‘Bolam’ to ‘Montgomery’ is result of evolutionary change to medical practice towards ‘patient-centred care’, (2017) 93 *Postgrad Med J* 46 (equating patient centred care with the ‘prudent patient test’ for disclosure); NICE, *NICE Clinical Guideline CG62 Antenatal Care for Uncomplicated Pregnancies* (NICE 2019), para 1.1.

risk etc – an obligation that will only have teeth if the patient is active in “*disclosing relevant information about her values*” or otherwise signposts “*that she has concerns of a particular kind that are relevant to risk disclosure question*”.<sup>77</sup> It remains to be seen how far doctors will be expected to go to uncover any patient values/ priorities, although patient passivity may not absolve the doctor of responsibility under the first limb of the materiality test.

Secondly, limited attention has been given to the first limb of the materiality test, namely “*a reasonable person in the patient’s position would be likely to attach significance to the risk*”. How should the reasonable person test be approached in practice? There is some evidence that Lords Kerr and Reed preferred “*the reasonable as commonly held*”<sup>78</sup> view,<sup>79</sup> notwithstanding the general reluctance of the courts to endorse that kind of approach elsewhere in the law (eg the law of torts). Conversely, Lady Hale appears to support a more situationally tailored approach that has regard to the specific treatment setting, available treatment options and patient circumstances.<sup>80</sup> If the latter approach is preferred, this will generate greater scope for variation across medical disciplines and patient encounters. It also has the capacity to make the legal position increasingly opaque, uncertain and complex.

*Thirdly*, our research interviews indicate that *Montgomery* has not been universally interpreted in the subtle and nuanced vein advanced by Herring/ Dunn et al..<sup>81</sup> That is not to say that the decision is universally unpopular with the medical profession, but there is some evidence that it introduces fresh and uncertain variables into the patient encounter (see appendix 9).

Fourthly, there is a residual issue about the extent to which the new test of materiality “*bleeds into the question of which alternative or variant treatments ought to be made available*”,<sup>82</sup> further diluting the impact of *Bolam* and emphasising the importance of *Montgomery*.

What is clear is that the judges in *Montgomery* were unwilling to leave information disclosure to formal professional ethical standards (notwithstanding similar approaches) because:

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<sup>77</sup> Dunn et al. (n70). See also Lee (n76),49.

<sup>78</sup> Ibid.

<sup>79</sup> *Montgomery* (n43), [94].

<sup>80</sup> *Montgomery* (n43), [111-113]. See also Dunn et al. (n70).

<sup>81</sup> (n70/71). See also Chapter 9

<sup>82</sup> Dunn et al. (n70).

*“It is...is necessary to impose legal obligations, so that even those doctors who have less skill or inclination for communication, or who are more hurried, are obliged to pause and engage in the discussion which the law requires”<sup>83</sup>*

This makes the implicit assumption that doctors are more likely to pay attention to legal obligations than ethical ones. This has logical force if the legal rules are sufficiently clear and determinate, although the real message may be that doctors should expect legal consequences if they flout or pay insufficient heed to rules or standards. However, even if these types of decisions/ practices are capable of being made ‘legal’, it does not follow that patient decision-making will be enhanced by this change. Patients still need to understand the information supplied; and doctors need to provide comprehensible information sensitive to individual patient characteristics/ treatment setting, as well as undertaking assessments of actual patient understanding.<sup>84</sup> None of this is an easy task within the resource/ time constraints of medical practice, especially when patients are involved in anxiety laden decisions. Indeed, it has been queried whether the real impact of *Montgomery* will be to limit medical power rather than promote patient autonomy,<sup>85</sup> although this outcome would be consonant with the views discussed earlier.<sup>86</sup> Whilst some participants have indicated that information sharing (and consent) processes could be used to prioritise the avoidance of legal risk, *Montgomery* anticipates these professional responses. The decision makes it clear that the assessment of materiality cannot be reduced to percentages and risk assessment remains a situation specific affair.<sup>87</sup> Further, a doctor’s duty is not:

*“fulfilled by bombarding the patient with technical information which she cannot reasonably be expected to grasp, let alone by routinely demanding her signature on a consent form.”<sup>88</sup>*

Again, this sounds sensible but the practicality of implementing this mandate in technically complex scenarios may well prove impossible. Further, this statement does not tell us what doctors must do - rather it is what they must not do<sup>89</sup> - and this could be problematic if the change in emphasis encourages doctors to abandon “*their patients to bad decisions, provided they have given the patient sufficient information*”.<sup>90</sup>

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<sup>83</sup> (n43), [93].

<sup>84</sup> *Ibid.*, [90].

<sup>85</sup> Foster and Miola (n20), 527. See also Ronli Sifris, ‘The involuntary sterilisation of marginalised women: power, discrimination, and intersectionality’ (2016) 25(1) *Griffith Law Review* 49.

<sup>86</sup> Dunn et al. (n70).

<sup>87</sup> *Montgomery* (n43), [89].

<sup>88</sup> *Ibid.*, [90].

<sup>89</sup> Rob Heywood and Jose Miola, ‘The Changing Face of Preoperative Disclosure: Placing the Patient at the Heart of the Matter’ [2017] 133 *LQR* 296.

<sup>90</sup> Alasdair Maclean, ‘From Sidaway to Pearce and beyond: Is the legal regulation of consent any better following a quarter of a century of judicial scrutiny’ (2012) 20 *Med L. Rev* 108.

Should the judiciary become the final arbiters of what patients know<sup>91</sup> - are judges properly equipped to adjudicate in cases like *Montgomery*?<sup>92</sup> First, picking up on an earlier remark, the idea that clinical decisions can be neatly divided into exclusively medical and non-medical components is contentious:

*“There is a radical shift from the position that everything that doctors do needs to be seen as ‘medical’ (the position in Sidaway) to the position that unless every aspect of the decision is driven by ‘medical science’ it is not a matter of professional expertise. Neither position seems to reflect adequately the messiness of clinical interactions, which are rarely ‘purely’ anything. The idea that scientific evidence determines (rather than guides) decision making has never been the philosophy of the Evidence-Based Medicine movement, which promotes ‘the conscientious, judicious and explicit use of current best evidence in making decisions about the care of individual patients’. To believe population-based science might determine individual clinical decisions underestimates the challenges of its ‘sheer volume’, which has made using clinical guidelines ‘unmanageable and unfathomable’, and the very limited degree to which participants in trials actually resemble patients in clinics. It also underestimates the contribution that values necessarily make to the production and use of evidence.”*<sup>93</sup>

This is a powerful indictment of segmented decision-making at a practical level,<sup>94</sup> and at first blush the decision in *Montgomery* appears to make the professional/patient interaction and dialogue even messier. Some do not see that this as a bad thing, but many of these interactions are taking place in a time and resource limited public sector environment. The ambitions of *Montgomery* may be worthy but requires adequate resourcing to be fully realised. Further, the idea of neatly separating technical/ pathogenic and non-technical/ non-pathogenic concerns in the context of fetal reduction seem to us to be especially problematic.

Secondly, on what basis is legal adjudication a better forum for resolving questions that fall into the ‘ethical’ category? Indeed, Lady Black suggests that the judiciary should:

*“exercise the restraint that is required of a court when it ventures into areas of social and ethical uncertainty, and especially when it does so in the abstract, setting out views which will be of general application (as is necessarily so in this case) rather than resolving a clearly defined issue of law or fact that has arisen between the litigants appearing before it ... Judges have also developed experience in dealing with life and death decisions, but it is experience of a different sort from that of the medical team which actually treats the patient, and of the professional bodies responsible for regulating and guiding them, and this limitation must be recognised and taken into account.”*<sup>95</sup>

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<sup>91</sup> Heywood and Miola (n89).

<sup>92</sup> (n43); see Jonathan Montgomery and Elsa Montgomery, ‘Montgomery on informed consent: an inexpert decision?’, (2016) 42 *J Med Ethics* 89.

<sup>93</sup> Montgomery and Montgomery (n92), 93.

<sup>94</sup> Cf Dunn et al. (n70).

<sup>95</sup> *NHS Trust v Y* (n62) [115].

Foster and Miola advance a range of arguments to support the involvement of the judiciary although none appear to be decisive.<sup>96</sup> They claim judges are better equipped than bodies like the GMC to respond to shifts in public values. However, it is not at all clear that the judiciary are better equipped to identify and respond to shifts in public values, and Lady Black has highlighted a remoteness in judicial perspectives that counts against exclusivity.<sup>97</sup> They also claim that judges frequently have to make and deliver structured decisions, although this is hardly the exclusive domain of the judiciary. Finally, they assert that the judiciary has the authority and obligation to decide cases, and the power to review decisions by professional regulators. Again, that is not an argument for or against a judicial role because it would be feasible to allocate this task and authority to another adjudication body

Thirdly, we might ask whether judicial deference to medical practice can be avoided. For example, in Lady Black's judgment in *An NHS Trust and Others v Y* she places "significant weight" on professional guidance (especially when emanating from the GMC) in the context of the cessation of life sustaining treatment.<sup>98</sup> We will come back to the association between autonomy and medical deference shortly.

Fourthly, there might be some merit in saving the law and legal adjudication for cases where professional ethical regulation has clearly failed or is otherwise insufficient.<sup>99</sup>

Having gaps between legal and ethical standards might also serve a valuable purpose:

*"aligning the law to the professional obligations leaves one at the mercy of the other. On the one hand, if the Supreme Court's intention is to follow the ethical standard, then the law will rely on that standard remaining high and prioritising patient autonomy. On the other, if the purpose is to force the GMC to maintain its current requirements at least – as they cannot be relaxed without the professional standard then being less demanding than the law, which would not be reasonable – then the law will have essentially performed a takeover of the professional ethical standard."*<sup>100</sup>

Although recent GMC (draft) guidance provides some evidence that the legal decision in *Montgomery* has influenced the alignment of professional ethical standards, it also highlights the importance of flexibility and the practical reality that gaps will need to be filled from time to time.<sup>101</sup> Of course, the question is then whether and how these gaps should be filled pending intervention by the law?

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<sup>96</sup> Foster and Miola (n20), 524.

<sup>97</sup> *NHS Trust v Y* (n62), [115].

<sup>98</sup> *NHS Trust v Y* (n62), [77]. See also Louise V. Austin, 'Grimstone v Epsom and St Helier University Hospitals NHS Trust: (It's Not) hip to be square' (2018) 26(4) *Med L Rev* 665 and Heywood & Miola (n89).

<sup>99</sup> Heywood & Miola (n89).

<sup>100</sup> *Ibid.* See also Lee (n76).

<sup>101</sup> GMC, *Decision making and consent: Supporting patient choices about health and care, Draft guidance for consultation* (GMC 2018), 2. For the importance of 'elbow room' for good medical practice, see Dunn et al. (n70); Herring et al. (n71).



If we take stock for a moment – what does all of this mean for fetal reduction and selective reduction? First, these procedures require doctors to make decisions (ie about whether to recommend or offer surgical intervention) against the backdrop of a specific legal framework (eg AA 1967). However, this does not mean that these medical decisions have been made purely legal, because we know that there are social and ethical judgements to be made, especially in the context of ground E cases. Secondly, we have a possible tension between the medical gatekeeping role (as per AA 1967) and the newly constructed legal disclosure obligation (as per *Montgomery v Lanarkshire Health Board*). This is because doctors' hands and choices are partly tied by the authorising grounds for termination and the wider framework in the AA 1967. The reality will be influenced by the scope of any legal constraint, by the available professional norms and by a doctor's willingness to become accountable for a specific interpretative path. Thirdly, we know that situational and contextual factors may influence the interpretation of the 'reasonable patient'. Our research context usually involves patients attending specialist tertiary referral centres with complex multiple pregnancies. These specialist environments offer doctors direct insight into what a reasonable patient in this situational context might reasonably want to know. Fourthly, when it comes to fetal medicine and the evaluation of multiple pregnancy risks, doctors are unlikely to be able to speak in terms of absolutes. As such, decision-making will be complex and difficult to categorise in black and white terms. Fifthly, in regulating medical decision-making we ought to know what makes doctors pay attention and change their behaviours. So, if we decide to make a medical decision a legal one, how can we know that this regulatory response will produce any difference in practice? The answer must be that we need empirical evidence, or at least a clear explanation about why doctors in a specific situational context (ie fetal medicine) are more likely to pay attention to one normative framework over another.

### 6.3.3 Multiple pregnancy – decision-making and patients

Unwarranted paternalism is an obvious risk for medical decision-making involving the assessment of competency;<sup>102</sup> and professional autonomy will only be tolerated as long as society perceives that the potential benefits of medical freedom are greater than the potential harms.<sup>103</sup> However, it may be problematic to perceive medical paternalism and patient autonomy as mutually exclusive<sup>104</sup> - the GMC now emphasises the

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<sup>102</sup> Charles Foster, 'The rebirth of medical paternalism: An NHS Trust v Y' (2019) 45(1) *J Med Ethics* 3.

<sup>103</sup> McAndrew (n11). See also Jonathan Montgomery (n53).

<sup>104</sup> Alison Pilnick and Robert Dingwall, 'On the Remarkable Persistence of Asymmetry in Doctor/Patient Interaction: A Critical Review' (2011) 72 *Social Science & Medicine* 1374, 1379. See also Stauch & Wheat (n46).

importance of patients and doctors making decisions together.<sup>105</sup> Teff also makes this telling point:

*“[D]octor-patient relationships are often fraught with uncertainty and ambiguity. There is no a priori reason to assume that a doctor or surgeon possesses the kind of psychological or moral insight that would enable him to decide unaided what is most appropriate”.*<sup>106</sup>

In multiple pregnancy, women may be presented with complex information about the statistical likelihood of alternate outcomes (disability, disease, miscarriage etc) with shifting risk patterns over short periods in the pregnancy. This presentation may follow referral to a specialist tertiary centre. The information may be unclear or equivocal, and the pregnant woman may be given a wide range of sources addressing the available clinical options. There is likely to be some anxiety about the woman’s life or health, family, and unborn babies. In our context, the parents may have to weigh the relative interests of their possible future children in the balance, making choices based on the ‘lesser of two evils’.<sup>107</sup> There is likely to be influence from healthcare workers, family, friends and other patients; the decision-making process might involve ethical or cultural considerations and resultant choices may be constrained by regulation or other factors.

Against this background, it might be more meaningful to adopt collaborative or shared decision-making processes, especially in the complex multiple pregnancy cases.<sup>108</sup> Greater patient participation may have the effect of enhancing trusting relationships and improving patient satisfaction,<sup>109</sup> although patient centric processes cannot guarantee trust<sup>110</sup> or primacy for patient autonomy.<sup>111</sup> Suggestions have been made about how the balance could be struck; and implementing *Montgomery* may not have to involve an arduous set of additional professional obligations.<sup>112</sup> Shared decision-making is now at the heart of the latest (draft) GMC guidance and is littered with a range of collaborative descriptors including ‘support’, ‘listen’ ‘share’, ‘understand’, ‘respect’ ‘recognise’ and involve’.<sup>113</sup> Indeed, the GMC expectation is that doctors will

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<sup>105</sup> GMC, *Consent: patients and doctors making decision together* (GMC 2008); GMC (101).

<sup>106</sup> H Teff, ‘Consent to medical procedures: Paternalism, self-determination or therapeutic alliance’, (1985) 101 *LQR* 450.

<sup>107</sup> Where fetal reduction is presented as a choice between the loss of one fetus and the loss of the entire multiple pregnancy or between the loss of one to prevent or reduce the risk of anomaly in those preserved.

<sup>108</sup> cf Oliver Quick, *Regulating Patient Safety. The End of Professional Dominance?* (2017 Cambridge University Press), 184.

<sup>109</sup> *Ibid.*, 185. See also, The Health Foundation, *Helping People Share Decision Making: A Review of Evidence Considering Whether Shared Decision Making is Worthwhile* (The Health Foundation 2012).

<sup>110</sup> McAndrew (n11).

<sup>111</sup> Dunn et al. (n70). See also Quick (n108), 183-184.

<sup>112</sup> *Ibid.*

<sup>113</sup> GMC (n101), 5.

tailor the information they provide “to reflect their [the patient’s] particular concerns, wishes and values”.<sup>114</sup>

However, we should sound a slight note of caution. First, healthcare professionals need to be able to establish a “*dialogue and therapeutic alliance with the patient*” to ensure a tailored and patient centric approach.<sup>115</sup> This will be difficult in resource or time poor environments addressing unrestricted consumer demand. Secondly, partnership processes are most appropriate where there are realistic options without clear evidence-based outcomes and benefits - so that no one course of action is overwhelmingly preferable. Thirdly, even when shared decision-making is prioritised, it does not guarantee more or better patient choice. Garrard et al. conducted an observational study in a single NHS hospital delivering primary antenatal care.<sup>116</sup> Although shared decision-making is an established priority in NHS maternity services,<sup>117</sup> no treatment choice was offered to patients in 75% of the antenatal decisions made. These findings may not be replicable, but the study does offer a possible framework for evaluating patient choices in future research (Figure 2):

<b>Valid options (Included)</b>	<b>Invalid options (Not included)</b>
The options were discussed and clearly available to be chosen when decisions were made.	Only one option was mentioned or discussed. Asking the patient for consent or approval on a single option ie “is that ok?” was not counted as a choice.
Patient adds an option, which is not excluded as invalid by the doctor and was considered when the final decision was made.	Doctor dismissed an option as invalid, and explicitly said this to the patient. It was not considered when the decision was finally made.
The patient was offered a single option but had a clear choice of whether to accept or reject it. The option had to be phrased so that either choosing or rejecting the intervention would be valid. In this situation the patient was offered a choice between doing nothing and the proposed course of action.	Direction of management was entirely dependent on clinical course, so that no alternatives were available to the patient. For example, the mode of delivery of twins in an otherwise normal pregnancy was entirely dependent on the position of the leading twin. If the leading twin was breech then the doctor told the patient she would need a caesarean section, but if the leading twin was head-down then a vaginal delivery could be considered.
Discussion between different options and their exclusion involved the patient. This represents a process of choosing between valid options and therefore each option was counted.	Where multiple options are discussed between healthcare professionals, but only one was offered to the patient. As such, only the offered option would be defined as valid or available.

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**Figure 2 – Decision-Making**

<sup>114</sup> Ibid. (added). See also NICE, *NICE Clinical Guideline CG62 Antenatal Care for Uncomplicated Pregnancies* (NICE 2019), para 1.1.

<sup>115</sup> Dunn et al (n70).

<sup>116</sup> Garrard et al. (n49).

<sup>117</sup> NHS Shared Decision Making Programme <<https://www.england.nhs.uk/rightcare/shared-decision-making/>> accessed 20 June 2018. See also *The NHS Long Term Plan* (NHS 2019), <<https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>> accessed 9 January 2019.

<sup>118</sup> Garrard et al. (n49), Figure 1.

### 6.3.4 The role of medicalisation

The criminal offence of procuring abortion<sup>119</sup> became explicitly medicalised by the case of *R v Bourne*,<sup>120</sup> although the foundation was laid a decade earlier in the Infant Life (Preservation) Act 1929.<sup>121</sup> The shift in focus to the pregnant woman made it possible to medicalise the termination issue, and legally mandated assessments of risk became the dominant territory of the medical profession.<sup>122</sup> Although medicalisation might exist because ‘*society delegates its responsibility to the medical profession*’,<sup>123</sup> there is evidence that the legislative reform (ie AA 1967) reinforced specific professional interests at that time.<sup>124</sup>

There is no legal right to a termination,<sup>125</sup> and the explicit recognition of maternal rights was rejected because of a perceived risk that doctors would be reduced to mere technicians in the process.<sup>126</sup> Medicalisation also plays an important role in the criminal law - the legality of invasive surgery<sup>127</sup> ultimately rests on the operation of the ‘medical exception’.<sup>128</sup> This has two elements - first consent is a necessary but insufficient requirement for invasive surgical procedures involving a competent patient. Second, a public policy justification (‘proper medical treatment’) will be required to make the procedure lawful. This is a problematic concept in terms of perspective and opacity;<sup>129</sup> and the doctors will be the primary decision-maker in terms of what constitutes proper medical treatment.<sup>130</sup> Whilst the operation of the medical exception has been criticised on paternalistic grounds,<sup>131</sup> Penney Lewis claims that:

*“by creating uncertainty about the lawfulness of a particular procedure, the medical exception forces a dialogue between doctors and lawyers that would otherwise not occur without the (theoretical) risk of criminal prosecution”.*<sup>132</sup>

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<sup>119</sup> Offences Against the Person Act 1861, s 58.

<sup>120</sup> [1939] 1 KB 687

<sup>121</sup> See the s 1(1) exception based on good faith preservation of the life of the mother.

<sup>122</sup> Michael Thomson (n27), 208.

<sup>123</sup> Miola (n14) 36

<sup>124</sup> Thomson (n27); McGuinness and Thomson (n13).

<sup>125</sup> Although it would be unlawful to undertake termination against the express wishes of a competent patient.

<sup>126</sup> Margaret Brazier and Suzanne Ost, *Bioethics, Medicine, and the Criminal Law, Volume III, Medicine and Bioethics in the Theatre of the Criminal Process* (Cambridge University Press 2013); McGuinness and Thomson (n13).

<sup>127</sup> In this research, we are concerned with surgical interventions.

<sup>128</sup> See Penney Lewis, ‘The Medical Exception’, (2012) 65 *Current Legal Problems* 355; *R v Brown* [1994] 1 AC 212.

<sup>129</sup> Margaret Brazier and Sara Fovargue, ‘Transforming wrong into right: What is “proper medical treatment”?’, in Sara Fovargue and Alexander Mullock (eds), *The Legitimacy of Medical Treatment: What role for the medical exception?* (Routledge 2015), 22.

<sup>130</sup> Jonathan Montgomery, *Health Care Law* (Oxford University Press 2003), 232.

<sup>131</sup> See for example, Sara Fovargue and Alexander Mullock, *The Legitimacy of Medical Treatment: What role for the medical exception?* (Routledge 2015), 10.

<sup>132</sup> Penney Lewis (n128), 375.

Although we agree that medical interventions may be influenced by the likelihood of criminal prosecution, we are less convinced that the medical exception forces a constructive dialogue outside the theatre of the court process.

Fetal reductions and selective terminations are likely to require a range of interconnected decisions to be made. There will be moral decisions - whether it is morally right to undertake the procedure or select an entity for termination; legal decisions – whether the authorising ground can be met; and technical decisions – the appropriate method, choice to employ etc. It may be difficult to separate these if normative considerations are hidden within, or otherwise confused with technical questions. Further, if professional standards or rules are incomplete or non-directive, the resulting space may be filled by the individual values of the healthcare professionals involved.<sup>133</sup>

### **6.3.5 Personal values, conscientious objection and professional candour**

Having considered the role played by professional ethical rules in non-technical situations, and the importance of doctors making decisions on a moral basis,<sup>134</sup> we turn to examine whether the personal values of healthcare professionals should play any role in medicine. First, it is important to understand how private and personal values are expressed by these professionals in the healthcare environment. Niels Lynoe claims that private restrictive values are rarely presented openly but nonetheless influence the clinical assessment of facts and patient trustworthiness.<sup>135</sup> Latent concealment can prevent the implementation of patient wishes but may occur accidentally because implicit bias can affect the acquisition of information and the treatment of minority group patients.<sup>136</sup> Further, healthcare professionals may not appreciate that their personal values are impacting on decision-making or patient treatment.<sup>137</sup> Some may consciously reign in their own personal views so that there is no functional impact on their clinical practices.<sup>138</sup> Either way, there needs to be

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<sup>133</sup> Foster and Miola (n20), 514.

<sup>134</sup> Jonathan Montgomery (n53).

<sup>135</sup> Niels Lynoe, 'Physicians' practices when frustrating patients' needs: a comparative study of restrictiveness in offering abortion and sedation therapy', (2014) 40 *J Med Ethics* 306. Cf Lisa Crowe and others, 'A survey of health professionals' views on acceptable gestational age and termination of pregnancy for fetal anomaly', (2018) 61(9) *European Journal of Medical Genetics* 493.

<sup>136</sup> Jeff Stone and Gordon B Moskowitz, 'Non-conscious bias in medical decision making: what can be done to reduce it?' (2011) 45(8) *Medical Education*, < <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2923.2011.04026.x/pdf> > accessed 19 January 2016.

<sup>137</sup> H. Hermann, M. Trachsel and N. Buller-Andorno, 'Physicians' personal values in determining medical decision-making capacity: a survey study', (2015) 41(9) *J Med Ethics* 739 (a quarter of respondents did not appreciate that their values impacted on their decision-making); Narinder Kapur, 'Unconscious bias harms patients and staff', (2015) *BMJ* 351:h6347.

<sup>138</sup> Crowe et al. (135).

recognition that we are addressing the behaviour of fallible human agents in the context of medical care and treatment.

Secondly, it is important that policy makers have in mind the possible impact of personal values upon individual stakeholder choices.<sup>139/140</sup> Patent personal values are easier to regulate than latent ones – the former can be explicitly excluded or recognised through ‘conscientious objection’ clauses. These legal clauses authorise individual professionals to manifest choices based on their own personal values, but are frequently qualified to ensure reasonable endeavours are employed to save life or prevent grave harm when immediately threatened.<sup>141</sup> Formal professional ethics can also play an important role in the regulation of conscientious objection<sup>142</sup> - for example, the GMC publication *Good Medical Practice* indicates that conscience objections should be disclosed to patients in a sensitive manner.<sup>143</sup> Patients should have the opportunity to seek advice or treatment from other professionals who may not hold the same objections.

Thirdly, even when values are personal in nature, they may lack the character of being ‘private’ when manifested through impactful conduct on others. The GMC explicitly directs doctors not to discriminate against patients or colleagues by allowing “*personal views to affect your professional relationships or the treatment you provide or arrange*”.<sup>144</sup> The GMC *Personal Beliefs and Medical Practice* adds an overriding duty on doctors not to discriminate and to respect the dignity and views of patients.<sup>145</sup> Despite these apparent limitations, Jose Miola claims that the fragmented nature of the law and professional ethics has tended to leave more space for personal values than would first appear.<sup>146</sup> It is also important that professional responses to the manifestation of personal values are rationally connected to an ethical framework and address individual patient interests, rather than the self-serving needs and reputation of that profession.<sup>147/148</sup>

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<sup>139</sup> Eg. Lynoe (n135); Nathanson and Becker (n26); Wendy Savage and Colin Francome, ‘British Gynaecologists attitudes in 2008 to the provision of legal abortion’, (2011) 31 *Journal of Obstetrics and Gynaecology* 322; Anastasia Theodosiou and Oliver Mitchell, ‘Abortion legislation: exploring perspectives of general practitioners and obstetric and gynaecology clinicians’, (2015) 30(2) *Reproductive Bio Medicine Online* 197; Crowe et al. (n 136).

<sup>140</sup> Oliver Quick, *A scoping study on the effects of health professional regulation on those regulated: Final report submitted to the Council for Healthcare Regulatory Excellence* (2011), 7-12.

<sup>141</sup> Eg. Abortion Act 1967, s 4(2).

<sup>142</sup> Doug McConnell, ‘Conscientious objection in healthcare: How much discretionary space best supports good medicine?’, (2019) 33 *Bioethics* 154.

<sup>143</sup> 2013 (updated 2019), paras 52 & 54.

<sup>144</sup> *Ibid.*, para 59.

<sup>145</sup> General Medical Council, *Personal Beliefs and Medical Practice* (GMC 2013), paras 8-16.

<sup>146</sup> Jose Miola (n14)

<sup>147</sup> Brassington (n25).

<sup>148</sup> Cf McAndrew (n11).

So, should there be any space left for private values in medical practice? Miola argues for greater legal intervention in non-technical decisions, and in circumstances where professional ethics and personal conscience have clearly failed.<sup>149</sup> The trajectory of modern jurisprudence has generally limited the ability of doctors to exercise personal conscience, by identifying and prioritising patient values.<sup>150</sup> However increased judicial decision-making can only be justified in restricting the exercise of individual conscience if they are “*preventing poor choices*” or “*mandating good ones*”.<sup>151</sup> Further, Jonathan Montgomery claims that statutory conscience clauses require specific justification and cannot be justified on the basis that:

*“they protect the exercise of conscientious discretion in the deployment of the moral tradition of medicine because they permit personal moral agency rather than the following of a professional identity. There is, thus, a radical inconsistency with the reasons for the general respect for conscientious professional discretion.”*<sup>152</sup>

Further, Montgomery claims that healthcare professionals should not ordinarily receive special treatment when their personal beliefs conflict with public expectations of their role because any exception would be based on their personal moral agency, and not their professional status. In those circumstances, situational factors and balancing interests (including those of the patient) should be brought into the balance.<sup>153</sup> However, Mary Neal takes a contrary position arguing that the essence of abortion conscience clauses<sup>154</sup> is that active participants should not be forced to share in the moral responsibility for what they perceive as a wrongdoing.<sup>155</sup>

There are further general points that can be made in support of professional conscience-based objections. First, there does appear to be a salient difference between an agent objecting to the performance of acts that they regard as immoral and an agent objecting to the delivery of services based on moral objection to that individual/ class of persons, or the agent’s perception of or belief in the personal characteristics of that individual or class. Secondly, heavy restriction or prohibition of conscience-based objection could drive out competing views, disrupt agent integrity,<sup>156</sup> and force doctors to deploy subtle underground practices that could impede patient

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<sup>149</sup> Jose Miola, ‘Making Decisions About Decision-Making: Conscience, Regulation, and the Law’, (2015) 23(2) *Med L. Rev* 263.

<sup>150</sup> *Ibid*, 278.

<sup>151</sup> *Ibid*, 281.

<sup>152</sup> Montgomery (n53), 219

<sup>153</sup> Montgomery (n53).

<sup>154</sup> *Eg* Abortion Act 1967, s4.

<sup>155</sup> Mary Neal, ‘When conscience isn’t clear: *Greater Glasgow Health Board v Doogan and Another* [2014] UKSC 68’, (2015) 23(4) *Med L. Rev* 678-9.

<sup>156</sup> Mary Neal and Sara Forvargue, ‘Conscience and Agent Integrity: A Defence of Conscience-Based Exemptions in the Health Care Context’, (2017) 24(4) *Med L. Rev* 544.

choice.<sup>157</sup> Thirdly, there is a broader issue whether restriction of conscientious objection would eliminate or narrow professional discretion to such an extent that it would impair the delivery of optimal medicine.<sup>158</sup> Finally, there is a danger in painting conscience-based objections as simple binary choices as this telling practitioner comment attests:

*“The decision on the part of obstetrics and gynecology [doctors-in-training] to opt in or out of abortion training is, for many, a complex one. Although the public debate surrounding abortion can be filled with polarizing rhetoric, [doctors-in-training] often discover that the boundaries between pro-choice and pro-life beliefs are not so neatly divided. Our objectives in this commentary are to encourage a more nuanced discussion [...] and to demonstrate that the clear distinction between being pro-life and pro-choice often breaks down when one is immediately responsible for the care of pregnant women.”<sup>159</sup>*

This creates a problem for absolutist regulatory positions which have the potential to drive out views and values that might otherwise contribute to the professional and public discourse. Absolutist positions on personal conscience might be clear and simple to communicate but are likely to come at a cost and with unforeseen consequences.

Taking stock, we know that fetal reduction and selective termination procedures are subject to the same statutory conscience provision as singleton terminations. We also know that there may be different moral considerations arising from the termination of ostensibly healthy and anomalous life. What we make of these differences is likely to be influenced by our views on disability and entity status. Doctors engaging in a career in fetal medicine are likely to be made aware of these choices during the early stages of their subspecialty training if not before. What we need to address is whether the legal norms (ie the statutory conscience clauses) add anything or have any purpose if the professional norms already offer a workable balance for doctors and patients. Existing qualified GMC opt outs already have patient interests in mind. The answer probably rests on the value placed on these conscience clauses as the political and societal price for achieving and maintaining a legal compromise in a polarised moral world. In our view, regular and positive legislative review would ensure that the basis of any compromise retained validity and currency.

## 6.4 Workplace and cultural norms

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<sup>157</sup> Lynoe (n135), 306. For an ethical discussion, see Special Edition of Journal of Medical Ethics (2017) 43 (4).

<sup>158</sup> Cf D. P. Sulmasy, 'Tolerance, professional judgment, and the discretionary space of the physician' (2017) 26 *Cambridge Quarterly of Healthcare Ethics* 18 and McConnell (n142).

<sup>159</sup> Janet Singer and others, 'Four residents' narratives on abortion training: a residency climate of reflection, support, and mutual respect', (2015) 126 *Obstet Gynecol* 56.



There is strong evidence that clinical practice, behaviours and professional identity are shaped and influenced by the dynamics and priorities of occupational environments and culture.<sup>160</sup> The executive summary to the Francis Inquiry report begins:

*“[C]ritical comments will be made about individuals and **organisations, policies and cultures**. It is extremely important that these are seen with these matters in mind. Much will be said about culture in the report. Individuals and indeed organisations acting in accordance with a culture, even a negative or unhealthy one, cannot always be held personally responsible for doing so.”<sup>161</sup>*

The report emphasises the contributory role played by an engrained culture of tolerance for poor standards and behaviour in the tragic events that unfolded at the Mid Staffordshire NHS Foundation Trust.<sup>162</sup> In using the term ‘culture’, we have in mind the shared understandings, behaviours and practices within a group of people – in our context, within specific healthcare institutions, professional disciplines or sections thereof.<sup>163</sup>

Part of the problem at Mid Staffordshire was that cultural and institutional practices were able to flourish because of the vacuum left by the law, professional standards and by regulators. This highlights the need for regulatory frameworks to address and delineate the appropriate space for institutional culture; and the best mechanisms for influencing/ restricting that space and any consequential impact where necessary. Francis called for a fundamental change of culture within healthcare organisations, one that puts patients’ interests first; and recommended several core strategies to tackle this issue.<sup>164</sup> The immediate governmental response was the imposition of a statutory duty of candour at an institutional level (on healthcare providers).<sup>165</sup>

In terms of medical decision-making, the following important observation was made by the Supreme Court in *Montgomery*:

*“In addition, a wider range of healthcare professionals now provide treatment and advice of one kind or another to members of the public, either as individuals, or as members of a team drawn from different professional backgrounds ... The*

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<sup>160</sup> See for example, Nathanson and Becker (n26); Professional Standards Authority, *Rethinking regulation* (PSA 2015), 13; Professional Standards Authority, *The regulator’s role in professional identity: validator not creator* (PSA 2018), chp 5.

<sup>161</sup> Robert Francis, *The Francis Report- Executive Summary* (2013), para 11 [emphasis added].

<sup>162</sup> Robert Francis, *The Francis Report - Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (HC 947, 2013), 171. Cf report of Ian Kennedy following the Bristol Royal Infirmary Inquiry (<[https://webarchive.nationalarchives.gov.uk/20090811143822/http://www.bristol-inquiry.org.uk/final\\_report/the\\_report.pdf](https://webarchive.nationalarchives.gov.uk/20090811143822/http://www.bristol-inquiry.org.uk/final_report/the_report.pdf) >accessed 5 April 2019).

<sup>163</sup> Joseph Millum, *The Moral Foundations of Parenthood* (2018 Oxford University Press), 15.

<sup>164</sup> Summarised as clear standards; openness, transparency, and candour; improved support and training; patient-centred leadership; and accurate, useful, and relevant information (Roger Brownsword, ‘Regulating Patient Safety: Is it Time for a Technological Response?’ (2014) 6 *Law, Innovation and Technology* 1-29).

<sup>165</sup> Care Act 2014, part 2.

*treatment which they can offer is now understood to depend not only upon their clinical judgment, but upon bureaucratic decisions as to such matters as resource allocation, cost-containment and hospital administration: decisions which are taken by non-medical professionals. Such decisions are generally understood within a **framework of institutional rather than personal responsibilities.***<sup>166</sup>

This highlights the complexity and overlapping nature of decision-making within the NHS and the challenge for regulators when choices are seen to be engaging institutional rather than individual professional responsibility. This framing of institutional responsibility has the potential to disengage individual agency with knock on effects for patient care and private values - in short, the move to bureaucratic resource driven models of healthcare has exclusionary implications for private values. Whilst this might be seen as a good thing, the shift from individual to collective institutional responsibility does have ramifications for the wider regulatory environment.

What do we know about the interface between cultural/ professional norms and personal attitudes? Nathanson and Becker make this telling observation about abortion practice in the US:

*“Liberal obstetricians will perform abortions irrespective of the normative climate in which they are located; however conservative obstetricians will perform abortions only if they are located in an environment where abortion is supported by prevailing professional norms”.*<sup>167</sup>

This suggests a complex interaction between personal attitudes and cultural norms, particularly, if individual clinicians are resistant to specific procedures or choices. The research also suggests that personal attitudes have a stronger impact on the initial decisions to terminate, than on the subsequent treatment delivered which is “*strongly determined by the normative climate of the hospital*”.<sup>168</sup> They conclude:

*“[P]hysicians will conform to the professional norms of universalism and affective neutrality unless behavior in conformity with these norms is in conflict both with their personal attitude and with prevailing norms in their communities of practice.”*<sup>169</sup>

Although we should exercise caution given the US context, these findings reinforce the importance of changing occupational culture, especially in aftercare. When regulators target clinical activity, they should avoid placing too much reliance on rules that completely exclude personal values because this may produce and drive covert values in the decision-making process.<sup>170</sup> They should also recognise that there is likely to be

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<sup>166</sup> (n43), (Lords Kerr and Reed) [75] [emphasis added].

<sup>167</sup> Nathanson and Becker (n26), 204.

<sup>168</sup> Ibid., 207.

<sup>169</sup> Ibid., 208.

<sup>170</sup> Niels Lynoe (n135), 309.

an uphill struggle in changing behaviours or outcomes if personal values and cultural norms are rallied against proposed changes to professional ethical norms.

## 6.5 Executive and public standards

The Government influences and directs standards in the healthcare profession and service providers through a variety of direct and indirect means. Governments of the day can influence the development of health policy and social discourse by commissioning reports<sup>171</sup> and constituting public inquiries. The Department of Health and Social Care can issue guidance that can be directive and influencing - for example, the Departments' guidance on abortion published following concerns expressed by the Director of Public Prosecutions.<sup>172</sup> The NHS can also issue policy guidance and seek to establish core principles and values.<sup>173</sup> The Government can propose legislation that will ultimately set the boundaries under which healthcare professionals operate and are regulated.<sup>174</sup> Politically the Executive can set agendas, influence societal views and engage in ethical discourse. There is also scope for prosecutorial bodies to influence how the criminal law responds to specific medical activities through the publication of prosecution policies.<sup>175</sup> Media publication of prosecutions are also likely to influence professional behaviours at a disciplinary and workplace level.

However, we also have clear evidence of the limits of executive power and influence - the events at Mid Staffordshire happened in spite of the wider regulatory regime. There is also the danger of excessively complex and contradictory public standards - the apparent desire for more oversight and regulatory intervention does not necessarily equate with better outcomes for patients or improved decision-making processes.<sup>176</sup> Against this background, a multi layered or faceted regulatory approach may better reflect the complexity of the healthcare environment and the reality that there is no single effective solution for patient safety.<sup>177</sup> Further, it is problematic to direct regulatory mechanisms exclusively against fallible human agents.

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<sup>171</sup> Eg Warnock Committee Report, *Report of the Committee of inquiry into Human Fertilisation and Embryology* (HMSO Reprint 1988)

<sup>172</sup> Department of Health, *Guidance in relation to requirements of the Abortion Act 1967* (DOH 2014a).

<sup>173</sup> Eg the NHS Constitution (NHS 2015),

<<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Pages/Overview.aspx>>accessed 4 March 2016.

<sup>174</sup> In the context of Abortion – Offences Against the Person Act, S58 and 59; Infant Life (Preservation) Act 1929; Abortion Act 1967 (as amended) etc.

<sup>175</sup> See for example, the recent DPP decision not to prosecute two doctors accused of undertaking sex selective terminations (chapter 4).

<sup>176</sup> See also Richard B. Macrory, *Regulatory Justice: Making Sanctions Effective* (2006).

<sup>177</sup> Quick (n108),178-9; The Health Foundation (n109), v.

## 6.6 The role of professional ethical regulation

So far, we have discussed ‘regulation’ as if it was an unambiguous term. It can be interpreted narrowly, as the activity of state sponsored or created regulators, or more broadly as a:

*“sustained and focused attempt to alter the behaviour of others according to defined standards or purposes with the intention of producing a broadly identified outcome or outcomes, which may involve mechanisms of standard-setting, information-gathering and behaviour-modification.”<sup>178</sup>*

We will use this broader definition to develop this section.

### Standard setting

Historically, professional ethical sources have proved to be highly influential on legal standard setting,<sup>179</sup> but should the law and legal actors be deferring to these sources? We have already addressed concern about the medical professions’ exclusive involvement in what are essentially ethical or social decisions. Jose Miola has convincingly argued that the relationship between the law and professional ethics has not been a mutually beneficial one – often neutralising or cancelling out the effect of the other creating a regulatory vacuum.<sup>180</sup> Miola highlights three specific issues with professional medical ethics: the cultural flaws in the medical profession;<sup>181</sup> excessive professional autonomy,<sup>182</sup> and the fragmentation of professional responsibility with adverse impact on standard setting.<sup>183</sup> All of these issues resonate to some degree in the health scandals that followed the publication of Miola’s work.<sup>184</sup>

There is also the question of which professional ethical rules should be followed on the legal stage - the formal, semi-formal or informal/ unofficial? Unfortunately, the courts have shown no consistent preference for one set over another.<sup>185</sup> There is some evidence that where the law is unclear, professional guidance will influence subsequent decisions by the judiciary.<sup>186</sup> It may be reasonable for professions to set standards at a higher level than the law – the law can be used to set minimum standards, whilst the

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<sup>178</sup> Julia Black, *Critical Reflections on Regulation Discussion Paper No4* (Centre for analysis of risk and regulation at the LSE 2002), 20.

<sup>179</sup> See for eg the deferential approach taken by Lord Goff to BMA guidance in *Bland* (n21). See also Jose Miola (n14), 163.

<sup>180</sup> Miola (n14), 209.

<sup>181</sup> *Ibid.*, 210.

<sup>182</sup> *Ibid.*, 211.

<sup>183</sup> *Ibid.*, 212.

<sup>184</sup> Most notably at the Mid Staffordshire NHS Trust.

<sup>185</sup> Cf Lord Goff’s deference to BMA guidance in *Bland* (n21); Lady Hale’s reference to NICE and RCOG guidance in *Montgomery* (n43) [110], [112] and [116] and Lady Black’s deference to GMC guidance in *Y* [62]. See also Miola (n14), 84 and Foster (n102).

<sup>186</sup> See for eg, *Montgomery* (n43) [69] - the DOH and the GMC chose to follow the authority of *Chester v Afshar* [2004] UKHL 41 rather than *Sidaway v Board of Governors of Royal Bethlem Hospital* [1985] 1 All ER 643.

profession enacts more exacting rules with professional implications for persistent or serious breaches.<sup>187</sup> However, the professions need to set those standards clearly, consistently and appreciate the difficulties that may arise when they use discursive guidance rather than directive codes or rules. This concern is reflected in the latest (draft) GMC guidance on decision-making with a clear differentiation between ‘*you must*’ and ‘*you should*’.<sup>188</sup> ‘*You must*’ is used to denote “*a legal requirement or a fundamental standard of ethical conduct applying to all doctors*”,<sup>189</sup> whereas ‘*you should*’ denotes more flexibility over how doctors meet an overriding duty/ principle, or a requirement that will apply to some but not all circumstances or “*where there are factors outside a doctor’s control that affect whether or how a doctor can follow that guidance*”.<sup>190</sup> Overall, doctors are expected to exercise judgement in the use of this (draft) guidance but the GMC suggests that decisions ought to be evidenced in case an explanation or justification is later required.

## **Behaviour modification**

As part of a scoping study for the Council for Healthcare Regulatory Excellence, Oliver Quick undertook four ‘elite interviews’ with healthcare professionals,<sup>191</sup> and participants were asked about how professional regulation affected their behaviour. The findings suggested that professional regulation “*was not very relevant in terms of impacting their clinical work*”, with most participants perceiving this type of intervention negatively and associating regulation with disciplinary functions.<sup>192</sup> Quick also undertook a literature review concerning the behavioural effects of regulatory activity and interventions on regulatees; and his findings can be briefly summarised as follows:

- There is a shortage of systematic knowledge on the main research question (ie how professional regulation affects the behaviour of regulatees)
- Internal organisational factors may influence compliance more directly than external professional or legal regulation.
- Behavioural change is much more likely to occur when a “*combination of factors conspire to convince practitioners to alter their practice*”. There is a suggestion that effective rules work by shifting regulatee attention.
- Healthcare professionals tend to prioritise clinical judgement over clinical governance.
- Compliance is far more likely when regulation is accepted as legitimate by practitioners.<sup>193</sup>

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<sup>187</sup> See Foster and Miola (n20); Brazier and Ost (n126), Chp 8.

<sup>188</sup> GMC (n101).

<sup>189</sup> *Ibid.*, 2.

<sup>190</sup> *Ibid.*

<sup>191</sup> Quick (n140). Their discipline, role and status are not otherwise identified.

<sup>192</sup> *Ibid.*, 18. See also, Professional Standards Authority (PSA), *The Regulator’s Role in Professional Identity: Validator not Creator* (PSA 2018), para 3.2.

<sup>193</sup> *Ibid.* 19-22. See also PSA (n192), para 3.10.

These findings feed into our earlier discussion on the value and impact of legal and professional norms. It is intended that this research will contribute or bridge some of the identified gaps, albeit within a specific contextual framework.

## **Information gathering**

In the context of information gathering, professional regulators and representatives have a distinct advantage over the courts. In compiling ethical rules or guidance, these bodies can gather, share and disseminate information about knowledge and practice with their membership. By doing so, they can directly influence future practice and enable forums for further discourse including the ventilation of disagreements within the membership. These features probably assist the development of new clinical practices, the collation of empirical evidence and are otherwise helpful in areas lacking consensus.

## **Medical ethical rules**

The key professional (representative) bodies in our subject area are the British Medical Association (BMA), the Royal College of Obstetricians and Gynaecologists (RCOG) and the British Maternal and Fetal Medicine Society (BMFMS). We have also highlighted relevant Royal College of Nursing guidance in table 4A (appendix F).

The BMA is a trade union and representative body for doctors in the UK, publishes the British Medical Journal (BMJ), offers a professional community and platform to influence associated policy and law. Its core values are defined as follows:

**“Expert**

*We are an indispensable source of credible information, guidance and support throughout doctors' professional lives.*

**Committed**

*We are committed to all doctors and place them at the heart of every decision we make.*

**Reliable**

*We are doctors' first port of call because we are trusted and dependable.*

**Challenging**

*We are unafraid to challenge effectively on behalf of all doctors.*

**Leading**

*We are an influential leader in supporting the profession and improving the health of our nation.”<sup>194</sup>*

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<sup>194</sup> BMA, *Medical Ethics Today: The BMA's Handbook of Medical Ethics & the Law* (BMA 2016), <<http://www.bma.org.uk/support-at-work/ethics/medical-ethics-today>> accessed 15 January 2016.

The BMA's core ethical guidance is contained in *Medical Ethics Today: The BMA's Handbook of Medical Ethics and the Law*,<sup>195</sup> and is supplemented by separate publications on specific subject matters. The most relevant source for our purposes is *The Law and Ethics of Abortion: BMA Views* published in November 2014 and later updated in June 2017 and October 2018. Under the heading 'Moral Scope' and in relation to the exercise of personal conscience it states:

*"In some cases a distinction can be made between legal and ethical obligations. There may be some tasks that fall outside the legal scope of the conscience clause but morally within it.*

*Generally, it will not be beneficial for women undergoing termination of pregnancy to be cared for by doctors who feel distressed or unhappy about their involvement in a procedure, and so providing individual patients are not disadvantaged, and continuity of care for other patients can be maintained, requests from doctors to opt out of involvement in termination procedures should be considered and accommodated wherever possible.*

*Where such tasks are unavoidable, health professionals must pursue a non-judgmental approach to the woman concerned.*"<sup>196</sup>

This extract highlights the discursive and equivocal nature of this source and the difficulty that might be created when relied upon as a platform for setting legal standards. Further, the promulgation of sources by representative bodies can never be regarded as fully objective or independent of associated professional interests.

RCOG provides information for patients, exams and continuing education for its members. It publishes 2 journals,<sup>197</sup> has a quality and audit role; and has undertaken a data audit for the Government in relation to abortion notification compliance by service providers.<sup>198</sup> RCOG produces and publishes 'Green Top',<sup>199</sup> Good Practice<sup>200</sup> and National Clinical<sup>201</sup> guidelines - the latter tend to be the most directive, although points are often framed as recommendations. The most relevant national clinical guideline is *Multiple Pregnancy: the management of twin and triplet pregnancies in the antenatal*

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<sup>195</sup> Ibid. See also BMA, *Ethics A to Z* (BMA), < <http://www.bma.org.uk/support-at-work/ethics/ethics-a-to-z> > accessed 15 January 2016..

<sup>196</sup> BMA, *The Law and Ethics of Abortion: BMA views* (November 2014) (updated October 2018), 10 (para 2.1.8.3).

<sup>197</sup> BJOG and TOG.

<sup>198</sup> Department of Health, *Matching Department of Health Abortion Notifications and Data from the National Down's Syndrome Cytogenetic Register and Recommendations for Improving National Compliance* (DOH 2014d).

<sup>199</sup> "Green-top Guidelines provide systematically developed recommendations which assist clinicians and patients in making decisions about appropriate treatment for specific conditions. Green-top Guidelines are concise documents providing specific practice recommendations on focused areas of clinical practice" (RCOG Guidelines < <https://www.rcog.org.uk/en/guidelines-research-services/guidelines/about-rcog-guidelines/#gtg> > accessed 16 May 2019).

<sup>200</sup> These provide "practical guidance to clinicians and managers on workplace issues identified through repeated requests from providers and managers of the service." (RCOG (n199)).

<sup>201</sup> "National Evidence-based Clinical Guidelines provide systematically developed recommendations which assist clinicians and patients in making decisions about specific conditions." (RCOG (n199)).



period,<sup>202</sup> although it excludes the topic of embryo (and implicitly fetal) reduction from its remit. There is also a Green Top guideline called *Monochorionic Twin Pregnancy, Management* that does address reduction and feticide in monochorionic pregnancies (see Table 4A/ Appendix F).<sup>203</sup> In terms of production, these guidelines:

*“contain most up to date data, they are extremely rigorous process in setting... use standardised methodology that (are) approved by NICE ... A project, a subject is proposed by any stakeholder, a topic for a guideline... that proposal goes to (the) quality assurance group to look at whether bring a scope for that guideline, if that scope is possible, choose a lead developer, goes through process. Systematic reviews. As close to a NICE guideline as possible. Less economic analysis. I guess that is one of the big differences between a green top. And they very much drive an awful lot of ... standards.”<sup>204</sup>*

There is now a focus on filling gaps and producing shorter more focused Green Tops, and *“trying to respond, listen to fellows and members, picking up where guidance is needed.”<sup>205</sup>* Good practice papers are based on *“expertise rather than 100% evidence and practical solutions how that might work”<sup>206</sup>* National clinical guidelines can take up to 3 years to produce and Green Tops have taken up to 2 years to produce historically.<sup>207</sup>

The BMFMS is a forum and membership organisation aimed at the core participants in this research. It has a number of aims including the dissemination of knowledge, the promotion of relevant research and encouraging the development of clinical guidelines. The Society runs and participates in consultations and runs events of interest to its membership. It contributes to the work of RCOG/ NICE and there is considerable overlap in membership between RCOG and the BMFMS.

## 6.7 Professional medical ethics - recommendations, codes & guidance

**Table 4A (appendix F)** provides a brief summary of the relevant professional ethical sources disseminated by representative bodies and regulators pertaining to the

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<sup>202</sup> RCOG, *Multiple Pregnancy: the management of twin and triplet pregnancies in the antenatal period* (NICE Clinical Guidance) (RCOG 2011a). See also RCOG, *Fetal Awareness: Review of Research and Recommendations for Practice* (RCOG 2010a); RCOG, *Termination of pregnancy for fetal abnormality* (RCOG 2010b); RCOG, *The care of women requesting induced abortion* (RCOG 2011b); NICE, *Twin and Triplet Pregnancy (CG129 Guideline Update) – Draft for Consultation* (NICE 2019).

<sup>203</sup> RCOG, Green-Top Guideline No. 51 (RCOG 2016).

<sup>204</sup> Participant E

<sup>205</sup> Participant E (emphasis added).

<sup>206</sup> Participant E.

<sup>207</sup> Participant E.



termination of pregnancy and fetal reduction/ selective termination in multiple pregnancy. What will be evident is that there are very few domestic sources that provide any detail, and which directly address fetal reduction/ selective termination as distinct procedures. Beyond the complexity of monochorionic twin pregnancy, the guidance is fairly limited.

[Note: updated NICE guidance on the Termination of Pregnancy<sup>208</sup> and Twin & Triplet Pregnancy<sup>209</sup> are anticipated later in 2019 following consultation.]

## 6.8 Deference in medicine

Sarah Devaney distinguishes medical paternalism – the claim that doctors are better placed than others to make healthcare related decisions – from deference which she describes as “*submissive acquiescence to [paternalism]*”.<sup>210</sup> Devaney argues that paternalism and deference to the medical profession have become uncoupled producing two primary consequences for medical deference.<sup>211</sup> First, the nature of deference has changed partly due to recent policy/ legal changes, demonstrated by the Supreme Court decision in *Montgomery*<sup>212</sup> with greater recognition of patient interests and an increasing desire for shared decision-making.<sup>213</sup> Secondly, “*the presence of deference to the medical profession has become more hidden*”<sup>214</sup> as paternalism itself dwindles or conceals itself following decisions like *Montgomery*. However, she argues that medical deference is very much alive because clinical encounters still involve an imbalance in “*terms of knowledge as well as formal and informal social power*”, and due to the increasing medicalisation (and validation) of “*personal and social problems*”.<sup>215</sup> This imbalance will be more prevalent in complex, fast changing, highly sensitive and/or personal medical scenarios (eg fetal reductions).

In the healthcare context, deference might be exhibited by legal actors, patients, the public and professional regulators/ tribunals. *Bolam* is the classic example of legal

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<sup>208</sup> NICE, *Termination of Pregnancy – NICE Guideline – Draft for Consultation* (NICE April 2019).

<sup>209</sup> NICE (n202).

<sup>210</sup> Sarah Devaney, ‘The Transmutation of Deference in Medicine: An Ethico-Legal Perspective’, (2018) 26(2) *Med L. Rev* 202 [added].

<sup>211</sup> *Ibid.*, 203-204.

<sup>212</sup> *Montgomery* (n43).

<sup>213</sup> Devaney (n210), 204-205.

<sup>214</sup> *Ibid.*

<sup>215</sup> *Ibid.*, 217-220. See also Samantha Peters and Douglas Bilton, D., “Right-touch” trust: thoughts on trust in healthcare’ in R. H. Searle, A-M I. Nienaber, S. B. Sitkin, (eds) *The Routledge Companion to Trust* (Routledge 2017); and in the abortion context, Sally Sheldon, *Beyond Control: Medical Power & Abortion Law* (Pluto 1997), 73.

deference to the medical profession;<sup>216</sup> some would argue that the AA 1967 and its subsequent enforcement also demonstrates continued legal deference to the medical profession.<sup>217</sup> Although *Montgomery*<sup>218</sup> has now been heralded by some as a victory for patient autonomy, it embodies existing GMC guidance (in part) and is therefore “*suggestive of a traditional deferential approach*” by the courts.<sup>219</sup>

In terms of the traditional clinical relationship between doctor and patient, online sources of information have proved important to enhancing patient knowledge, although the quality / value of these sources is variable, and subject to the resources, education and skills of the patients involved.<sup>220</sup> Devaney also claims that deference “*re-emerges*” when using external information in the clinical encounter because, in many cases, the patient will need professional co-operation and assistance to access any choice(s).<sup>221</sup> We would add a further consideration - the sheer volume and complexity of available information, and the time limited nature of clinical encounters makes deference more likely in practice.<sup>222</sup> In addition, patients may be forced to show deference to structural factors inherent in the healthcare system, including inevitable NHS constraints on funding, treatment choices etc.<sup>223</sup> Constraints to access and choice are apparent in abortion services across the UK;<sup>224</sup> and law makers are subject to heavy lobbying and influence by professional bodies in the abortion context.<sup>225</sup> Of course, deference is not necessarily a bad thing, and given the knowledge/ skills imbalance between a doctor and patient, it may be an entirely rational response in complex and technical decision making scenarios.<sup>226</sup> Further, deference to professionals may occur “*because our society gives greater weight to their autonomy*”.<sup>227</sup> Again, whilst the space for professional autonomy may have shrunk in healthcare, many patients still place weight and value on professional skills/ knowledge in certain contexts.<sup>228</sup> We can debate how far this should go beyond the delivery of technical treatments but from personal experience there are some decisions where

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<sup>216</sup> Bolam (n66).

<sup>217</sup> Brownsword and Wale (n8).

<sup>218</sup> Montgomery (n43).

<sup>219</sup> Devaney (n210), 208-209.

<sup>220</sup> See for eg, Roger Brownsword and Jeff Wale, ‘Regulating in the Global Village: The Case of Non-Invasive Pre-Natal Tests’. In: E Symeonidou-Kastanidou and others (eds) *Medicine, Law and the Internet* (Greece: Nomiki Bibliothiki S. A.2018), XV-378.

<sup>221</sup> Devaney (n210), 212-216. See also Sheldon (n215).

<sup>222</sup> J. S. Blumenthal-Barby, ‘That’s the doctor’s job’: Overcoming patient reluctance to be involved in medical decision making’, (2017) 100 *Patient Education and Counseling* 14.

<sup>223</sup> Devaney (n210), 214-217.

<sup>224</sup> DHSC, *UK Abortion Statistics, England and Wales: 2017* (DHSC Revised December 2018), para 2.34.

<sup>225</sup> Thomson (n27).

<sup>226</sup> Devaney (n210), 224-225.

<sup>227</sup> Dave Archard, ‘Book Review: Dominic Wilkinson and Julian Savulescu, Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus’ (2019) *Med L. Rev.*, fwz003, <<https://doi.org/10.1093/medlaw/fwz003>> accessed 4 February 2019.

<sup>228</sup> The Health Foundation (n109), 30.

patients will expect a strong medical steer. Perhaps, the key is whether the patient actively chooses to submit to medical control, rather than passive acquiescence to a state of affairs, although we accept that this may be difficult to spot or differentiate in practice.

## 6.9 Conclusions

What do we make of the professional, personal and cultural norms as they pertain to decision-making about fetal reductions or selective termination? We make four specific observations:

First, these procedures (and abortion generally) give rise to strong and divergent personal views that cannot be ignored, even when the professional normative frameworks recognise the legitimacy of such practices. Indeed, we have highlighted the danger of driving out all moral conflict or manifestations of dissent, at least while healthcare services are delivered by human agents. We would argue that society should make some space for personal values providing these positions do not unnecessarily conflict with the delivery of care and public expectations of the professional healthcare role. Importantly, we should avoid driving personal values underground – if moral space can be safely created, then it should be. This will be situation specific and we would argue that these matters are more appropriately addressed at a local occupational level rather than through blunt fixed national positions. In this respect, we have questioned the need for separate statutory conscience clauses in addition to the professional normative framework. Ultimately, the issue will fall to be determined by broader societal and political considerations around the termination of pregnancy.

Secondly, we have observed that whilst we do have a professional normative framework relating to the termination of pregnancy, there are few sources addressing fetal reduction or selective termination per se. This may not be surprising given the number of procedures involved but makes it more likely that the legal norms will be more directly relevant to medical practice in this area. It is also evident that the professional frameworks do little to obviate the inherent uncertainties built into the current legal norms. The AA 1967 casts an inevitable shadow over medical practice. However, these medical decisions have not been made purely legal, because we do know that doctors are making social and ethical judgements especially in the context of ground E cases.

Thirdly, these decisions are being made in specialist tertiary centres and patients will know from referral that their pregnancy and related treatment issues are atypical. We also observe that fetal reductions and selective terminations and the surgical methods used are atypical within pregnancy care. This creates a foundation for patient deference to the medical decision-makers.

Fourthly, and linked to our previous point, whilst tertiary centres offer specialist knowledge, skills and resources, they also have the capacity to elevate the role of workplace and subspeciality practice norms.

More generally, we have considered whether there is an internal morality to medicine and the healthcare profession. We have argued that there is an internal normative framework, albeit one that is influenced by external forces, especially in our research context. Professionalism remains important for standard setting, education and enforcement purposes. There are signs that clinical encounters have generally got messier and more is being expected from stakeholders in terms of engagement and responsibility. Increasing societal and legal emphasis on patient autonomy has undoubtedly contributed to these changes. However, there are also wider structural and cultural considerations, especially within the NHS framework, that have distorted or impacted upon this evolution. Importantly, the resourcing of healthcare directly influences the delivery of change, and successful regulatory reforms are unlikely without significant resourcing support. Bureaucratic and institutional changes have also impacted on individual professional autonomy and warrant new, or at least reconsidered forms of regulation that address institutional responsibility/culpability. However, it is also evident that cultural issues need to be tackled from within and blunt external regulatory measures are unlikely to work in isolation.

We have considered the important role played by professional medical ethics and professional regulation. The relationship with the law is complex but there appears to be space for divergence providing ethical obligations are kept more demanding than their legal counterparts. The appropriate gap will be influenced by a range of factors, including the self regulatory performance of the medical profession but the law should be slow to takeover the professional standard unless there are good justifications for raising legal standards and only if stakeholder outcomes are likely to improve as a result.

Finally, we are not convinced that medical practice can be neatly sub divided into exclusive categories of ownership; many medical decisions will have non-technical and ethical components where patient centric and collaborative decision-making processes are clearly warranted. What is less clear is whether the law is an effective vehicle to

achieve improvements in decision-making and patient centric care. Certainly, the law provides an incentive and prompt for active change, but the ambitions or threats of the law are not enough on their own to deliver change. Indeed, we have emphasised the importance of patients as knowledgeable and active participants in their own care<sup>229</sup> – something that requires positive encouragement, support and resources from the medical profession and funders to achieve. Shared decision-making can only be realised if we create the space for meaningful dialogue between HCP and patients - we need to leave some space for medical expertise and cannot boil everything down to inflexible rules. Regulators and legal actors need to think carefully how professional guidance/ standards are created/ used in practice and in the adjudication process. Greater clarity about mandatory and discretionary components are likely to assist regulators and regulatees alike. It is to the effective regulation of decision-making that we now turn our attention.

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<sup>229</sup> Cf Quick (n108), 183

# Chapter 7 – Regulating Decision-Making in the Clinical Encounter

## Contents:

- 7.1 Introduction
- 7.2 Healthcare professionals as ‘choice architects’
- 7.3 Regulatory models, legitimacy and effectiveness
- 7.4 UK healthcare regulation – the story so far
- 7.5 Influencing patient decision-making
- 7.6 Priorities: patient centred care and shared decision-making
- 7.7 Conclusions

## 7.1 Introduction

This chapter builds upon earlier discussion of clinical decision-making by framing healthcare professionals as ‘choice architects’, before evaluating possible models, mechanisms and priorities for regulating decision-making in the clinical encounter. We also examine contemporary responses to regulation across the wider UK healthcare system. One of the key considerations, is how best to regulate healthcare services with a view to maximising patient safety. There are general options, but we should be aware of our situational practice context. The safety of pregnant women should be at the heart of any decision to ‘reduce’ a multiple pregnancy. However, there will be an overarching and concurrent clinical responsibility to preserve and support human life, creating possible tension when professional and personal values diverge. So, in order to maximise patient safety, we need to consider how the situational features of multiple pregnancy and fetal reduction might impact on the regulation of decision-making in this context. Conversely, we cannot ignore the broader considerations and difficulties involved in regulating for cultural change.

## 7.2 Healthcare professionals as ‘choice architects’

There are several possible decision-makers and choice facilitators in the clinical encounter, including the patient, their family, the hospital/ service provider and the treating professionals.<sup>1</sup> Although patients should be choosing their treatment, the healthcare professionals will be acting as ‘*choice architects*’<sup>2</sup> because it is they who decide - subject to any bureaucratic, legal or professional constraint - what and how information is communicated, and which treatment options are offered. Those treatment recommendations should be evidence-based and include option(s) which the treating professional perceives are likely to offer the patient the best average (or perhaps, least bad) outcome in the known circumstances.<sup>3</sup> There may be different priorities and perspectives around ‘best outcome’, setting up practical and ethical tensions in the clinical encounter, especially around information exchange.<sup>4</sup> These tensions can be exacerbated by consumerism, ambiguity or uncertainty,<sup>5</sup> differential moral considerations or values that “*make it harder for a benevolent doctor to adopt his or her patients’ point of view*”,<sup>6</sup> and by plain conscious bias.<sup>7</sup> These tensions and differential priorities are not limited to the doctor/ patient relationship but may also occur in the relationships with the wider medical team.

Healthcare professionals will generate a hypothesis when a patient’s condition or disease needs to be distinguished from other conditions/ diseases with similar features or presentation, with a view to making a differential diagnosis. They will gather data by investigation to test their hypothesis, before selecting/ offering a course of treatment or withholding action. Resource considerations may feed into the investigation, selection and offer processes as a result of budgetary limits or constraining institutional policies. There is evidence that some healthcare professionals may use their past experiences inappropriately during these processes,<sup>8</sup> by overestimating risk or prevalence,<sup>9</sup> or

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<sup>1</sup> Harold C. Sox, Michael Higgins and Douglas K. Owens, *Medical Decision Making* (J Wiley & Sons 2013), 148.

<sup>2</sup> David Avitzour and others, ‘Nudging in the clinic: the ethical implications of differences in doctors’ and patients’ point of view’, (2018) *J Med Ethics* DOI: 10.1136/medethics-2018-104978; I G. Cohen and others., *Nudging Health: Health Law and Behavioural Economics* (John Hopkins University Press 2016).

<sup>3</sup> Sox et al. (n1), 6.

<sup>4</sup> Avitzour et al. (n2); Helena Serra, ‘Gamble on the Uncertain. Negotiating Medical Decision-Making’ (2016) 12(4) *QSR* 44-59. For discussion of the clinical encounter as a form of argumentation, see Peter J. Schulz and Sara Rubinelli, ‘Arguing for the Patient: Informed Consent and Strategic Maneuvering in Doctor–Patient Interaction’, (2008) 22 *Argumentation* 423.

<sup>5</sup> H Teff, ‘Consent to medical procedures: Paternalism, self-determination or therapeutic alliance’, (1985) 101 *LQR* 450.

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

<sup>7</sup> Eg., Niels Lynoe, ‘Physicians’ practices when frustrating patients’ needs: a comparative study of restrictiveness in offering abortion and sedation therapy’, (2014) 40 *J Med Ethics* 306.

<sup>8</sup> Sox et al. (n1). 11.

<sup>9</sup> *Ibid.*, 38.

judging probability based on ease of recall.<sup>10</sup> Indeterminate or vague professional, institutional or other regulatory requirements may also impact on the accuracy of any clinical risk assessment.

As healthcare professionals control how and when they communicate information to patients (subject to regulatory/ bureaucratic constraints) this reduces the opportunities for a “*neutral’ choice environment*”.<sup>11</sup> That is why the legal and professional requirements on information disclosure are so important to actual patient choice. In any event, communicating difficult and emotive subjects to patients can be problematic and words become “*the enemy of clarity in expressing uncertainty*”.<sup>12</sup> Uncertainty is a common feature of prognosis and a prevalent factor in multiple pregnancy where the parents are often presented with complicated, emotive and shifting assessments of risk. These are important situational features in our research context. The GMC emphasises that doctors should be upfront and clear with patients in situations when the evidence:

*“of the benefits, harms and burdens of a particular option is unclear or there is uncertainty about the clinical effect of a particular intervention on an individual patient...”*<sup>13</sup>

Written, visual and non-verbal decision-making and communication aids may be helpful for patients in these situations or when addressing difficult/ complex information, although the impact/ value may depend upon the type of aid/ decision and the extent of the uncertainty involved.<sup>14</sup>

We should also recognise that decisions are made in variety of contexts and not just inside the formality of the patient consultation.<sup>15</sup> As a consequence, decisions will be subject to a range of contextual, relational and power considerations. For example, medical decisions to treat may be influenced by social/ workplace pressures and behaviours. A junior doctor may feel that they have to moderate or alter a proposed course of treatment for a patient because of feedback from senior members of the medical team. The local culture of decision-making will influence the space and freedom that the junior doctor will have to negotiate their position. In fetal reduction, we also need to be alert to the possible decision-making space between (1) referral

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<sup>10</sup> Ibid., 44.

<sup>11</sup> Avitzor et al. (n2).

<sup>12</sup> Sox et al. (n1), 29.

<sup>13</sup> GMC, *Decision making and consent: Supporting patient choices about health and care, Draft guidance for consultation* (GMC 2018), para 32.

<sup>14</sup> Ibid., para 27; The Health Foundation, *Helping People Share Decision Making: A Review of Evidence Considering Whether Shared Decision Making is Worthwhile* (The Health Foundation 2012).

<sup>15</sup> Serra (n4), 45-46.



and consultation at the fetal medicine centre and (2) thereafter until any procedure occurs. How parents use these spaces is likely to be important.

### 7.3 Regulatory models, legitimacy and effectiveness

In this section, we examine basic regulatory models, policy instruments and the essential features of regulatory legitimacy, efficiency and effectiveness.

#### Regulatory models/ instruments

There are two basic regulatory models and the chosen form can impact on the efficiency and effectiveness of any regulatory intervention.<sup>16</sup> *Top down* regulatory models tend to use hard law instruments to direct behaviours and make the explicit distinction between regulator and regulatee.<sup>17</sup> The AA 1967 is a relevant example because this legal framework clearly mandates how doctors behave in a specific context. *Bottom up* regulatory models generally have less hard law and either blur the distinction between regulator/regulatee or involve some element of self-regulation by the regulatee.<sup>18</sup> Professional body codes for example, illustrate an element of self regulation by the professional membership. In either case, there is evidence that reciprocal and co-operative enterprises between the regulator and regulatee tend to work best in practice.<sup>19</sup>

Policy makers and regulators can use a range of policy instruments to influence/ restrict regulatee behaviours and to achieve intended goals. For discussion purposes, we shall divide these into authority, organisational, informational and incentive based instruments. Authority instruments may take the form of hard law or other enforceable rules demanding action from the regulatees framed in negative (do not do X) or positive (do Y) terms. Legal constraints or requirements can be combined with sanctions for breach, although policy makers/ regulators need to have regard to proportionality and to the effectiveness of any behaviour modification/ outcome.<sup>20</sup> It should also be recognised that sanctions have a *ex post* effect – they “discourage but do not prevent”.<sup>21</sup> Further, any regulatory constraint or requirement ought to make enough of

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<sup>16</sup> Roger Brownsword and Morag Goodwin, *Law and the Technologies of the 21<sup>st</sup> Century: Text and Materials* (Cambridge University Press 2012) 27.

<sup>17</sup> *Ibid.*

<sup>18</sup> *Ibid.*

<sup>19</sup> *Ibid.*

<sup>20</sup> I. Glenn Cohen, *Patients with Passports: Medical Tourism, Law, and Ethics* (OUP 2015).

<sup>21</sup> Karen Yeung and Mary Dixon-Woods, 'Design-Based Regulation and Patient Safety: A Regulatory Studies Perspective', (2010) 71 *Social Science & Medicine* 502-509.

a difference to the given concern to warrant the specific interference with the regulatee's liberty (ie proportional interference).<sup>22</sup>

Organisational policies can influence how regulatee services are delivered and determine who bears the ultimate responsibility for outcomes. For example, the medical monopoly of pregnancy termination plays an important role in controlling how associated services are organised and delivered across the UK. The arrangements for public funding can impact on how 'authority' based instruments (ie the AA 1967) operate in practice. Organisational policies can also influence the relationship between regulator, regulatee and key stakeholders, and this might include deciding what space should be left for self governance.

Informational policy instruments are usually directed to educating and providing key information to stakeholders. These instruments can place the disclosure burden on the regulator, or regulatee, or use a combined approach to shape behaviours and outcomes. The direct involvement of the regulator as an educator is far from uncontroversial although not altogether uncommon. Informational instruments have proved important in the abortion debates and patient access to termination services North and South of the Irish border. Greasley suggests that informational policies can be used to great effect when combined with negative or prohibitory authority instruments.<sup>23</sup> For example, combining legal restriction of late terminations of pregnancy, with informational programmes designed to encourage early termination, with a view to minimising the impact of the authority constraint.

Finally, incentive policy instruments can influence stakeholder decision-making, by using persuasive offers to divert or influence choices, or default rules that require active decision-making to avoid an otherwise determined outcome. In the abortion context, there has been some debate about the default use of medical methods for publicly funded terminations in the early stages of pregnancy.<sup>24</sup> Again, funding and structural issues (eg availability and location of service providers) can all influence particular reproductive choices in any given context.

The nature of the relationship between regulator/ regulatee and influencer/ influencee is also important. There is a difference between the anonymous regulation of the '*statistical citizen*' by a State regulator and instruments/ behaviours used by healthcare professionals to influence known and identifiable patients, not least because of the

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<sup>22</sup> Kate Greasley, *Arguments about Abortion: Personhood, Morality and Law* (Oxford University Press 2017), 220.

<sup>23</sup> *Ibid.*, 212.

<sup>24</sup> Jane Fisher and others, 'Termination for fetal anomaly: Are women in England given a choice of method?' (2015) 35(2) *Journals of Obs & Gynae* 168.

immediacy and directness of the latter relationship.<sup>25</sup> There may be differing obligations between the parties and trust is usually a more immediate consideration in a direct clinical relationship. The nature of the relationship may also affect the objectivity, or at least the external perception of the decision-making. These considerations might apply to different types of professional regulator/ regulatee, and regulators have increasingly recognised the importance of evaluating 'distance' and demarking roles in the regulated relationship.<sup>26</sup> These factors should be borne in mind when using policy instruments to direct or influence regulatee behaviour. In our context, the nature of the relationship between the healthcare team and the parents may be influenced by the timing of the referral to the tertiary unit. Complex multiple pregnancies tend to be referred in the early stages, creating a greater opportunity to build a meaningful and trusting relationship with the clinical team. Urgent or late referrals may have reduced opportunities, and a range of situational factors including the location of the medical unit and local referral practices will also feed into the relational equation.

## **Legitimacy**

The broader concern of legitimacy necessitates examination of the normative considerations and the political, societal and economic constraints of particular forms of regulatory intervention.<sup>27</sup> In earlier chapters, we identified several reasons why it might be legitimate for a State or a State sponsored regulator to interfere with the creation, selection, continuance or ending of human life, albeit in limited circumstances.<sup>28</sup> Specifically, there might be clearly defined benefits for the human race, or specific communities, in restricting the commercial exploitation or genetic modification of human life. State regulation also has an important role in facilitating public knowledge and providing a transparent forum for public accountability.<sup>29</sup>

Whilst, we broadly adopt a Millian position,<sup>30</sup> it is our contention that legitimate State interference with the freedom of others, whether directly or through delegated agents, requires adherence to the following basic conditions:

1. Policy makers/ regulators need to be transparent and clear about the goals and outcomes that they are intending to achieve through interference in the

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<sup>25</sup> Avitzour et al. (n2)

<sup>26</sup> Professional Standards Authority (PSA), *Rethinking regulation* (PSA 2015); PSA, *The regulator's role in professional identity: validator not creator* (PSA 2018), chp3.

<sup>27</sup> Yeung & Dixon-Woods (n21).

<sup>28</sup> In the context of reproduction and reproductive technologies, see Erin Nelson, *Law, Policy & Reproductive Autonomy* (Hart 2013), 268.

<sup>29</sup> Ibid.

<sup>30</sup> As per Elizabeth Wicks, *The State and the Body: Legal Regulation of Bodily Autonomy* (Hart 2016).

freedom of others (for eg, in the freedom of women to make unrestricted choices about their pregnancy).<sup>31</sup> This requires identification of the intended beneficiaries and the specific mischief/ harm the interference is designed to prevent/ limit, or the positive behaviours that it is seeking to promote.

2. Any interference should be proportionate and only involve absolutely necessary restrictions upon individual freedom (ie minimal regulation).<sup>32</sup> However, there also needs to be recognition that even small or apparently straightforward interventions can be difficult to implement if they disrupt *“established routines and understandings of professional role.”*<sup>33</sup>
3. Wherever possible, any intervention and the narrative message conveyed by that intervention should be consistent and coherent with associated regulatory frameworks.<sup>34</sup>
4. There should be clarity about the target(s) of regulation<sup>35</sup> - for example, in the context of abortion whether legal prohibitions/ sanctions are intended to limit the professional power of healthcare professionals, protect the unborn entity, protect pregnant women or to have a wider remit.
5. Wherever possible, any intervention should endeavour to address foreseen problems and avoid unplanned consequences or regulatory gaps.<sup>36</sup> Of course, there might be good reasons to create deliberate gaps or differences when *“translating moral conclusions in to legal norms”*.<sup>37</sup> In the health context, we also want to keep sufficient space for professional judgement and to avoid unnecessary barriers for innovation.<sup>38</sup>
6. There should be some mechanism for public accountability, especially for the regulator.<sup>39</sup>
7. Regulators should be careful to maintain their objectivity and independence from the regulatee. This in turn raises questions about the legitimacy of self regulatory models and we agree that, as a general rule, regulators ought to avoid *“becoming too intimately involved in putting improvement into effect”*,<sup>40</sup> or undertaking roles that should be primarily the function of the regulatee. In the healthcare context, this condition would make service providers

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<sup>31</sup> Yeung & Dixon-Woods (n21)

<sup>32</sup> Professional Standards Authority, *Right-touch Regulation in Practice: International Perspectives* (PSA 2018), 3.

<sup>33</sup> The Health Foundation, *Safer Clinical Systems: Evaluation Findings* (The Health Foundation 2014), 18.

<sup>34</sup> Yeung & Dixon-Woods (n21); PSA International Perspectives (n32); Jeff Wale, 'Don't forget the legal framework: the public provision of non-invasive prenatal testing in England and Wales' (2015) 15 *Medical Law International* 203.

<sup>35</sup> PSA Rethinking Regulation (n26); PSA, International Perspectives (n32).

<sup>36</sup> PSA International Perspectives (n32), 3-5.

<sup>37</sup> Greasley (n22), 212.

<sup>38</sup> PSA Rethinking Regulation (n26), 9.

<sup>39</sup> PSA International Perspectives (n32).

<sup>40</sup> PSA Rethinking Regulation (n26).

responsible for the actual delivery and improvement of patient safety, and regulators responsible for the identification/ enforcement of any breach in standards.

We have left open the legitimacy of non-State sponsored regulatory interventions although our core conditions would still apply. An issue for all regulators is whether they are acting out of self interest, and whether they are in a position to objectively assess the impact and legitimacy of their interference with others. In our research context, we have a mixed model approach with top down and bottom up regulation in play. The top down regulation by the AA 1967 arguably falls foul of our basic conditions, most notably around the clarity of the regulatory targets and goals. As we have observed, there is arguably a disconnect between the legal and professional norms, especially in relation to fetal reductions.

### **Efficient and effective models of regulation**

In this section, we are concerned with the most efficient and effective forms of regulation for achieving a desired aim or objective.<sup>41</sup> We should not automatically equate increased regulation with better regulation or stakeholder outcomes, because sometimes it can be more effective to deregulate (ie reduce control/ interference) and concentrate regulatory efforts on specific targets and outcomes.<sup>42</sup> It is also necessary to balance out the effort and cost necessary to achieve a desired outcome (efficiency). Efficient and effective forms of regulation should strive for longevity – having the fluidity and capacity to facilitate early responses to technological change and shifts in public opinion may prove advantageous in the longer term. For example, the Professional Standards Authority emphasises the importance of ‘agility’ in their policy concept of ‘*Right Touch Regulation*’ in the healthcare context.<sup>43</sup> Fixed or static regulatory approaches generally require regular oversight by the Legislature or Executive to keep them up to date and this tends to create delay and inertia.<sup>44</sup>

Standard setting may also influence the longevity and responsiveness of any given model, and frameworks operating with precise standards may avoid arbitrariness but lack adaptability in changing circumstances. Vague or broadly defined (loose) standards can give greater flexibility and adaptability and may delegate power in ways that afford wider discretion to the regulator or regulatee.<sup>45</sup> The uncertainty of loose

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<sup>41</sup> Yeung & Dixon-Woods (n21).

<sup>42</sup> PSA Rethinking Regulation (n26).

<sup>43</sup> PSA International Perspectives (n32), 3.

<sup>44</sup> For discussion of regulatory compromise, see Roger Brownsword and Jeffrey Wale, ‘Compromise Medicalisation’, in C. Stanton and others (eds), *Pioneering Health Care Law Essays: In honour of the work of Professor Margaret Brazier* (Routledge 2015).

<sup>45</sup> Timothy Endicott, ‘The Value of Vagueness’, in Andrei Marmor and Scott Soame (eds) *Philosophical Foundations of Language in the LAW* (OUP 2014), 26.

standards may also encourage restrictive behaviour by a regulatee fearing the consequences of breach.<sup>46</sup> However, there are also disadvantages to loose regulatory structures because the residual space tends to become filled by personal/professional discretion and undesirable human practices. We have already observed how the broad or vague framing of standards in our legislative framework (eg AA 1967, s1(1)) has created interpretive difficulties for clinicians and legal actors.

Effective regulatory frameworks usually engage stakeholders on a regular and instrumental basis. Regular public engagement can be important in establishing or maintaining trust in a regulatory framework or body but does not guarantee acceptance. The Professional Standards Authority commissioned research highlighting the importance of regulatory alignment when regulatory standards fell in line, out of line or short of professional attitudes.<sup>47</sup> Interestingly, the evidence suggested that when regulatory standards were in line with professional attitudes, the standards were seen as valid and valuable but not influencing of practice. When the regulatory standards fell short (but not incompatibly so), they were neither perceived as valid or influencing.<sup>48</sup> However, when the regulatory standards were out of line with professional attitudes, they were dismissed and unlikely to change practices unless actively enforced.<sup>49</sup> This suggests that regulators/ policy makers need to think carefully about regulatory alignment before they introduce changes, and reinforces the need for active consultation with stakeholders to assess the extent and risk of divergence. In relation to fetal reductions, we might be concerned by evidence of significant divergence between legal regulation and professional practice (see chapter 9). We ought to know why that divergence is occurring but if significant attitudinal and practice changes are required, active engagement, inspection and enforcement measures are probably warranted until these changes have bedded in. Of course, excessive divergence may also weaken the power and influence of the regulator, and there is recognition that local, collaborative and regulatee solutions may be more effective over the longer term.<sup>50</sup>

Policy makers also need to have an eye on the wider cultural, political and economic environments that may constrain or influence regulation,<sup>51</sup> and strike an appropriate balance between individual values, professional discretion and strict (legal) rules.<sup>52</sup> Striking a balance in an area of ethical and legal compromise is necessarily

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<sup>46</sup> *Ibid.*, 27.

<sup>47</sup> PSA, Professional Identity (n26), 3.10.

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

<sup>49</sup> *Ibid.*, chp 3.

<sup>50</sup> PSA Rethinking Regulation (n26), 18-19.

<sup>51</sup> Keith Hawkins, *Law as a Last Resort: Prosecution Decision-Making in a Regulatory Agency* (Oxford University Press 2002), 154; Roger Cotterrell, 'Theory and Values in Socio-legal Studies', (2017) 44(1) *Brit J Law & Soc* S19-36.

<sup>52</sup> Oliver Quick, *Regulating Patient Safety. The End of Professional Dominance?* (2017 Cambridge University Press), 56.

problematic. Although there is danger in drawing too many comparisons across regulatory environments, Professor Macrory's work on the regulation of business offers some helpful pointers.<sup>53</sup> He agrees with Quick that we should be looking to regulatory offences and mechanisms that focus on behaviour/ compliance modification.<sup>54</sup> Whilst Macrory acknowledges the importance of sanctions for regulators - including as an inducement to compliance - he argues that "*advice and incentives should play a key role in ensuring regulatory compliance*"<sup>55</sup> Here the advice and incentives would be primarily directed at regulatees rather than stakeholders generally.

Finally, effective professional regulation usually requires adequate funding, and this may require the State to play some role in the process,<sup>56</sup> although self funding by professional levies, registration charges or enforcement penalties is possible for larger professional memberships.

#### 7.4 UK healthcare regulation – the story so far

It is evident that professional and legal regulation has failed to deliver satisfactory patient safety in domestic healthcare to date,<sup>57</sup> but it is unrealistic to perpetuate the idea that we can eradicate the risk of patient harm altogether.<sup>58</sup> The Health Foundation has identified a range of organisational matters acting as barriers to improved patient safety predominantly in the NHS, including inconsistent staffing, problems with support systems/ structures, workload pressures, multiple competing priorities, cultures and lack of process design and standardisation.<sup>59</sup> These organisational factors also create a gap or dislocation between regulatory expectations and actual outcomes at ground level. Accordingly, some have suggested that healthcare regulators should "*focus on governing rather than erasing the gap between regulation and performance.*"<sup>60</sup> There is no doubt that the complex interaction between multiple regulators have contributed to a confusing and an unnecessarily bureaucratic regulatory model in the UK.<sup>61</sup>

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<sup>53</sup> Richard Macrory, *Regulatory Justice: Making Sanctions Effective* (November 2006).

<sup>54</sup> Quick (n52).

<sup>55</sup> Macrory (n53), para 1.11.

<sup>56</sup> Nelson (n28).

<sup>57</sup> Robert Francis, *The Francis Report - Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (HC 947, 2013); Quick (n52), 21; PSA, *Rethinking Regulation* (n26), 21.

<sup>58</sup> PSA *Rethinking Regulation* (n26), 9

<sup>59</sup> The Health Foundation, *Safer Clinical Systems* (n33).

<sup>60</sup> R Huising and S Silbey, 'Governing the gap: forging safe science through relational regulation', (2011) 5 *Regulation & Governance* 14-15. See also Quick (n52), 55.

<sup>61</sup> PSA, *Right-touch Reform: A new framework for assurance of professions* (PSA 2017). See also Law Commission, *Regulation of Health Care Professionals, Regulation of Social Care Professionals in England* (Law Com No345 2014).

Francis suggests that we need to address the issue of patient safety at many different levels, including changes to the culture within hospitals and the NHS.<sup>62</sup> Regulation seems unlikely to deliver changes in clinical behaviour on its own and the most effective regulatory mechanisms require a multi-faceted and consistent approach.<sup>63</sup> It is clear that reliance on individual patient complaint systems has limits, has a largely ex post effect and does not address concerns at a system level.<sup>64</sup> The introduction of a statutory duty of candour and increased consistency across professional regulators represents just one possible legal response to these concerns. Quick argues this type of legal regulation can be helpful in directing change, shifting the balance of power and establishing the trust necessary for proper patient centred care.<sup>65</sup> The court system and the threat of litigation also “*focuses institutional action to take patient safety seriously*”,<sup>66</sup> but we should not:

*“overstate the capacity of law for improving patient safety. Reformed medical education, training, greater resources and the creation of a shared culture of safety are much more integral.”<sup>67</sup>*

Although, legal actors have continued to be deferential to the medical profession and professional sources,<sup>68</sup> there is no guarantee that non-deferential legal intervention will enhance patient autonomy or improve decision-making because the law is an inherently blunt tool for shaping behaviour in a complex bureaucratic system. We also need to be cautious about making doctors or others mere technicians or removing professional judgement from the medical process altogether.<sup>69</sup> Indeed, the Professional Standards Authority acknowledges that “*generally patient care benefits from a strong professional identity*”,<sup>70</sup> and identity is linked to the exercise of discretion.

Due to a combination of scandal, increased external scrutiny and State intervention, we now have a more independent and robust regulatory healthcare environment than we had in the past.<sup>71</sup> Quick argues that we should now move from the idea of regulating professions towards the more challenging task of regulating for patient safety and trust,<sup>72</sup> and emphasises the importance of active patient engagement:<sup>73</sup>

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<sup>62</sup> Francis (n57).

<sup>63</sup> Quick (n52); Oliver Quick, *A scoping study on the effects of health professional regulation on those regulated* (2011) (Final report submitted to the Council for Healthcare Regulatory Excellence).

<sup>64</sup> Francis (n57), 1011-1016. See also Craig Kuziemsky, ‘Decision-making in healthcare as a complex adaptive system’, (2016) 29(1) *Healthcare Management Forum* 4.

<sup>65</sup> Quick (n52), 182-183. See also Oliver Quick, ‘Regulating and legislating safety: the case for candour’ (2014) 23 *BMJ Qual Saf* 614.

<sup>66</sup> Quick Scoping Study (n63), 17.

<sup>67</sup> Quick (n52), 182.

<sup>68</sup> For a contemporary example of professional guidance shaping legal duty, see *ABC v St George's Healthcare NHS Trust & Ors* [2017] *EWCA Civ* 336

<sup>69</sup> PSA Rethinking Regulation (n26), 9.

<sup>70</sup> PSA Professional identity (n26), chp 8.2.

<sup>71</sup> Quick (n52), 67.

<sup>72</sup> *Ibid.*, 50.

<sup>73</sup> *Ibid.*, 51. Participant E agrees.



*“Shifting the focus to regulating patient safety, as opposed to the traditional focus on regulating the medical profession, is important. Regulating patient safety means that it is both necessary and legitimate to involve patients, and this requires regulation to be seen as a collaborative enterprise between patients and professionals”.*<sup>74</sup>

Earlier, we touched upon the use of regulatory offences against healthcare providers rather than individual professionals,<sup>75</sup> and in this chapter, we have highlighted how important organisational factors can be in the delivery of regulatory aims. This focus on organisations and systems can also be defended by the ‘*fallible agent critique*’ which recognises that individual professionals are fallible, and human errors are better explained by or attributed to systemic/ environmental factors than individual human agency.<sup>76</sup> Of course, there is scope to use technology to directly regulate human behaviour or actions and reduce the fallibility of human operations.<sup>77</sup> Clearly, any effective regulatory healthcare environment also needs to have an eye on the wider management, resource and delivery systems and relational dependencies operating within the NHS.<sup>78</sup>

## 7.5 Influencing patient decision-making

We have already touched on the use of incentives designed to alter or influence behaviours, choices and outcomes. We can further categorise these forms of regulatory intervention as nudges, boosts and other incentive schemes intended to benefit the primary decision-maker. Nudges “*seek to affect decision-making by semi-conscious or unconscious “altering defaults” in the framing of choices*”,<sup>79</sup> and correct any detrimental behaviours impacting on the decision-maker or others.<sup>80</sup> In some cases, the nudge may be intended to alter an agent’s actual preference albeit for beneficent reasons.<sup>81</sup>

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<sup>74</sup> Ibid., 52.

<sup>75</sup> Ibid., 181.

<sup>76</sup> Yeung & Dixon Woods (n21).

<sup>77</sup> Roger Brownsword, ‘Regulating Patient Safety: Is it Time for a Technological Response?’ (2014) 6 *Law, Innovation and Technology* 1; Yeung & Dixon-Woods (n21).

<sup>78</sup> Kuziemy (n64) 4; Huising & Silbey (n60).

<sup>79</sup> Richard Ashcroft, ‘Incentives, Nudges and the Burden of Proof in Ethical Argument’, (2017) 43(3) *Journal of Medical Ethics* 137. See also Cass R. Sunstein, *Choosing Not to Choose: Understanding the Value of Choice* (OUP 2015); I G. Cohen et al. (n2).

<sup>80</sup> Ralph Hertwig, *Beyond nudging: how to boost medical decision making*, 16<sup>th</sup> Biennial European Conference of the Society for Medical Decision Making, 13 December 2016.

<sup>81</sup> Ashcroft (n79).

We have previously encountered nudges in the context of ‘framing’ - when narrative emphasis is placed on specific risks, harms or benefits for a particular end.<sup>82</sup> In the obstetric context, a nudge might be used to encourage pregnant women to undergo natural childbirth by setting this as the default option at antenatal appointments. Nudges might also entail collective efforts by regulators, employers and managers that all push employees in a unified direction, or at least to prioritise attention to a specific issue or goal.<sup>83</sup>

Conversely boosts are designed to “*extend people's decision-making competence rather than co-opting their deficits*”.<sup>84</sup> Boosts “*can target the individual's skills and knowledge, the available set of decision tools, or the environment in which decisions are made*”.<sup>85</sup> In the obstetric context, this might involve the use of informational or decision aids; direction to specialist support organisations or the operation of parent forums for complex pregnancies. Boosts might also involve tailored (rather than default) consent processes or medical consultations in informal (non-clinical) or informational environments. The use of online support groups<sup>86</sup> and informal consulting areas are well established in many fetal medicine and fertility units. These mechanisms may be valuable in addressing the decision-making space after referral and between consultations.

Other incentive schemes might offer rewards or other benefits to encourage the primary decision-maker to choose a specific option. For example, the offer of free transport to clinics or preferential booking arrangements on specific days of the week. The difference between incentives and nudges is not clear,<sup>87</sup> but some commentators distinguish the use of default rules and incentives – with the latter explicitly and openly targeting the decision-maker.<sup>88</sup>

The concept of ‘boosts’ has become increasingly popular due to the emphasis on enhancing existing competence, and because nudges have attracted negative criticism<sup>89</sup> due to their tendency to treat individuals as “*mindless, passive decision makers*”.<sup>90</sup> Even supporters of nudging, accept that limits need to be placed on the use

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<sup>82</sup>Till Grüne-Yanoff and Ralph Hertwig, ‘Nudge Versus Boost: How Coherent are Policy and Theory?’, (2016) 26 *Minds & Machines* 149, 155/ 173.

<sup>83</sup> Quick Scoping Study (n63), 20-21.

<sup>84</sup> Ashcroft (n79).

<sup>85</sup> Grüne-Yanoff and Hertwig (n82), 152.

<sup>86</sup> J W M. Aarts and others, ‘Patient-focused internet interventions in reproductive medicine: a scoping review’, (2012) 18(2) *Hum Reprod Update* 211.

<sup>87</sup> Ashcroft (n79).

<sup>88</sup> Sunstein (n79).

<sup>89</sup> For a comparative analysis, see Grüne-Yanoff and Hertwig (n82).

<sup>90</sup> *Ibid.*

of personalised default rules<sup>91</sup> because of the potential for abuse.<sup>92</sup> For example, Sunstein accepts that default rules may not be appropriate in circumstances when people would prefer to actively choose, when learning is important or where the decision-making population is not heterogenous.<sup>93</sup> Decisions relating to fetal reduction and pregnancy termination appear to be the kind of decision that Sunstein would exclude from nudging, although he suggests that familiar and non-technical decisions are more appropriate for active choosing.<sup>94</sup>

There is also a difference between generalised policy nudges by the State and specific nudging activity in the clinical relationship because:

*“the doctor-patient relationship involves a different type of trust from the state-citizen relationship; a doctor’s moral duties towards the patient are different from the state’s duties towards the citizen: a doctor would nudge an actual patient personally, while the state would nudge a ‘statistical citizen’ anonymously”*.<sup>95</sup>

This is an important consideration which counts against the use of nudges in the clinical encounter. For these reasons, non-directive information disclosure and counselling are an important part of patient care, and professionals should avoid the use of default positions when options exist. Providing patients with up to date and balanced informational sources and tools to support decisions is likely to counter any default professional practices and may enhance active patient engagement in many cases.<sup>96</sup>

## 7.6 Priorities: patient centred care and shared decision-making

The NHS long term plan<sup>97</sup> aims to address many of the organisational barriers to patient safety identified previously,<sup>98</sup> including:

- Recruitment drives, resources and support to address inconsistent staffing and workload pressures.<sup>99</sup>

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<sup>91</sup> Sunstein (n79) distinguishes between personalised and non-personalised default rules.

<sup>92</sup> See Avitzour et al. (n2).

<sup>93</sup> Sunstein (n79), 18-19.

<sup>94</sup> Ibid.

<sup>95</sup> Avitzour et al. (n2)

<sup>96</sup> The Health Care Foundation (n14), para 3.1. See also J. S. Blumenthal-Barby, 'That's the doctor's job': Overcoming patient reluctance to be involved in medical decision making', (2017) 100 *Patient Education and Counseling* 14.

<sup>97</sup> *NHS Long Term Plan* (NHS 2019).

<sup>98</sup> As per The Health Foundation (n33).

<sup>99</sup> NHS (n97), chp 4.

- The introduction of “digitally enabled care’ which includes online appointment access and information portals, interoperable networks and telephone/ video patient consultations.<sup>100</sup>
- The introduction of a new service model (addressing primary and community healthcare) with a view to rationalising and streamlining the delivery of local care.<sup>101</sup>
- Improving public accountability and engagement through the creation of an NHS Assembly which draws upon a wide range of stakeholders.<sup>102</sup>
- An emphasis on the ‘collective endeavour’ in the delivery of healthcare (ie co-ordinated systems and services).<sup>103</sup>

Patient centred care, shared responsibility for health and shared decision-making are at the heart of contemporary regulatory thinking<sup>104</sup> and the NHS long term plan.<sup>105</sup> We have considered the differences between patient centred care and care driven exclusively by patient autonomy – the latter leaving little space for professional discretion or personal values. We also have spoken of shared decision-making as a collaboration between the patient and healthcare professional. The Health Foundation, whilst acknowledging the absence of any fixed single meaning, identifies the defining characteristics of shared decision-making as:

*“fostering a real partnership, whereby the health professional is seen as an expert on the effectiveness and potential benefits and harms of treatment options and the patient is viewed as an expert on themselves, their circumstances, attitudes to illness and risk, values, preferences and the extent to which treatment options might fit within their lifestyle. Both parties need to be willing and able to share information and accept responsibility for joint decision making.”<sup>106</sup>*

This fits closely with the interpretation of *Montgomery v Lanarkshire Health Board* by Dunn et al.<sup>107</sup> and the concept of the active engaged patient. We should also appreciate that shared decision-making is a component of several initiatives for the delivery of patient centred care.<sup>108</sup>

So what strategies are the most appropriate for supporting and delivered shared decision-making? The Professional Standards Authority (PSA) speaks of empowering

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<sup>100</sup> Ibid., chp 5.

<sup>101</sup> Ibid., chp 1.

<sup>102</sup> Ibid., chp 7.7.

<sup>103</sup> Ibid., chp 7.13

<sup>104</sup> GMC (n13).

<sup>105</sup> NHS (n97), para 1.37-1.38.

<sup>106</sup> The Health Foundation (n14), 2.

<sup>107</sup> Michael Dunn and others, ‘Between the Reasonable and the Particular: Deflating Autonomy in the Legal Regulation of Informed Consent to Medical Treatment’, (2019) 27(2) *Health Care Anal.* 110.

<sup>108</sup> The Health Foundation (n14), 2.

patients to ask questions and challenge proposed treatment or service delivery<sup>109</sup>, and the NHS of empowering patients in their wider role as a key stakeholder.<sup>110</sup> This entails giving patients a greater voice in their own medical care and in wider structural/ institutional decisions (eg NHS Assembly). The PSA recognises that making patients “*distrustful*” of clinical interactions or decisions may not be a helpful narrative, and have recommended additional research on empowerment issues.<sup>111</sup> Although Quick says we cannot mandate patient involvement in healthcare safety, the Health Foundation have suggested a range of patient centric strategies aimed at supporting shared decision-making including the use of multi media information sources (including personalised information prescriptions);<sup>112</sup> patient held/ online records;<sup>113</sup> decision aids and communication tools;<sup>114</sup> agreed action plans;<sup>115</sup> group patient sessions;<sup>116</sup> and individual education/ coaching.<sup>117</sup> Blumenthal-Barby makes similar recommendations to help engage patients and agrees that they should be encouraged to ‘*express their values and ask questions*’.<sup>118</sup> Many of these strategies are already employed by our participants (chapter 9).

In terms of professional centric strategies for supporting shared decision-making, the evidence suggests that specific training on the use of decision and communication tools might be helpful.<sup>119</sup> Training is important if professionals do not have the relevant skills for developing shared decision-making without support.<sup>120</sup> The Health Foundation did not find any empirical evidence regarding system strategies, but they recognised the importance of organisational structure and culture in persuading patients and professionals that there was value in change.<sup>121</sup> They found no clear evidence whether active or passive strategies were more effective but the “*evidence suggests that proactive strategies may be necessary to sustain change*”.<sup>122</sup> So there is evidence that organisational, informational and incentive based policy instruments can be helpful in modifying patient/professional behaviours, attitudes and changing priorities at a local level. However, the Health Foundation also highlighted the importance of concordance – it is not enough that professionals engage in shared decision-making – patients have got to want and be able to use any opportunities for active engagement.<sup>123</sup> For the

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<sup>109</sup> PSA Right-touch (n61), 2.69-2.70.

<sup>110</sup> NHS (n97).

<sup>111</sup> PSA Right touch (n61), 2.70.

<sup>112</sup> The Health Foundation (n14), 14-15.

<sup>113</sup> *Ibid.*, 15.

<sup>114</sup> *Ibid.*, 15-19.

<sup>115</sup> *Ibid.*, 18-19.

<sup>116</sup> *Ibid.*, 20.

<sup>117</sup> *Ibid.*, 19.

<sup>118</sup> Blumenthal-Barby (n96)

<sup>119</sup> The Health Foundation (n14), 20-22.

<sup>120</sup> *Ibid.*, 8.

<sup>121</sup> *Ibid.*, V / 22. See also Blumenthal-Barby (n96).

<sup>122</sup> *Ibid.*, 22.

<sup>123</sup> *Ibid.*, 28-29.

reasons already discussed, some patients may be reluctant or unwilling to take on this responsibility in the medical context.<sup>124</sup> There is also the need to address the inherent tension between the delivery of evidence based medicine and patient driven treatment.<sup>125</sup> This is likely to be influenced by situational factors and certain types of medical care and treatment may be more amenable to shared decision-making approaches.

We have already expressed concern about the removal of professional discretion from the clinical encounter. We agree with Yeung and Dixon-Woods that there is a:

*“need to focus on how professional discretion can be optimally deployed, rather than seeking solutions solely in target-hardening and environment-altering approaches”*<sup>126</sup>

There are several strategies that might be helpful in strengthening the role of the professional. First, there is a need to reframe institutional and individual obligations of candour, emphasising the positive rather than negative outcomes of disclosure.<sup>127</sup> It does seem prudent to persuade professionals of the benefit of disclosure, and not just the adverse consequences of failure.

Secondly, the PSA have suggested the use of formative spaces for professionals to discuss adverse events and/or difficult cases.<sup>128</sup> This is not a new concept in clinical medicine, but greater recognition and use of team decision-making and reflective spaces might be helpful, especially when combined with greater organisational legal responsibility.<sup>129</sup> These spaces should not be used just for problem areas but also to address changes in system or practice.

Thirdly, there is a reflective value to decisional regret - when a patient wishes, with the benefit of hindsight, that they had made a different decision about a treatment.<sup>130</sup>

Professionals should not see this type of regret as a threat – it can help individual/team learning and future patient encounters – and creating space/ mechanisms for reflecting on such outcomes may be helpful to professional learning.<sup>131</sup> Decisional

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<sup>124</sup> Samantha Peters and Douglas Bilton, D., "Right-touch" trust: thoughts on trust in healthcare' in R H. Searle, A-M I. Nienaber, S. B. Sitkin, (eds) *The Routledge Companion to Trust* (Routledge 2017); Sarah Devaney, 'The Transmutation of Deference in Medicine: An Ethico-Legal Perspective', (2018) 26(2) *Med L. Rev* 202; Blumenthal-Barby (n96)

<sup>125</sup> The Health Foundation (n14), 29.

<sup>126</sup> Yeung & Dixon-Woods (n21).

<sup>127</sup> PSA, *Response to the NHS Improvement's consultation on developing a patient safety strategy for the NHS* (PSA 2019), para 5.3.

<sup>128</sup> PSA Right touch (n61). See also Gerry McGivern and Michael D. Fischer, 'Reactivity and reactions to regulatory transparency in medicine, psychotherapy and counselling', (2012) 74(3) *Social Science and Medicine* 289.

<sup>129</sup> Royal College of Physicians, *Doctors in Society – Medical professionalism in a changing world – Report of a working party* (RCP 2015)

<sup>130</sup> K. Watson, 'Reframing Regret', (2014) 311 *JAMA* 27.

<sup>131</sup> Sam Rowlands and Jeffrey Wale, 'Sterilisations at delivery or after childbirth: Addressing continuing abuses in the consent process', (2019) *Global Public Health* < <https://doi.org/10.1080/17441692.2019.1583265> > accessed 28 February 2019.

regret can be a feature of fetal reduction – either because the parents later regret the decision to reduce or because of the subsequent loss of a pregnancy resulting from the termination procedure.

Fourthly, local workplace strategies to support shared decision-making may be more effective than top down regulatory strategies especially when there is effective consultation and engagement with staff.<sup>132</sup> There may also be scope to address the structural design and delivery of healthcare within tertiary fetal medicine units so as to enhance the quality and process of decision-making. As we shall see, there appears to be evidence of some regional variation in clinical practice.

Fifthly, when national implementation is required, there should be active dialogue/ adaptation that reflects upon and acknowledges the practical difficulty of implementation, in preference to authority solutions that fail to recognise these issues.<sup>133</sup> The positive local promotion of change is much more likely to be enacted than change from outside that is perceived in negative way.<sup>134</sup>

## 7.7 Conclusions

In closing, we make four general points, before considering what our findings might mean for the regulation of fetal reduction and selective termination.

First, it is evident that healthcare delivery in the UK is notoriously complex and bureaucratic, and the resulting regulatory frameworks are neither efficient or effective. Healthcare professionals have proved resistant or otherwise removed from regulatory efforts to change their behaviours and patient outcomes. Agile, flexible and co-operative models of regulation appear to offer the best hope for maximising patient safety. Recognition that human agents are fallible, and that health is a collective endeavour is important. On that basis, system-based and organisational accountability should be prioritised accordingly.

Secondly, shared decision-making is a key feature of patient centred care – a concept that retains a place for professional discretion providing it supports the effective delivery of patient safety and care. In this chapter, we have identified a range of

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<sup>132</sup> PSA Right touch (n61), 35.

<sup>133</sup> Described by Huising and Silbey as '*relational regulation*' (n60).

<sup>134</sup> PSA Right touch (n61), 30-31.

supportive organisational, informational and boosting strategies that should be prioritised wherever possible.

Thirdly, the preferred framing of healthcare change should emphasise the benefits for stakeholders and not just the penalties or consequences of any breach of standard. That is not to say that regulators should hide these consequences, but stakeholders need a good reason to change attitudes and behaviours - there will always be those individuals who choose to circumnavigate change for their own benefit or other unexplained reasons. Marginalising these counterproductive behaviours is key to achieving effective change.

Fourthly, there is the tricky dilemma of how best to facilitate and develop active patient engagement – a factor that we believe is central to the success of any form of collaborative decision-making process. Again, we have highlighted a series of tools and strategies that might be developed by healthcare professionals and providers to support engagement, although the most effective responses are likely to be situationally driven.

It is this situational concern that is especially pertinent to our research context. The most appropriate and effective strategies for supporting decision-making and patient care in tertiary fetal medicine are likely to be subtly different from other medical practice areas. This view recognises the importance of the specific clinical relationship and environments in which decisions are made. These reduction procedures are usually undertaken in specialist tertiary referral units, against a distinctive cocktail of ethical issues and a background of specific legal regulation.<sup>135</sup> These distinctive features should not be ignored when we regulate for decision-making process in this arena. Clearly, we have to consider the shadow of the Abortion Act 1967, and its regulatory impact on professional practice, when examining the wider regulation of healthcare services. It may be that we have to revise both the specific and the general regulatory structures to achieve the specific goals of regulation in this context. Our overarching conclusion about situationality also aligns with the specialist delivery of healthcare which recognises that the technical/ care needs of patients and their families are likely to differ markedly based on medical context. It is against this background, that we move to examine the stakeholder perspectives of these procedures.

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<sup>135</sup> Eg the Abortion Act 1967 (as amended).



# Chapter 8 – Existing Research: Stakeholder Perspectives

Contents:

- 8.1 Introduction
- 8.2 Clinical research
- 8.3 Qualitative research
- 8.4 Quantitative research
- 8.5 Other research
- 8.6 Conclusions

## 8.1 Introduction

In this chapter, we examine existing research and project data addressing a range of stakeholder perspectives focusing on fetal reduction, elective termination and abortion generally. We have used a wide range of clinical, scientific, sociological, psychological and professional studies to inform our research; to provide an appropriate foundation for reviewing our qualitative data and to enrich the discussion of the subject matter in subsequent chapters.

## 8.2 Clinical research

In Table 2A (Appendix E) we have produced a summary of relevant clinical case studies and literature reviews addressing fetal reduction and selective termination in multiple pregnancy. This review helped inform the interview process and enabled us to gain a better understanding of the wider clinical context.<sup>1</sup> All sources were identified using repeat searches across several databases including PubMed, Web of Science, Science Direct, Scopus and Google Scholar. This database exercise was supplemented by focussed keyword searches against obstetric and human

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<sup>1</sup> For methodological underpinning, see M Vaismoradi, H Turunen and T Bondas, 'Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study', (2013) 15(3) *Nurs Health Sci* 398, 401.

reproduction journals and using relevant information from specialist medical conferences.<sup>2</sup>

The clinical research demonstrates a degree of consensus on the need for these procedures with specific emphasis on improving perinatal outcomes. Very little attention is paid to the wider regulatory context or to the ethical issues. The contemporary research appears preoccupied with the case for reducing twin and triplet pregnancies; and specifically, the benefits and risks associated with singleton preservation where a clear international consensus has yet to emerge.<sup>3</sup> Timing appears to be critical and the research indicates that there is a key period in multiple pregnancies between 11/12 - 16 weeks gestation.<sup>4</sup>

There is evidence that artificial reproductive techniques (ART) impact on the need for these procedures, with an elevated risk of multiple gestation<sup>5</sup> and monochorionic pairing<sup>6</sup>. ART is also closely associated with maternal age and the use of these procedures.<sup>7</sup> Monochorionic (MC) pregnancies generate complex clinical management issues, including specific complications like TTTS, TAPS and TRAPS. Whilst it is now possible to reduce a single fetus in a MC pair, the risk of fetal death for the co-twin remain high<sup>8</sup>. In certain triplet pregnancies (Dichorionic (DC) Triplets – with a MC twin pair), the central issue is whether to reduce the MC pair or just one fetus in that pair. If the former option is taken, care needs to be taken that the remaining fetus is capable of viable birth and is free from hidden anomaly that might otherwise impact on the decision-making process.

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<sup>2</sup> RCOG, *Management of Multiple Pregnancy conference 16 November 2015*; The Royal Society of Medicine and BPAS, *Decriminalisation and demedicalisation: Rethinking family planning for the 21<sup>st</sup> century conference 10 June 2015*.

<sup>3</sup> Cf J, Haas and others, 'Pregnancy outcome of early multifetal pregnancy reduction: triplets to twins versus triplets to singletons', (2014) 29 *Reproductive Biomedicine Online* 717; Yaniv Zipori and others, 'Multifetal reduction of triplets to twins compared with non-reduced twins: a meta-analysis', (2017) (35(1) *Reproductive Bio-Medicine Online* doi.org/10.1016/j.rbmo.2017.04.001; Yaqiong Liu and others, 'Clinical outcomes of multifetal pregnancy reduction in trichorionic and dichorionic triplet pregnancies: A retrospective observation study', (2019) 58 *Taiwanese Journal of Obstetrics & Gynecology* 133; R Katie Morris. and Mark D. Kilby, 'Fetal Reduction', (2010) 20(11) *Obs, Gynae & Reprod Med* 341.

<sup>4</sup> Yan Liu and others, 'Effect of selective second- trimester multifetal pregnancy reduction and its timing on pregnancy outcome' (2017) 10(3) *Int J Clin Exp Med* 5533-5537. See also Morris and Kilby (n3) who distinguish 'selective late feticide' following late diagnosis of anomaly which they claim should be offered in the early 3rd trimester to avoid the risks of miscarriage/ preterm labour etc (at 342).

<sup>5</sup> Robert L. Klitzman, 'Reducing the number of foetuses in a pregnancy: providers' and patients' views of challenges', (2016) 31(11) *Human Reproduction* 2570; Morris and Kilby (n3).

<sup>6</sup> Mariano Mascarenhas and others, 'Obstetric outcomes of monochorionic pregnancies conceived following assisted reproductive technology: A retrospective study' (2014) 7(2) *J Hum Reprod Sci* 119.

<sup>7</sup> Mohamed Satti and others, 'Selective Fetal Reduction Versus Expectant Management in Triplet Pregnancies After IVF-ET' (2016) *Obstetrics & Gynecology* 127: 64S.; DOH *Abortion Statistics, England and Wales* (2016), para 2.50.

<sup>8</sup> P Chaveeva and others, 'Intrafetal laser ablation for embryo reduction from dichorionic triplets to dichorionic twins', (2017) *Ultrasound in Obs and Gynae* < <https://doi.org/10.1002/uog.18834> >accessed 29 May 2018; Xinlu Meng and others, 'Forty-five consecutive cases of complicated monochorionic multiple pregnancy treated with microwave ablation: a single-center experience', (2019) *Prenatal Diagnosis* DOI.org/10.1002/pd.5423; Morris and Kilby (n3), 342.

### 8.3 Qualitative research

Table 3A (Appendix E) provides an overview of relevant qualitative studies and identifies the data collection and analytical methods used by the researchers.

Qualitative data addressing the perspectives of healthcare professionals is fairly limited and tends to focus on terminations on the ground of anomaly,<sup>9</sup> generalised attitudes to abortion,<sup>10</sup> and on practices outside of England and Wales.<sup>11</sup> In our analysis, we have made it clear when the research participants or procedures are outside of the UK.

#### Healthcare professional (HCPs) perspectives

A study by Statham, Solomou and Green<sup>12</sup> has certain similarities to this research although the interview data was collected within NHS fetal units and primarily concerns termination on the ground of fetal abnormality. The study is interesting because the researchers:

*“aimed to understand the decision-making experiences of fetal medicine professionals working within [a] legal framework”.*<sup>13</sup>

The participants acknowledged the difficulty of working within the law and their own ethical frameworks. The researchers found some concern/ perceived inconsistency around the differential time limits for lawful termination and this is vividly captured by one participant:

*“I think if you extend your argument, then you shouldn’t use fetal abnormality as an indicator for termination at all. And I agree that fetal abnormality is an indicator for termination. So therefore I must think that there is a difference between the two.”*<sup>14</sup>

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<sup>9</sup>Helen Statham, Wendy Solomou and Jasper B. Green, ‘Late termination of pregnancy: law, policy and decision making in four English fetal medicine units’, (2006) 113(12) *BJOG: An International Journal of Obstetrics and Gynaecology* 1402; Ruth H. Graham and others, ‘The role of feticide in the context of late termination of pregnancy: a qualitative study of health professionals’ and parents’ views’, (2009) 29 *Prenat Diagn* 875; Melody A. Menezes and others, ‘Taking Its Toll’: The Challenges of Working in Fetal Medicine. (2013) 40(1) *Birth: Issues in Perinatal Care* 52; Robyn Lotto, Lucy K. Smith and Natalie Armstrong, ‘Clinicians’ perspectives of parental decision-making following diagnosis of a severe congenital anomaly: a qualitative study’, (2017) 7 *BMJ Open* e014716; Lisa Crowe and others, ‘Negotiating acceptable termination of pregnancy for non-lethal fetal anomaly: a qualitative study of professional perspectives’, (2018) 8(3) *BMJ Open* e020815.

<sup>10</sup> Allyson Lipp, ‘A review of termination of pregnancy: prevalent health care professional attitudes and ways of influencing them’, (2007) 17(13) *Journal of Clinical Nursing* 1683; Katie Gallagher, Davinia Porock and Alison Edgley, ‘The concept of nursing in the abortion services’, (2010) 66 *Journal of Advanced Nursing* 849; Carrie Purcell and others, ‘The changing body work of abortion: A qualitative study of the experiences of health care professionals’, (2016) *Sociology of Health and Illness* ISSN 0141-9889:1; J Nicholson, P Slade and J Flethcher, ‘Termination of pregnancy services: Experiences of gynaecological nurses’, (2010) 66(10) *Journal of Advanced Nursing* 2245; Ellie Lee, Sally Sheldon Sheldon and Jan Macvarish, ‘The 1967 Abortion Act fifty years on: Abortion, medical authority and the law revisited.’ (2018) 212 *Social Science and Medicine* 26, <<https://doi.org/10.1016/j.socscimed.2018.07.010>> accessed 18 May 2019

<sup>11</sup> Eg., Menezes et al. (n9); Klitzman (n5).

<sup>12</sup> (n9).

<sup>13</sup> Statham, Solomou & Green (n9), 1402.

<sup>14</sup> *Ibid.*, 1406.

However, the absence of time limits for fetal anomaly/ protection of maternal life were seen to be serving a range of important purposes,<sup>15</sup> and under ground E, participants appeared to be more concerned whether “*the condition met the ‘severity’ criterion and rarely referred to certainty of prognosis.*”<sup>16</sup> Where uncertainty existed, there was evident desire to build consensus amongst colleagues,<sup>17</sup> and the input of neonatologists and paediatricians on likely treatment options often proved helpful to decision-making in this context.<sup>18</sup> Importantly, when fetal units decline a termination on legal grounds, this can create consequential difficulties for other providers and healthcare professionals:

*“Now, that is a very delicate issue. Basically if I and my consultant colleague here consider the issue and say, no, it’s not legal, that puts any other unit in the country under extraordinary difficult pressure if they’re challenged and they decide to do it.”*<sup>19</sup>

Finally, the study notes some important shifts in attitudes around acceptable ground E conditions and concludes that “*research is needed to monitor attitudes to, and interpretation of, UK abortion legislation.*”<sup>20</sup>

The Carrie Purcell et al. study of Scottish NHS hospitals picks up on the difficulty for HCPs in working with abortions in the later stages of pregnancy and the move away from hands on intervention to medical methods of termination.<sup>21</sup> Lisa Crowe et al. explore how HCPs negotiate terminations for non-lethal fetal anomaly so as to make them morally acceptable.<sup>22</sup> Again, the study highlights perceptions of inconsistency in the legal framework:

*“...if you can terminate a healthy baby just because the mother wants to, I don’t see why you can’t terminate a baby with a minor abnormality if the mother wants to. (Medical Professional 10).”*<sup>23</sup>

Whilst this displays some conceptual misunderstanding about the AA 1967, it raises an important question about the role of maternal choice in the decision-making process. When ground C conditions are met, medical professionals are able to displace some of the decision-making burden by claiming respect for maternal choice.<sup>24</sup> Whilst rejecting a formalised list of ground E conditions, this study emphasises the importance for

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<sup>15</sup> Ibid.

<sup>16</sup> Ibid.

<sup>17</sup> Ibid.

<sup>18</sup> Ibid. 1407.

<sup>19</sup> Ibid. 1407.

<sup>20</sup> Ibid., 1402.

<sup>21</sup> Purcell et al. (n10), 10-11.

<sup>22</sup> Crowe et al.(n9). The study included hospital consultants and social care professionals.

<sup>23</sup> Ibid.,3.

<sup>24</sup> Ibid., 5.

HCP's in 'fixing' patients and of perceptions of pain/ normality in 'negotiating' whether a condition/ anomaly can fall under ground E.

Again, Lotto et al. pick up on the issue of legal uncertainty around ground E, with some participants perceiving the legislative drafting as a failure to reach consensus rather than a flexible solution for practical use.<sup>25</sup> Indeed, the potential for decisions to be scrutinised and challenged, left some participants feeling vulnerable; and this perception of vulnerability may be restricting patient options especially after 24 weeks gestation. The study also corroborates the Statham et al. findings regarding the use of multi disciplinary decision-making, or as they frame it, '*corporate*' approaches to complex and difficult cases. These strategies serve "*to remove the responsibility from an individual by placing it on a group*" and potentially reduces variation within a hospital, although not necessarily between institutions.<sup>26</sup> Although participants saw themselves as facilitators, they also wanted active rational parental engagement in the decision-making process, occasionally creating tension or breakdowns in the clinical relationship.<sup>27</sup>

Richards et al. address HCP perspectives following loss from a twin pregnancy.<sup>28</sup> The transferability of the study is limited because it only addresses the perspectives of those professionals working within a single NHS hospital, but it does highlight the importance of bereavement skills and training to facilitate appropriate responses to parental needs. This finding is echoed in the study by Lafarge et al. which found that HCPs lacked:

*"insight into women's long-term coping processes and the potential for positive growth following TFA, which is consistent with a lack of aftercare following TFA reported by women."*<sup>29</sup>

Klitzman provides a US perspective from HCPs, ART providers and patients involved in multi-fetal reductions.<sup>30</sup> Although, this study combines a range of stakeholder perspectives, we will address it here for the ease of presentation. The study should be approached with caution because it concerns multiple pregnancies created by ART and communications/ decision-making before and after embryo transfer. However, what is interesting is the way in which patients approached the possible future risk of reduction

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<sup>25</sup> Lotto et al. (n9).

<sup>26</sup> Ibid. For the value of reflective spaces away from the regulators, see Professional Standards Authority, *The regulator's role in professional identity: validator not creator* (PSA 2018).

<sup>27</sup> Ibid.

<sup>28</sup> Judy Richards and others, 'Health professionals' perspectives on bereavement following loss from a twin pregnancy: A qualitative study' (2016) 36 *Journal of Perinatology* 529.

<sup>29</sup> Caroline Lafarge and others, 'Pregnancy termination for fetal abnormality: Are health professionals' perceptions of women's coping congruent with women's accounts?', (2017) 17(1) *BMC Pregnancy and Childbirth* 60. TFA=Termination for fetal abnormality.

<sup>30</sup> Klitzman (n5).

and the actual presentation of a decision to reduce. Those parents desperately wanting a family seemed more willing to accept the possible future risk of reduction, than they did in factual situations when an actual reduction was recommended and/or warranted. For some participants, the risk of multiple pregnancy seemed very remote when set against the wider background struggle to conceive. In many cases, an agreement to reduce a high order multiple was a precondition of embryo transfer,<sup>31</sup> and funding was not always available for the reduction procedure in any event.<sup>32</sup> The need to “*weigh multiple risks and uncertainties*” was problematic for “*desperate patients*” who “*cannot fully anticipate these tradeoffs*”.<sup>33</sup> Despite the intuitive nature of this statement, some clinicians still perceive reduction as an “*easy, rational decision*” without that perspective.<sup>34</sup>

Klitzman notes that some patients and providers:

*“appear more willing to reduce three fetuses to two than two to one, feeling that the data that twins face more risks than singletons are insufficiently compelling”.*<sup>35</sup>

He also notes that twin reductions make some physicians “*uncomfortable*”<sup>36</sup> – a point raised by many of the participants in this research. In terms of actual decision-making, the following important points also surface from the study. The ART providers (who may require agreement to possible future reduction) are unlikely to be the clinicians involved in any subsequent reduction procedure. Klitzman records the doctors “*often felt that ultimately, the decision was the patients*”, and notes the “*tensions concerning how much to challenge patients*”.<sup>37</sup> One physician participant makes this telling comment:

*“We wrestle with the competing ethical areas of patient autonomy versus the physicians’ social responsibility to do what’s right for society... [Twins] have premature delivery and use up resources rapidly.”*<sup>38</sup>

Klitzman concludes that a combination of education initiatives, updated professional guidance and the publication of clinic outcomes are warranted. However, the paper’s most important contribution is the emphasis placed by clinicians on benefits rather than

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<sup>31</sup> Klitzman (n5), 2572.

<sup>32</sup> Ibid., 2573.

<sup>33</sup> Ibid.

<sup>34</sup> Ibid.

<sup>35</sup> Ibid., 2573-2574.

<sup>36</sup> Ibid., 2574.

<sup>37</sup> Ibid.

<sup>38</sup> Ibid.

future risks, in combination with the potentially competing desire that patient autonomy should prevail.<sup>39</sup>

Finally, there is a recent qualitative study by Ellie Lee et al. considering UK consultants undertaking (or having recently undertaken) terminations in their work in obstetrics/gynaecology or in sexual/ reproductive health.<sup>40</sup> Although the study appears to focus on singleton terminations, there are some interesting observations. First, in most accounts there was emphasis on the “*primacy of the woman as the decision-maker*”.<sup>41</sup> Secondly, decision-making was not seen as the exclusive domain of doctors, although medical expertise was valuable in difficult and complex cases, and termination services were seen as a part of medical care.<sup>42</sup> Thirdly, there was a strong sense that the current law “*undermines their medical professionalism*” in terms of the “*exercise of clinical judgement, and the ability to act as a ‘good doctor’*”.<sup>43</sup> The participants singled out criticism for dual certification, nurse participation and home administration, and the (perceived) threat of criminal prosecution.

### Parental perspectives

A study by Sarah Meaney et al. addresses parental participants who have lost a co-twin with congenital abnormality<sup>44</sup> and picks up on a matter implicit in the Klitzman study - parents were simply “*not prepared for the complications they experienced in [multiple] pregnancy*”.<sup>45</sup> Again, clinicians encouraged parents to focus on the “normal” rather than the anomalous reduced twin, and consequently parents felt that their opportunity to grieve was diminished. The ongoing psychological impact of multi-fetal pregnancy loss is well recognised.<sup>46</sup> The researchers also note the need for clear education provision to parents.

In a similar vein, Richards et al. looked at UK mothers who had suffered a loss from a twin pregnancy but continued to receive hospital support for their surviving twin.<sup>47</sup> This study preceded their research output addressing HCP perspectives (see above). Some of the women connected the emotional support provided by healthcare staff with

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<sup>39</sup> Ibid., 2575.

<sup>40</sup> Lee et al. (n10).

<sup>41</sup> Ibid., 29.

<sup>42</sup> Ibid.

<sup>43</sup> Ibid.

<sup>44</sup> Sarah Meaney, Paul Corcoran and Keelin O'Donoghue, 'Death of One Twin during the Perinatal Period: An Interpretative Phenomenological Analysis', (2017) 20(3) *Journal of Palliative Medicine* <<https://doi.org/10.1089/jpm.2016.0264>> accessed 29 May 2018.

<sup>45</sup> Ibid. [Emphasis and context added].

<sup>46</sup> Jennifer Kelland and Rosemary Ricciardelli, 'Mothers of Multiple Perspectives on Fetal Reduction and Medical Abortion', (2014) 5(2) *J Motherhood Initiative for Research and Community* 126; Morris and Kilby (n3); 342.

<sup>47</sup> Judy Richards and others, 'Mothers' perspectives on the perinatal loss of a co-twin: A qualitative study' (2015) 15 *BMC Pregnancy & Childbirth* 143.

their perception of professional competence. Overall, the study highlights the vital importance of trust, and the continuity of information and staffing.<sup>48</sup> Small changes in this context had a significant impact on the well-being of patients. The women involved also described impairment of perception and their ability to make informed decisions following the loss with consequential loss of control.

Interestingly, Kelland and Ricciardelli did not find support (from 41 women who had multiple pregnancies in Canada) for the reduction of twin to singleton pregnancy for non-medical reasons.<sup>49</sup> The:

*“idea of reducing a twin pregnancy is particularly troubling; for some it appears rooted in the bond they note in their twins or even in their personal experiences and love they felt for their children.”<sup>50</sup>*

The authors make the bold assertion that these reductions are “*primarily related to lifestyle and personal situations*”<sup>51</sup> although there may be cases where medical risks to the woman and twins arise.

Britt and Evans address the views of pregnant woman in the context of multi-fetal pregnancy reduction in the US <sup>52</sup>. This study considers decision difficulty against three conceptual “frames” or ways of “*describing and thinking about decision options*”<sup>53</sup>: (1) a moral belief that life begins at conception; (2) a medical belief in the statistics regarding risk, and risk prevention through reduction; and (3) a lifestyle belief that a balance of children and career has normative value. There was some evidence of parents “*having to reduce, and not having a choice*” and using the medical belief frame to construct or support their decision to reduce across these conceptual frames.<sup>54</sup> Those with an intense conceptional frame (frame 1) found significant decision difficulty around fetal reduction; and in those cases, frame 2 can be conceived as a medical necessity to lift or alleviate:

*“some of the burden of making the decision to reduce by minimizing the discretion that the woman and her partner appear to have in the matter”.*<sup>55</sup>

This is consistent with the findings of Graham et al. (addressing late terminations of pregnancy for fetal anomaly) where feticide was conceptualised by patients as being

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<sup>48</sup> See also Robyn Lotto, Natalie Armstrong and Lucy K. Smith, ‘Care provision during termination of pregnancy following diagnosis of a severe congenital anomaly - A qualitative study of what is important to parents’, (2016) 43 *Midwifery* 14; NICE, *NICE Clinical Guideline CG62 Antenatal Care for Uncomplicated Pregnancies* (NICE 2019), para 1.2.2.

<sup>49</sup> Kelland and Ricciardelli (n46), 123-140.

<sup>50</sup> *Ibid.*, 134.

<sup>51</sup> *Ibid.*, 127.

<sup>52</sup> David W. Britt and Mark I. Evans, ‘Sometimes doing the right thing sucks: Frame combinations and multi-fetal pregnancy reduction decision difficulty’, (2007) 65 *Social Science & Medicine* 2342.

<sup>53</sup> *Ibid.*, 2343.

<sup>54</sup> *Ibid.*, 2354.

<sup>55</sup> *Ibid.*, 2355.



difficult but necessary.<sup>56</sup> This is a similar conceptual process used by HCPs,<sup>57</sup> although with parents, the displacement is to the professionals caring for them.<sup>58</sup>

The Kelland and Ricciardelli study (building upon the Britt and Evans approach) divide their frames into reductions for medical and non-medical reasons – the latter defined as “*lifestyle, financial or other personal (reasons)*”.<sup>59</sup> Their participants were preoccupied with situations where “*medicine or medical experts were “proven” wrong*”.<sup>60</sup> In addition, many of the participants avoided “*the possibility of even making decisions*” about termination “*by opting not to not undergo genetic screening when pregnant*”.<sup>61</sup> Kelland and Ricciardelli also found participants making the distinction between abortion and fetal reduction although “*some women express feeling conflicted in their own responses*”.<sup>62</sup>

The impact of the internet in obstetric decision making is considered by Lagan et al. in relation to woman in the US, Australia and New Zealand.<sup>63</sup> The findings confirm that the internet is playing an important role in many aspects of pregnancy - online information is filling parental needs between appointments and the gaps created by the finite time available for antenatal appointments.<sup>64</sup> Women reported that the availability of online information was both supportive and reassuring.<sup>65</sup> The internet also had an important role to play in terms of sharing experiences although the quality of information was difficult to evaluate.<sup>66</sup> However it was clear that online sites helped inform choices and helped share decision-making with HCPs.<sup>67</sup> The study therefore argues that it is important that this online use is recognised and HCPs should be helping women by directing them to suitable and reliable sources of information that they need.<sup>68</sup> However, NICE have recently highlighted the lack of evidence on the use of non leaflet media to communicate information to pregnant women.<sup>69</sup>

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<sup>56</sup> Graham et al. (n9). See also Caroline Lafarge, Kathryn Mitchell and Pauline Fox, ‘Termination of pregnancy for fetal abnormality: A meta-ethnography of women’s experiences’ (2014) 22(44) *Reproductive Health Matters* 191; Kelland and Ricciardelli (n46) 123-140.

<sup>57</sup> Crowe et al. (n9).

<sup>58</sup> Lotto et al. ‘Care provision’ (n48) – this study talks of “*offsetting responsibility onto the clinicians*” (p18).

<sup>59</sup> (n46), 124 (added).

<sup>60</sup> Ibid., 131.

<sup>61</sup> Ibid., 133. The double negative appears to be a typographical error.

<sup>62</sup> Ibid., 135.

<sup>63</sup> Briege M. Lagan, Marlene Sinclair and W. George Kernohan, ‘What is the impact of the Internet on Decision-Making in Pregnancy? A Global Study’ (2018) 38(4) *Birth* 336.

<sup>64</sup> Ibid., 339. See also J. S. Blumenthal-Barby, ‘That’s the doctor’s job’: Overcoming patient reluctance to be involved in medical decision making’, (2017) 100 *Patient Education and Counseling* 14, 16.

<sup>65</sup> Ibid.

<sup>66</sup> Ibid., 341.

<sup>67</sup> Ibid. 342-343.

<sup>68</sup> Ibid., 344.

<sup>69</sup> NICE, *NICE Clinical Guideline CG62 Antenatal Care for Uncomplicated Pregnancies* (NICE 2019).

## 8.4 Quantitative research

In this section, we examine relevant quantitative research relating to the attitudes of healthcare professionals,<sup>70</sup> parents<sup>71/72</sup> and their proxies.<sup>73</sup> Again, many of the studies relate to generalised attitudes and perspectives to abortion.

### Healthcare professional perspectives

In a questionnaire study by Dommergues et al.,<sup>74</sup> HCPs working within a French maternity hospital with a fetal medicine centre gave their opinion on the use of feticide at the second or third trimester. The majority had positive opinions on feticide, expecting it would avoid fetal or neonatal pain and this assisted overall patient management.

In a questionnaire study by Theodosiou and Mitchell, GPs, Obstetricians and Gynaecologists<sup>75</sup> affiliated with a single UK NHS hospital gave their views on abortion reform. A significant majority felt that abortion law in Northern Ireland should be changed to align with the rest of the UK. There was less agreement around broader amendment to the AA 1967, although possible areas for amendment included changes to the 24-week time limit, the legal definition of fetal abnormalities, termination on request, and the dual practitioner certification requirement. The researchers observed that many of the participants “*justified their views in terms of personal morality, rather than best practice guidelines and evidence.*”<sup>76</sup>

In a questionnaire survey of UK HCPs working in fetal medicine and associated fields, Crowe et al. observed that where fetal anomaly was less serious, gestational age was an important consideration.<sup>77</sup> Similarly, prognosis was an important factor alongside

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<sup>70</sup> Eg., Marc Dommergues and others, 'Feticide during second- and third-trimester termination of pregnancy: Opinions of health care professionals', (2003) 18(2) *Fetal Diagnosis and Therapy* 91; Anastasia A Theodosiou and Oliver Mitchell, 'Abortion legislation: exploring perspectives of general practitioners and obstetric and gynaecology clinicians', (2015) 30(2) *Reproductive Bio Medicine online* 197.

<sup>71</sup> Eg., N Bajos and others, 'Access to health care for induced abortions: qualitative and quantitative approaches', (2003) 51 *Revue d'épidémiologie et de Santé Publique* 631; Jane Fisher and others, 'Termination for fetal anomaly: Are women in England given a choice of method?' (2015) 35(2) *Journal of Obs & Gynae* 168.

<sup>72</sup> Eg., Ruth Graham and others, 'Experiences of Reproductive Loss: the importance of professional discretion in caring for a patient group with diverse views', in: S Earle, C Komaromy, L Layne, (eds) *Understanding Reproductive Loss: Perspectives on Life, Death and Fertility* (Ashgate, 2012), 205.

<sup>73</sup> Eg., NCT and TAMBA, *Maternity Services and Multiple Births: A joint report by NCT and the Twins and Multiple Births Association*, < <https://www.tamba.org.uk/document.doc?id=733> >accessed 11 April 2017. This report is based on survey data from 1338 respondents in 2015.

<sup>74</sup> (n70). Cf Ronitt Leichtentritt and Galia Weibery-Kurnik, 'No one sees the fathers: Israeli fathers' experience of feticide' (2016) 168 *Social Science Medicine* 159.

<sup>75</sup> (n70).

<sup>76</sup> Theodosiou (n70), 201.

<sup>77</sup> Lisa Crowe and others, 'A survey of health professionals' views on acceptable gestational age and termination of pregnancy for fetal anomaly', (2018) 61(9) *European Journal of Medical Genetics* 493.

gestational age. This study is also interesting because some participants clearly differentiated between their personal and professional views on these issues suggesting that HCPs may be able and willing to work “*within a professional paradigm despite it being in conflict with their own personal opinions.*”<sup>78</sup> However, this does not address the possible impact of unconscious bias discussed in chapter 6.

### **Parental perspectives**

Bajos et al undertook a qualitative and quantitative study of women who had undertaken abortion in France.<sup>79</sup> Their research highlights the importance of visible termination services and the promotion of information delivered to healthcare professionals.

A questionnaire survey by Fisher et al. involving members of a UK parent support organisation examined the availability of patient choice for medical and surgical methods of termination for fetal anomaly.<sup>80</sup> Notably, only 14% of parents were offered a choice of method with a significant fall after 14 weeks’ gestation (to 8%). This is a very low finding given that national guidance suggests that a choice of methods should be offered where appropriate and available. Although the majority (78%) underwent a medical termination, 88% of that group chose that option because it was the only method offered. Interestingly 60% of those who were offered a choice had a surgical termination and this might suggest that greater choice could have an impact on the statistical trend towards medical abortion in singleton pregnancies. What is not clear, is how much public health resource considerations are playing a role, but if consequential factors are restricting patient choice this has obvious ethical implications.

### **Parental proxy perspectives**

A joint report by the National Childbirth Trust (NCT) and the Twins and Multiple Births Association (TAMBA),<sup>81</sup> addresses the implementation of the key NICE guidance in relation to multiple pregnancy.<sup>82</sup> Headlines from the report include:

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<sup>78</sup> Ibid., 497.

<sup>79</sup> (n71).

<sup>80</sup> Fisher et al.(n71). For the value of this choice, see Jane Fisher and Caroline Lafarge, ‘Women’s experience of care when undergoing termination of pregnancy for fetal anomaly in England’, (2015) 33(1) *Journal of Reproductive and Infant Psychology* 69; Jane Fisher and Caroline Lafarge, ‘Women’s perceptions of care when undergoing termination of pregnancy for fetal anomaly’, (2015) 33(1) *Journal of Reproductive and Infant Psychology* 69.

<sup>81</sup> (n73).

<sup>82</sup> NICE Quality Standards (QS46) *Multiple Pregnancy: Twin and Triplet Pregnancies* (NICE 2013). See also RCOG, *Multiple pregnancy: the management of twin and triplet pregnancies in the antenatal period (NICE Clinical Guidance)* (RCOG 2011a).

- Relevant NICE guidance is still not fully or equally implemented across the UK and there is no specific guidance for intrapartum care for multiples.<sup>83</sup> Full implementation is evaluated at 10-18% of units.
- Average gestation rates are currently 35.3 weeks for twins and 31.8 weeks for triplets
- The results show that average levels of compliance with NICE measures have increased from 58.8% in 2010/11 to 69.1% in 2014/15.
- The rates of NICE compliance and parent satisfaction vary across the regions of England. The North East is the highest performing regions with overall 71.5% compliance, whilst the South East and West Midlands are the lowest both with 61.1%.

This report highlights that compliance with national guidance/ standards can be patchy, incomplete and can take significant periods of time to embed into practice. Although we may be getting close to 70% average national compliance, it still leaves a fair number of centres/areas with incomplete adoption, and suggests we probably need something else to direct behaviour and compliance. Of course, we cannot discount NHS workload and resources as a partial explanation for the incomplete pattern of implementation and compliance.

A subsequent report by TAMBA on *Twin Pregnancy and Neonatal Care in England* records higher rates of NICE guideline compliance (73%+).<sup>84</sup> Interestingly, the report also comments that smaller cohorts of multiple pregnancies may result “*in poorer care, patient satisfaction and outcomes*”.<sup>85</sup> This could have implications for the number, location and size of tertiary fetal medicine units.

## 8.5 Other research

There is a range of other research around the role of personal attitudes, values and professional norms in the wider context of abortion.<sup>86</sup> One important consideration for

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<sup>83</sup> See now NICE, *Twin and Triplet Pregnancy (CG129 Guideline Update) – Draft for Consultation* (NICE 2019).

<sup>84</sup> TAMBA, *Twin Pregnancy and Neonatal Care in England, November 2017* (TAMBA 2017).

<sup>85</sup> *Ibid.*, 6.

<sup>86</sup> Eg., Constance A. Nathanson and Marshall H. Becker, ‘Professional Norms, Personal Attitudes, and Medical Practice: The Case of Abortion’, (1981) 22 *Journal of Health and Social Behaviour* 198; S L Marshall, D Gould and J Roberts, ‘Nurses attitudes towards termination of pregnancy’, (1994) 20 *Journal of Advanced Nursing* 567; W. Savage and C. Francome, ‘British Gynaecologists attitudes in 2008 to the provision of legal abortion’, (2011) 31 *Journal of Obstetrics &*

the parental stakeholders is the potential stigma associated with NHS funded but independent sector delivered abortion services (eg British Pregnancy Advisory Service, Marie Stopes International). There is a significant discrepancy between Scotland and England/Wales - Scotland has a much higher proportion of terminations delivered directly within the NHS care framework.<sup>87</sup> This has less relevance for fetal reduction and selective termination in multiple pregnancy where the procedure is probably going to be undertaken within an NHS fetal medicine unit.

The Nuffield Council on Bioethics' (NCOB) report on '*Critical care decisions in fetal and neonatal medicine: ethical issues*'<sup>88</sup> concluded:

*"that the adoption of more stringent legislation would risk introducing new legal constraints to the current pragmatic and flexible process of decision making".*<sup>89</sup>

The report supported the use of professional guidance "*accompanied by a strong sense that it should not be too restrictive*".<sup>90</sup> They endorsed further clarification of when a baby is 'born alive' and a code of practice on late terminations and the use of feticide.<sup>91</sup> They concluded that birth should remain "*the significant moral and legal point of transition for judgements about preserving life*" and decisions for the benefit the fetus should only be made with the consent of the pregnant woman. They also proposed that new procedures in fetal surgery should only be offered within a protocol approved by a research ethics committee.<sup>92</sup>

Finally, there is interesting study that examines multi fetal pregnancy reduction from the Shiite perspective within the UK.<sup>93</sup> The study concluded that fetal reductions that occur in emergency situations (no option or 'ordinary' indication) are permitted before the time of ensoulment (the point at which a soul is acquired). Anomaly and importance<sup>94</sup> were appropriate criteria in the selection process.

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*Gynaecology* 322; L H Harris and others, 'Dynamics of Stigma in Abortion Work: Findings from a Pilot Study of the Providers Share Workshop', (2011) 73(7) *Social Science & Medicine* 1062; Niels Lynoe, 'Physicians' practices when frustrating patients' needs: a comparative study of restrictiveness in offering abortion and sedation therapy', (2014) 40 *J Med Ethics* 306.

<sup>87</sup> Edna Astbury Ward, 'Abortion 'on the NHS': The National Health Service and abortion stigma', (2015) 41 *J Fam Plan Reprod Health Care* 168.

<sup>88</sup> NCOB 2006, <<http://nuffieldbioethics.org/project/neonatal-medicine>>accessed 20 July 2018. For discussion of the role of the Nuffield Council, see Roger Brownsword and Jeff Wale, 'Testing Times Ahead: Non-Invasive Prenatal Testing and the Kind of Community We Want to Be', (2018) 81(4) *MLR* 646.

<sup>89</sup> NCOB (n88), 183.

<sup>90</sup> *Ibid.*, 182.

<sup>91</sup> *Ibid.*, 153.

<sup>92</sup> *Ibid.*, 152.

<sup>93</sup> A Z. Bigdoli and F A. Ardbili, 'Permissibility of Multifetal Pregnancy Reduction from The Shiite Point of View' (2017) 10(4) *International Journal of Fertility & Sterility* 380.

<sup>94</sup> The example offered is fetal health.

## 8.6 Conclusions

Drawing these sources together, we make five general remarks and one specific observation about fetal reduction/ selective termination:

First, team-based decision-making is encouraged in difficult and complex cases, especially when there is some doubt over the legality of a termination. Whilst this approach will not prevent individual prosecution, it probably makes it harder to demonstrate bad faith and non-compliance with the AA 1967. This reinforces the need for institutionally focused forms of regulation that encourage the uptake and implementation of national rules and guidance. Shared decision-making within clinical teams may make it harder for hidden personal values to take hold, providing care is taken to avoid dominance by any single individual.<sup>95</sup> It is noteworthy that self assessment and reflective spaces for professionals are seen as an important part of healthcare reform by the Professional Standards Authority.<sup>96</sup>

Secondly, uncertainty over legality may have both positive and negative consequences for parental engagement. On the one hand, it may encourage HCPs to seek active patient engagement in the termination decision. On the other, this process may create tension and conflict in the clinical encounter or act as a hurdle to patient access in some cases.

Thirdly, whilst decriminalisation of abortion may alleviate some of the pressure on HCPs and patients, regulators would still have to police the concept of 'proper medical treatment'. The absence of criminal restriction seems unlikely to resolve all issues around acceptable anomaly and gestational time limits. Indeed, decriminalisation may force professionals to hide their personal values and increase the degree of regional variation, creating unnecessary disparity around access.

Fourthly, there is a need for balance in the communication of risks/ benefits in the patient encounter. It can be problematic to prioritise patient autonomy whilst placing exclusive or primary emphasis on the benefits of a procedure. Of course, there will be cases where the benefits clearly outweigh the risks, but the risks still need to be disclosed if they are likely to be material to that patient's decision-making or a reasonable patient in those circumstances.

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<sup>95</sup> CF also Helena Serra, 'Gamble on the Uncertain. Negotiating Medical Decision-Making' (2016) 12(4) QSR 44.

<sup>96</sup> PSA (n26), chp 3.

Fifthly, there is a conflict between resource-based decision-making and a public narrative supporting open-ended patient choice. Patient decision-making and choice is likely to be constrained by a range of contextual barriers including time or option limits.<sup>97</sup> The NHS commitment to enhancing patient choice<sup>98</sup> is laudable but we should not fool ourselves that this without restriction.

In respect of our specific observation, whilst the need for informed decision-making is well established, we should recognise the considerable weight and difficulty of decision-making in relation to fetal reduction and selective termination. The need to weigh multiple risks, shifting uncertainties and disclosures, make it important that there is a proper dialogue between HCPs and parents, and not just unilateral exchanges of information. Variations in education, intelligence and background knowledge will need to be catered for, ideally using a range of media.<sup>99</sup> Continuity of care is likely to enhance the therapeutic dialogue and facilitate this process.<sup>100</sup>

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<sup>97</sup> Blumenthal-Barby (n64).

<sup>98</sup> NHS, *The NHS Long Term Plan* (NHS 2019), 24-25.

<sup>99</sup> Cf Blumenthal-Barby (n64).

<sup>100</sup> As per NICE (n69).

# Chapter 9 – Interview Data and Emerging Themes

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## 9.1 Introduction

In this chapter, we examine the interview data from our research participants. We have divided the discussion under thematic headings emerging from the interview process and our cyclical analysis of the raw transcript data. Outline theme definitions are available at **Table 1A (appendix C)**. Participants are designated 'P' with a differentiating letter for each individual participant (eg **PA** = Participant A etc). Please note that all quotes are taken from direct transcriptions of participant interviews and have not been edited unless expressly stated.

## 9.2 Terminology

There was a broad measure of agreement over descriptors and the central goals of fetal reduction/ selective termination. **PA** identifies a high order multiple as a



pregnancy involving “triplets or even more, four or five”,<sup>1</sup> and describes the aims of fetal reduction as:

*“reducing the morbidity and the adverse outcomes for the baby related to the fact that they are higher order to improve their chances of the pregnancy going further and reduce the risk of severe and moderate brain (damage)”.*<sup>2</sup>

For this participant, consequential considerations and the high/ low order distinction appears more important than any other procedural distinction:

*“the reason I made the distinction between high order and twins, in higher order you are reducing effectively one normal and somehow you don't have an issue about that, you are improving two, what's the phrase I can use without putting a value on it, without putting a judgement on it, you know you take the heartbreak of one”.*<sup>3</sup>

Similarly, **PB** made no clear distinction between the two procedures but could “see why people would use them in that way.”<sup>4</sup> When probed about the possible procedural distinction, **PC** responded that the labels are not used consistently enough to be important:

*“If there was consistent terminology that was agreed upon where selective termination was reserved for anomalies for instance and selective reduction for non-anomaly that would not be an unreasonable thing to do I think that so much overlap it is not particularly useful distinction. When you discuss selective termination, the word ‘termination’ has, particular implications, whereas a ‘reduction’ of numbers of babies may be a more...”*<sup>5</sup>

This suggests that labels are sometimes being used to frame the discussion in less emotive terms. However, they acknowledge that the term ‘reduction’ might involve “equivocation”<sup>6</sup> and “some people might find it confusing” because it “(d)oesn't really tell you exactly what is happening.”<sup>7</sup> The only participant to make the formal distinction was **PD**:

*“Fetal reduction is where ... we use it where we are trying to reduce the risks attributable to a multiple pregnancy. We use selective termination as terminating pregnancy for one baby usually abnormal baby ... the stated intention is different.”*<sup>8</sup>

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<sup>1</sup> Participant A.

<sup>2</sup> Participant A (added).

<sup>3</sup> Participant A.

<sup>4</sup> Participant B.

<sup>5</sup> Participant C.

<sup>6</sup> Participant C.

<sup>7</sup> Participant C. Cf Jeffrey Wale, ‘Selective termination of pregnancy and fetal reduction in multiple pregnancy: terminology, blurred lines and ethical discourse’, <  
[https://www.researchgate.net/publication/303882409\\_Selective\\_termination\\_of\\_pregnancy\\_and\\_fetal\\_reduction\\_in\\_multiple\\_pregnancy\\_terminology\\_blurred\\_lines\\_and\\_ethical\\_discourse](https://www.researchgate.net/publication/303882409_Selective_termination_of_pregnancy_and_fetal_reduction_in_multiple_pregnancy_terminology_blurred_lines_and_ethical_discourse)>accessed 20 July 2018.

<sup>8</sup> Participant D. PD identifies 2 roles for selective termination: “one to prevent the birth of the baby who will suffer or will be abnormal be handicapped according to the law but also to prevent that baby from compromising the other baby”.

However, **PD** later concedes that this is a “*fairly arbitrary*” distinction.<sup>9</sup> Overall, these findings are consistent with views expressed elsewhere, namely whilst terminology is not unimportant, fixed categorisation is not terribly helpful in actual medical practice.<sup>10</sup>

### 9.3 Problem areas

The participants were asked to provide examples of problem areas – specifically, those circumstances which tended to generate complex decisions and considerations. **PC** recognises the inherent tension and finely balanced considerations involved in triplet reductions:

*“With dichorionic triplets you win and you lose by doing a reduction. If do a reduction you increase the risk of miscarriage, you have stuck a needle into someone but if they don’t miscarry you reduce the risk of very premature births and death. If you leave them alone, lower risk of miscarriage and slightly higher risk of premature birth and subsequent death. If you do simulation based on the numbers, the results are in the two arms... actually the same. On one you take on 3 babies and in other you take on 2. You may reduce the risk of handicap in the reduction group because the gestational is a little bit longer- finely balanced.”<sup>11</sup>*

Against this background, the participant would not:

*“**direct to reduction**...outcomes for our triplets tends to be very good. Often comes down to how parents cope with triplets. If they come holding their head in hands. This is really terrible news. So difficult for our family unit to cope and actually got 3 other kids ... or whatever... might be the... rather than the medical. Very finally balanced.”<sup>12</sup>*

This makes it clear that non-medical (socio-economic) factors may often be decisive in triplet pregnancies. The opening statement also fits with our earlier description characterising doctors as choice architects.

**PA** singles out reductions involving triplet pregnancies with a monochorionic pair:

*“yes often there only say reduce only 1 then you’ll have to talk to them and say actually yes we can reduce one but we are not completely out the woods because you’re carrying twins and you’re carrying the ones that are associated with higher problems, try and sort one out and then 5 weeks later we may find out we can’t predict if we go down that route we just got to be aware”<sup>13</sup>*

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<sup>9</sup> Participant D.

<sup>10</sup> Wale (n7); C M. Ogilvie, ‘Multiple pregnancy, fetal reduction and selective termination’, (2013) 26 (6) *Reproductive Bio-Medicine Online (Elsevier Science)* 52.

<sup>11</sup> Participant C.

<sup>12</sup> Participant C (emphasis added).

<sup>13</sup> Participant A.

Again, consequential considerations dominate the concern. **PC** also highlights the difficulty of chorionicity in twin pregnancies:

*“They are so much more complicated... there is a temptation to try and make things fits into neat boxes and protocols. Many things are amenable to that but I also believe strongly that some things are really difficult. Maybe this is one of those areas”<sup>14</sup>*

This highlights the importance of discretion/ flexibility and the practical difficulty created by fixed rules.

**PA** articulated some hesitancy about the reduction of a twin pregnancy with a healthy pair:

*“(I) would want to understand the reason underpinning the request. I would try to understand at least. I would offer a second opinion and even sometimes, an external second opinion because I think it is very hard sometimes. It is not a value-based. I'm not making any judgements on expecting parents but I guess sometimes it can be very difficult to make very very tough decisions in very short period of time”<sup>15</sup>*

Is this paternalistic resistance, recognition of the uncertainty of clinical benefit or simply the creation of a reflective space based on past experience of parental regret? **PD** has a similar reticence about healthy twin reduction:

*“clearly the benefits are clearly less than they are with triplets because the pre-existing risk is not very high. So, we tend to say we don't usually do it. We have done it and it's been my sort of policy to say yes we'll do it if the alternative is a total termination and that's people who have usually said if you don't do it I'll terminate the whole pregnancy. In which case I have done it under those circumstances”<sup>16</sup>*

Again, this appears to highlight resistance to parental demands based upon consequential considerations either for the pregnant woman or the unborn entity. Similarly, **PB** did not believe there were medical indications for reducing twins to a singleton, although their primary concern was the risk of a live birth after attempted reduction.

**PD** notes an interesting upward trend in the number of IVF related pregnancies from abroad and a corresponding increase in chorionicity:

*“the proportion of multiple pregnancies that contain monochorionic twins has undoubtedly increased ... I'm sure there are figures but I haven't seen them, but*

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<sup>14</sup> Participant C.

<sup>15</sup> Participant A.

<sup>16</sup> Participant D.

*they have increased. So probably 50% of our ... have got monochorionic twins*<sup>17</sup>

Finally, **PD** admitted that where there were limits to the technical evaluation of risk:

*“several ifs down a decision tree or the what might happen tree and we are not that good at predicting the future.”*<sup>18</sup>

Again, consequential considerations dominate.

## 9.4 Timing

One of the key clinical themes for the participants was the timing of intervention during the pregnancy. There are competing risks/ considerations, and the window of opportunity appears to be small, limiting time for reflection and deliberation.

Nonetheless, there appears to be a broad measure of agreement over timing. **PA** says:

*“everyone should have a scan between 11 and 14 weeks most people ... 12-13 weeks. They will be referred up to immediately to have a chance to discuss, they will then you give them a week or something like that to make a decision”*<sup>19</sup>

**PB** tries to see pregnant woman:

*“a bit before around the 11 week mark to float the idea see if that's something they wish to pursue. If it is something they wish to pursue we may end up doing it a little after 12 weeks because part of the decision-making process would be ... are there ... is there one of the fetuses that is clearly anomalous”*<sup>20</sup>

Similarly, **PC** says that most patients are seen around 11-12 weeks:

*“There are different pockets.... One fetus has an abnormality or suspected abnormality, that's one one bunch of patients we would see and there the discussion is around the effect that the abnormality will have on the baby and whether you want a selective termination based on that in the same way that you would have for a singleton and that kinda bye the bye. Something to take into account if it's a very minor abnormality, **some parents will want a termination for pretty minor things.**”*<sup>21</sup>

This suggests that the participant may be evaluating parental reasons although not necessarily with a negative outcome for the requestor. **PC** categorises monochorionic

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<sup>17</sup> Participant D.

<sup>18</sup> Participant D.

<sup>19</sup> Participant A.

<sup>20</sup> Participant B.

<sup>21</sup> Participant C (emphasis added).

pregnancies as an additional group, with a further bunch of “*multi fetal reductions where trying to reduce the risk of pre-term birth, usually triplets, quads and above.*”<sup>22</sup>

**PD** describes a slightly earlier practice in high order multiples (from about 10 weeks), although core decisions are usually made around the 11<sup>th</sup> week of pregnancy:

*“there were usually be seen by us and counselled by one of the consultants or counselled under the supervision of one of the consultants here. Then they would see a midwife. Then they would go away and then they would come back to the appointment for a nuchal scan and in the meantime they might ... might have made their wishes clear to the midwives by telephone and so when they come back to do the nuchal scan and we are going to make sure that we are not going to leave a baby that was abnormal. So, we will be looking fairly carefully at 11 week and that's why do the nuchal scan here”*<sup>23</sup>

When asked whether there was a cut-off date for these procedures, **PA**'s response demonstrates evidence driven decision-making:

*“you don't really want to do any reduction after 16 weeks...really want to do it as soon as possible, the tissue bulk is so high and the only other time that you may do it is if you find a problem after 32 weeks so that if you then go into labour the consequences don't affect the other one it is mainly term but....”*<sup>24</sup>

**PB** says there is no cut-off date but notes that there:

*“is reasonable data that suggest if you wait until after 16 weeks there is a significantly higher rate of total pregnancy loss if you do a selective reduction”*<sup>25</sup>

This participant also records pockets around the 12/ 20 weeks scans when anomalies may be revealed. Similarly, **PC** agrees “*that a reduction at 12 weeks the risk is smaller than the risks of a reduction at 16 weeks...*”<sup>26</sup> and this fits with the overall profile of risk:

*“Principally we are talking about if you do not reduce a multi fetal pregnancy, there is a risk of spontaneous MFP loss and the risk of premature birth. They are the 2 big categories. You lose the pregnancy because mother miscarries at 15-17 weeks with babies or you actually have an early preterm at 28-30 weeks. Not really concerned at prematurity beyond 34-35 weeks because those babies tend to do very well anyway.”*<sup>27</sup>

In terms of early intervention, **PC** acknowledges there are differential jurisdictional practices:

*“I know that there is a fashion in the States to do it really early – 8 weeks- my nightmare scenario done an embryo reduction from 3 to 1 and then find that one you have left behind has a congenital abnormality which couldn't be detected early. I would say take a balance. really want to take a careful*

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<sup>22</sup> Participant C.

<sup>23</sup> Participant D.

<sup>24</sup> Participant A.

<sup>25</sup> Participant B.

<sup>26</sup> Participant C.

<sup>27</sup> Participant C.

*detailed at 12 weeks. If any baby has any abnormality, even if the procedure was intended just for a reduction, any abnormality or even a small mark...*<sup>28</sup>

So again, we have consequential considerations influencing domestic practice. Then there is the question of whether there ought to be a waiting period between the decision and surgical intervention. **PA** emphasises the importance of a short delay:

*"not in my practice. If they know they've got twins they come, then obviously we scan again .... then we have a whole discussion then they go away then we ... never offer and reduce never do not my practice. However devastating, for example, especially those where there is a problem they have a clear they want I will always say you have to come back at least have one night. I have a very strong ..."*<sup>29</sup>

Similarly, **PC** says that whilst the procedure could be *"done on the day. Generally, like them to sleep on it for a day."*<sup>30</sup> **PD** notes an in-built practice-based delay:

*"It would be a minimum of week and so that's why ... we would want to see them to give them the opportunity to discuss it. I would divide them into three groups. First Group who couldn't possibly contemplate it and that's the end of the conversation and that's very straightforward and then the other two thirds probably 1/3 think about it and do it and the other third think about it and don't do it"*<sup>31</sup>

but admits they have acceded to immediate patient requests *"if she is clear that she wants it done."*<sup>32</sup> These responses suggest that beneficent considerations are influencing professional practices, although the delays may be patient centred and more prevalent when the parental stakeholders are equivocating.

When asked about the legal time limit for termination, **PC** responds:

*"The 24-week cut off for termination that would only become an issue if a late request for a reduction in an abnormality... not be possible but really never come across that. Parents will know from early on and because most are related to fertility treatments most come very early on"*<sup>33</sup>

When asked about the possible introduction of a legal cut-off date for all terminations, **PB** claimed this would just create *"different groups of complex patients...there are tiny numbers handful after 24 weeks."*<sup>34</sup>

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<sup>28</sup> Participant C. Cf M S. Kim and others, 'Procedural and obstetric outcomes after embryo reduction' (2019) 53(2) *Ultrasound in Obstetrics and Gynecology* 214.

<sup>29</sup> Participant A.

<sup>30</sup> Participant C.

<sup>31</sup> Participant D.

<sup>32</sup> Participant D.

<sup>33</sup> Participant C.

<sup>34</sup> Participant B.

## 9.5 Frequency

**PA** estimated 3-4 conversations about fetal reduction in high order cases each year but acknowledges that the option is not automatically offered in healthy twin pregnancies:

*“it’s only in the presence of abnormality again probably two or three times a year.”<sup>35</sup>*

**PB** estimated he undertook relevant discussion about fetal reduction less than 10 times per year:

*“I would not think as many as one /month. There are lots of different categories that if you tot up. We would see a number of triplet pregnancy there will be a discussion about selective reduction. We would see a number of pregnancies each year where there might be a selective twin anomaly and there would be a number of pregnancies each year where there might be complications like severe growth restriction rather than an anomaly. Particularly in MC twins where they are prone to selective IUGR and other issues risks because if you have a DC twin and ones very small and it might die it might kill the other one in the process or least it can harm and so the management is more complex”<sup>36</sup>*

Interesting, this participant estimated that: *“a little less than half of triplets would go for selective reduction.”<sup>37</sup>* **PC** would discuss the options with *“5 or 6 triplets per year...and quads even less than that, maybe 1 a year”<sup>38</sup>* **PD** estimated:

*“6 reductions per year and selective termination 3 to 4 on average. It may be a few more reductions than that, it is not in double figures but it might be up to 10”<sup>39</sup>*

Overall, these participants appear to be undertaking a meaningful proportion of the reported procedures in England and Wales on an annual basis.<sup>40</sup>

## 9.6 Training

These procedures are mainly encountered during postgraduate or sub-speciality stages of training:

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<sup>35</sup> Participant A.

<sup>36</sup> Participant B. IUGR= Intrauterine growth restriction.

<sup>37</sup> Participant B.

<sup>38</sup> Participant C.

<sup>39</sup> Participant D.

<sup>40</sup> Department of Health and Social Care (DHSC), *Abortion Statistics, England and Wales: 2017* (DHSC Revised December 2018).

*“In terms of actual doing the technical aspects this was only in the final stages of our training Oh Actually witnessing the counselling around the discussions around this in the final stages when you're under subspeciality.”<sup>41</sup>*

## 9.7 Power

This theme focuses on the power balance between doctor and patient. **PC** conceives the patient relationship and decision-making process as a collaborative arrangement:

*“What you normally do is in advance of the mother coming, look at what the abnormality is. Look at the latest literature and see what the benefit and risk ratio is and then given counselling and even reach a decision together with parents. Not strictly advising... not so much advising. Let's make a decision together. What is the most reasonable thing based on the balanced risks and benefits”<sup>42</sup>*

Ultimately, it is the parents that “*have to deal with the babies not I. Right they are in charge of that decision*”.<sup>43</sup> This was the most patient centric response but reflects the reality of the long-term caring obligations for a child or children with or without disability. Tellingly, **PC** had this to say about parental/ patient communications:

*“The way you counsel patients can be coloured by people's perceptions and so for example, thinking about fetal abnormality, there are different approaches absolutely. Sometimes you learn as much about how not to do things as well as much as how to do things. Yeah, I very much reached a conclusion it is impossible to predict as a clinician how parents think about things. A lot of time of the time has to be spent digging, uncover ...”<sup>44</sup>*

First, this raises a question about how far doctors need to go to unearth patient values and priorities – whilst knowledge of these matters is undoubtedly helpful to collaborative decision-making, should we convert this into a legal obligation?

Secondly, it begs the question whether we can create sufficient space for learning, without endangering patient safety? **PA** certainly emphasises the importance of knowing “*the context in which in which it is being asked ...why that request is being made*”,<sup>45</sup> giving the impression that patient disclosure is the key to unlocking access to the procedure. Although **PC** provides powerful support for shared decision-making, he acknowledges this may not happen in wider clinical practice:

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<sup>41</sup> Participant A. For the importance of training in decisions about subspecialty, see Ellie Lee, Sally Sheldon Sheldon and Jan Macvarish, 'The 1967 Abortion Act fifty years on: Abortion, medical authority and the law revisited.' (2018) 212 *Social Science and Medicine* 26, 28, <<https://doi.org/10.1016/j.socscimed.2018.07.010>> accessed 18 May 2019

<sup>42</sup> Participant C.

<sup>43</sup> Participant C.

<sup>44</sup> Participant C.

<sup>45</sup> Participant A.



*“To say ‘go away make your own decision’. That is a real cop out. That’s the other extreme from the directive and I have seen that happen as well. Often in my view that is lack of knowledge sometimes or understanding from the clinician’s perspective. So one way around this is to leave all the evidence on table”.<sup>46</sup>*

Effective knowledge and skills training may help address any reluctance to engage in shared decision-making.

Another way that doctors can exercise power is through the framing of risks and benefits:

*“One way of counselling is to say to look at this on both sides the positive side and the negative side. The positive side is often that actually the chance are that whatever you do things will turn out ok because even though the risk of say prematurity is high say 10-15% after a reduction but that means there is an 85-90% chance of not having that complication. So there 2 ways always of looking at the two sides of the coin. Talking back through what the chances are of going wrong but also what the chances are of things turning out absolutely fine. Whether we do decision A or decision B”<sup>47</sup>*

Although the GMC emphasises the need for consistency and balance in this context,<sup>48</sup> it is the doctors who are the ultimate architects of the informational landscape and choices presented to parents.

As indicated, there was reticence about the reduction of healthy twin pairs by some of the participants<sup>49</sup>:

*“reducing a twin to singleton pregnancy because mother does not want a twin pregnancy. I think that is a really difficult choice, twins actually do very very well and certainly increasing the risk of overall pregnancy loss and so you know in the end these are actually although apparently simple issue ... actually easier in a triplet because in the twin the chance of a normally healthy outcome for both baby is very high without abnormality. **Frankly, we are trying to steer the parents away from going down the reduction route. Really strong feelings about it. If the choice is about terminating both babies you know if don’t offer. Maybe it is a reasonable thing.**”<sup>50</sup>*

These responses suggest that personal/ professional values may be creeping in, allowing beneficent and consequential considerations to influence the clinical response.<sup>51</sup> Again, the highlighted segment matches our earlier description characterising doctors as choice architects.

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<sup>46</sup> Participant C.

<sup>47</sup> Participant C.

<sup>48</sup> General Medical Council, *Decision making and consent: Supporting patient choices about health and care, Draft guidance for consultation* (GMC 2018), para 27.

<sup>49</sup> See also Participant A (n15) and Participant D (n16).

<sup>50</sup> Participant C (emphasis added).

<sup>51</sup> Interestingly, participant B also observes that in twin pregnancies, women are “less likely to seek information that they will have to make very difficult decisions about”.

There is further evidence of resistance when treatment is demanded - **PA** is clear that patients will “*have to come back at least have one night*”<sup>52</sup> – but this is consistent with the need for reflection and deliberation emphasised in the latest GMC draft guidance.<sup>53</sup> However, in terms of professional compulsion, **PC** says:

*“I think about self-determination. Whose self-determination are we talking about: the parent, the clinician, the unborn fetus? Don’t have that either in law or reality. It is between different people. Never been in a situation when I have declined a parent request but I can see where that might occur and then I would not want to get involved. Got to be ok for clinician so long as the patient is properly looked after. I can’t or I am not prepared to but here... and that’s fine. I don’t see that’s a problem.”*<sup>54</sup>

So, here the specific emphasis is on the accommodating professional values, conscientious objection and clinical judgement in practice.

## 9.8 Parental support

This theme addresses varying forms of parental support. **PA** make the point that parental, and typically maternal support is clinically driven and fact specific, rather than default. External agencies like TAMBA and ARC are used by the clinical team to provide additional support and information for parents.<sup>55</sup> Mention was made of parent to parent support mechanisms, although in practice, the response has been a little mixed because it is “*(d)ifficult to match people’s expectations ... different expectations and baggage.*”<sup>56</sup> Again, there was mention of the supportive role played by the wider midwifery team during the tertiary management process, who would “*provide emotional counselling support.*”<sup>57</sup> A range of other professionals may be brought into consult with the clinical team and the parents, especially for ongoing pregnancies requiring surgical intervention:

*“We will very often ask a paediatrician to see them and generally for the ongoing pregnancy we will ask a paediatric surgeon to see them if the baby is likely to need surgery. That tends to be in pregnancies that are confirmed to be ongoing rather than to aid a decision for termination.”*<sup>58</sup>

This confirms that the level of support is moderated by the clinical decision-maker. Parents in tertiary centres have generally seen a medical team elsewhere prior to

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<sup>52</sup> Participant A.

<sup>53</sup> GMC (n48), para 23.

<sup>54</sup> Participant C.

<sup>55</sup> Participant C.

<sup>56</sup> Participant C.

<sup>57</sup> Participant A.

<sup>58</sup> Participant D.

referral. One participant suggested that parents with prior knowledge (eg of anomaly), are generally better prepared on arrival than other patients.<sup>59</sup>

In terms of one to one support, participants describe a range of aids and narratives to help parents. **PC** describes the importance of developing workable narratives: “*you create stories that you know function well for most people work in 15-20 minutes bursts.*”<sup>60</sup> The same participant admits that they:

*“use pictures as well. You know depending on the parents’ understanding. May give them an abstract and often with drawings as well. We are talking about proportions of things. Explaining risk. Do this quite a lot for other things. For example... chance of intellectual impairment in children, brain abnormality on ultrasound, there is a 30% chance of impairment and 70% of non-impairment. There the same. We talk to them of 1/3 chance. A toss of a coin although different.”*<sup>61</sup>

This use of visual aids and infographics is encouraged by the GMC in their latest draft guidance on decision making and consent.<sup>62</sup>

In a critique of regulatory guidance, **PE** argues:

*“It is fine having all the details of every bit of evidence but you got make them easier for people to get the key messages. Look at areas where they can go ...”*<sup>63</sup>

This is consonant with the GMC draft guidance which encourages a tailored information sharing process reflecting their “*particular concerns, wishes and values*”,<sup>64</sup> the available options and the patient’s knowledge and understanding of “*their condition, prognosis and the possible options*”.<sup>65</sup> It is also evident that information sources are not enough on their own to support or improve decision-making. Patients still need to be persuaded or encouraged to read and understand the materials:

*“A lot of hospitals give women that sort of information based on (anonymised) guidelines, info sheets. A lot of women do not read them, do not retain them. Not a lot of opportunity to gauge how far they understand them... we are trying within those organisations to make info a bit more attractive women so that they have to have a discussion eg about forceps delivery, know a little bit about it, then have an easier explanation about what is to come, less time explaining.”*<sup>66</sup>

So, having active patient engagement with information sources, might help bridge the consultative process and make any clinical encounter more effective/ efficient.

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<sup>59</sup> Participants C.

<sup>60</sup> Participant C.

<sup>61</sup> Participant C.

<sup>62</sup> GMC (n48), para 27.

<sup>63</sup> Participant E.

<sup>64</sup> GMC (n48), 5.

<sup>65</sup> Ibid., para 13.

<sup>66</sup> Participant E. Cf GMC (n48), para 20.

## 9.9 Influences

This theme focuses on professional and legal influences/ effects. For **PA**, it is peer practices that are important:

*“what guides my behaviour is what the peer practices for doing or how you do a certain thing or when you offer something and the framework for multidisciplinary group What is underpinning those sort of things is actually what underpins good medicine so getting the sense that this does not feel right and so maybe I need to speak to another colleague... maybe this is quite complex maybe I need do speak to another colleague or something like that you know but those are very good underpinning general medical principles that are across , you use it for anything... for a broken bone...”<sup>67</sup>*

There is more hesitance about the impact/ value of professional guidelines, especially for more experienced doctors:

*“I think it does ... I hesitate... the answer is yes but I guess some of us who have been trained at a time when there wasn't guidelines on everything, we were trained by good medicine and that good medicine or the practice is not changed or we are up to date with the literature I mean oh that's what people do, there is the big influence of that”<sup>68</sup>*

Multiple informational sources may be of greater value for evidence-based medical practice:

*“one of the thoughts that came to my mind is this related to the prevalence of a certain thing. Is this something usually prevalent then guidelines actually much better, if a rare condition it could be the literature that may hold to some extent although also depends to some extent something is investigated or studied or is amenable to be studied. For something like outcome rates for selective reductions you would get the big centres, the big regions publishing their series.”<sup>69</sup>*

From **PB**'s perspective, the professional sources are something of a mixed bag - the BMA has produced little of relevance, but some RCOG guidance could be helpful:

*“(Commenting on RCOG) yes, the termination for fetal abnormality is quite a useful document. The ethics of late termination I personally do not find it particularly helpful document because it doesn't actually in the end help you with the difficult decisions. It kind of waffles around these very difficult decisions and we all know that...”<sup>70</sup>*

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<sup>67</sup> Participant A.

<sup>68</sup> Participant A.

<sup>69</sup> Participant A.

<sup>70</sup> Participant B. This participant acknowledges that the Nuffield Council on Bioethics “produces papers that are relevant to some of the (ethical) issues that we deal with.”

*“I suppose more relevant to the majority of fetal medicine consultants was guidance about the law in relation to babies born potentially alive after a termination. **That’s the statement that is most influential to practice**”<sup>71</sup>*

With one or two exceptions, the professional guidance sits in the background for **PC** with peer research and workplace considerations taking priority:

*“(commenting on guidance changes made over last 5 years) I don’t think so, no, I think there are minor adjustments. I very much take the scientific view or perspective... I think the research or the work space is the most important to me.”<sup>72</sup>*

*“there is some NICE guidance on MP management on twin pregnancy” ...” No except the legal framework for the termination of pregnancy”<sup>73</sup>*

*“yes, .... Almost the regulatory framework is the background upon which you then build with guidance and fine tune with research. Becomes one consideration. You don’t think about the linear relationship between them.”<sup>74</sup>*

**PD** had not used any BMA guidance but derived some assistance from some RCOG guidance and clinical reviews:

*“There is the risk benefit to the baby and the mother. The RCOG have some guidelines on that and they’re quite useful. There are quite a few reviews out there that we tend to look at every now and then.”<sup>75</sup>*

There was also positivity about the impact of IVF guidance and regulation:

*“in the UK we are very fortunate to have the regulations around the IVF practice, high order has really dropped in terms of an issue I think.”<sup>76</sup>*

**PE** makes this important point about regulating the obstetric environment:

*“Problem with Obstetrics is that it is extraordinarily variable environment. Cannot create guidelines for every eventuality and a lot rests on professionalism, professional decision-making.”<sup>77</sup>*

There is also evidence that vague or broad legal rules will facilitate evolutionary interpretation:

*“we have essentially interpreted the law in a way that most people in our position interpret it, which is basically legal before 24 weeks under whatever clause you want to use and we would use clause E and it’s only legal after 24*

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<sup>71</sup> Participant B (emphasis added).

<sup>72</sup> Participant C.

<sup>73</sup> Participant C.

<sup>74</sup> Participant C.

<sup>75</sup> Participant D.

<sup>76</sup> Participant A.

<sup>77</sup> Participant E

*weeks if you actually fit the criteria for clause E and of course that is very open to interpretation and you do different things.”<sup>78</sup>*

This interpretation is consonant with the findings of earlier research,<sup>79</sup> and is an excellent example of the weak constraints imposed by current legal norms on this participant’s medical practice. This fits with our earlier analysis suggesting that medical decisions are being made on the basis of criterion, or upon interpretations that do not square with a literal interpretation of the AA 1967. This is an important observation when we also consider the relatively weak influence of professional ethical norms recorded by our participants.

However, the threat of individual litigation does appear to have a significant focussing effect for **PB**:

*“it clearly has because the first iteration of that suggested that if you embarked on a termination of pregnancy with the intent of the baby not surviving but it did survive and if you did not treat a baby born you could find yourselves being prosecuted for murder and that is clearly is quite focussing. I don’t think that has ever happened but the more recent guidance recognises, I think, the reality that some parents will not opt for feticide before late termination in which case there are circumstances where you may with clear prior agreement with parents, midwives, neonatologists and everyone else make a clear written plan go ahead, that you will only provide comfort only care once born”<sup>80</sup>*

Another participant mentioned the detrimental effect that the fear of litigation could have on medical practice:

*“there is some mention in literature about how cases against Doctors can lead to avoidance behaviour, over investigation, over prescribing ... you know. The whole system of GMC and the legal profession which is intended to protect the patients, may in the intention to protect that one patient may have side effects on the practice of that Doctor that effects a whole bunch of other people”<sup>81</sup>*

This echoes consequential and proximity concerns around medical regulation.

Although uncertainty around the law can provide flexibility, it can also be an unhelpful influence on professional practice:

*“So we are all of us I guess acutely aware that you can find yourself in a court on both sides of the argument if you don’t do a termination and turns out that you have a baby that has major genetic problem that you thought might be there but you couldn’t prove it ...but you could equally ...you could end up with [anonymized] doing a termination and somebody feels you shouldn’t have done that. So, the law isn’t particularly helpful because there isn’t a lot of case law to help us. The RCOG utterly duck the issue saying it’s terribly difficult. They*

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<sup>78</sup> Participant D. For a discussion on evolutionary interpretation by doctors, see Roger Brownsword and Jeffrey Wale, ‘Compromise Medicalisation’, in C. Stanton and others (eds), *Pioneering Health Care Law Essays: In honour of the work of Professor Margaret Brazier* (Routledge 2015).

<sup>79</sup> See for eg, Robyn Lotto, Lucy K. Smith and Natalie Armstrong, ‘Clinicians’ perspectives of parental decision-making following diagnosis of a severe congenital anomaly: a qualitative study’, (2017) 7 *BMJ Open* e014716.

<sup>80</sup> Participant B.

<sup>81</sup> Participant C.

*provide a few scenarios, but they don't actually give a conclusion what to do with these scenarios and I know that different units have different policies. Some will have a formal ethical committee to consider these cases. When I started here, and I was the sole practitioner for [anonymized] years and therefore felt very exposed in terms of making the decisions I considered doing that and then realised I realised in the end I was going to carry the can. If the ethicists said yes and I said no.”<sup>82</sup>*

These closing remarks emphasise the responsibility and accountability resting on the shoulders of individual doctors.

## 9.10 Culture

There was acknowledgement of the impact of workplace culture and variation on local clinical practices:

*“yes and between institutions. Working at [anonymised] for example is very different from what we do here. Try to support parents through the decision-making process. Being directive is not our thing.”<sup>83</sup>*

The implication being that some workplaces and local cultures offered less supportive decision-making processes. **PD** also acknowledges differentials in local practice and the influence of culture within his workplace and of professional views across the country. Workplace resourcing and time management are also highlighted by **PE**:

*“I think the problem is we are having a lot of discussions about patient decisions in NHS which is a time poor environment and that is the area where cases/decisions come across in a time poor environment caused by NHS or professional causes... giving patient time to choose. There are opportunities in NHS. It is just how you approach it, how you document it, how you run your consultations and how you persuade the NHS you can protect yourself from litigation if you spend another 10 minutes for providing time for good decision making.”<sup>84</sup>*

This suggests that organisational and time management skills may be critical professional attributes for building sufficient time for shared decision-making in publicly funded healthcare environments.

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<sup>82</sup> Participant B.

<sup>83</sup> Participant C.

<sup>84</sup> Participant E.

## 9.11 Personal values

This theme focuses on the personal values and beliefs of clinicians. There was some appreciation that the personal values of trainees and doctors could change over time with experience and learning.<sup>85</sup> The existence of personal values were not seen as problematic per se but there was mixed evidence about the actual effect on clinical practice. For example, **PA** discloses a (sympathetic) reluctance to the reduction of a healthy twin pair:

*“your effectively doing something in effect doesn't come naturally that bit the request is a bit like someone somebody saying you know what actually I want to end a perfectly healthy arm I know it is different I'm not trying to equate one to the other but I guess the point I'm trying to make for somebody to try to do something that you don't necessarily feel may be necessary on the basis of the wellbeing, of the physical wellbeing of the mother or the baby yes maybe mental wellbeing”<sup>86</sup>*

Whilst, this statement appears to be underpinned by concern for the wellbeing of the mother rather than explicit personal values, the participant agrees that having knowledge of objective supporting criteria makes it easier to go along with the parental request:

*“it's easy where they got a very objective circumstantial situation around them that actually makes it easy to understand their decision, so for example, they just on their own, they've got no family support they've got no one, this or you know that is driving their positions it is easy.”<sup>87</sup>*

**PD** was much clearer about the role of his personal beliefs in practice:

*“If I think it's legal I will do it irrespective of my own personal beliefs or whatever it's not for me to say.”<sup>88</sup>*

and reflected upon the lessons that could be learned from past experience:

*“It is not a situation where people usually do and I can remember 15 years ago somebody did request one and I said you shouldn't do that and the baby ended up born very preterm and handicapped and I kinda thought I had no right to do that because it was legal and so now I would do it, because it is legal and very clearly fulfils the criteria for clause E.”<sup>89</sup>*

In contrast, **PC** doubted it was ever possible to completely divorce personal values when addressing parental requests for treatment.<sup>90</sup>

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<sup>85</sup> Participant C.

<sup>86</sup> Participant A.

<sup>87</sup> Participant A.

<sup>88</sup> Participant D.

<sup>89</sup> Participant D.

<sup>90</sup> Participant C (n54).



## 9.12 Ethical vs Legal

This theme addresses the tension between ethical/ legal issues and is neatly encapsulated in this exchange about the weekly discussion of rare or complex cases:

*“Question will (discussion) extend to ethical issues?”*

*Answer can do if we've got somebody who is exploring termination of pregnancy in a situation where I'm not sure whether clause E might be met that would be something we might discuss.*

*Question is there any other avenue that you would have in the institution or within your professional to have that dialogue?*

*Answer yes so if we are considering late ... very late terminations ... so as soon as we are post 24 weeks. Where the viability of the baby we see that that as ethically different to sub 24 weeks and now you could argue that the law doesn't because it says you can do a termination under clause E handicap but actually the law does because you can't do terminations for different reasons after 24 weeks so clearly there is a bit of uncertainty about the law itself is there a difference about pre and post 24. **Clearly there is a difference because Society thinks it differently and [anonymized] found themselves investigated by the DPP because they did a termination based with a baby with a cleft lip and I know others who have been investigated for late feticide.**<sup>91</sup>*

Again, the reference to the threat of litigation/ criminal investigation and individual accountability suggests that defensive mechanisms are in play especially in proposed terminations after 24 weeks. There is clearly the potential for ethical/ legal conflict around viability – an area which receives limited attention in general discussions about conscientious objection.

## 9.13 Legal framework

This theme dwells on the legal frameworks for termination of pregnancy.<sup>92</sup> In the following exchange, we observe **PA** going over and above the strict legislative requirements for certification:

*“Question if you're involving more than two colleagues - the law doesn't require you to do it but what I'm trying to understand is it driven by that case trying to introduce reflectiveness on the part of the parents?”*

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<sup>91</sup> Participant B.

<sup>92</sup> See also participant E (n77)

**Answer** *yes for both ... what always try to say however difficult the position is what's harder is the time after and you have to make sure had enough time in what is available – the time and the opportunity to reflect*

**Question** *those processes those cautious processes allow that ambition?*

**Answer** *I hope it will allow ... it is not so much to drive their position but for them to feel because people do regret their decision, but they need to feel and if that was to unfortunately happen, they need to feel they have not just made a decision by speaking to one person*

**Question** *would you be fair to describe to give them an opportunity to pause and reflect rather than drive or nudge the decision?*

**Answer** *exactly*<sup>93</sup>

This participant claims he is driven by the desire to build in reflective opportunities for parents, rather than by defensive or resistant practices/ values. In contrast, **PB** maintains a strict approach in relation to requests for the reduction of healthy twin pairs because *“that wouldn't fit the Abortion Act criteria in terms of...”*<sup>94</sup> Most of **PB's** terminations in multiple pregnancy:

*“pretty much exclusively fall under clause E of the Abortion Act. And so, unless there is a significant risk of serious handicap then I don't believe that there is a sufficient risk of handicap having twins is higher, there is a risk of having cerebral palsy in twins than a Singleton mainly as a result of prematurity but...”*<sup>95</sup>

**PD** conceives the legal framework in straightforward terms albeit with an interesting spin on ground E before 24 weeks gestation.<sup>96</sup> In addressing late terminations in pregnancy (ie post 24 weeks) some institutions operate an internal discursive mechanism for reaching decisions, especially in areas of uncertainty:

*“So usually there would be a neonatologist and essentially our line is if with that degree of abnormality, the baby would have treatment withdrawn as a neonate if it is delivered, we would feel that it was reasonable to offer termination. So, I don't think we would offer termination if we found a late diagnosed Down's syndrome, a child with Downs because if that baby was delivered it will be given full resuscitation. If you have major inter-cerebral haemorrhage where it's likely to be poor very poor the baby was born you would not assist with ventilating, you might consider that.”*<sup>97</sup>

This is consonant with the findings of earlier research,<sup>98</sup> and shows patient autonomy being relegated for entity-based considerations in late terminations. Here, the legal

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<sup>93</sup> Participant A.

<sup>94</sup> Participant B.

<sup>95</sup> Participant B.

<sup>96</sup> Participant D (n78).

<sup>97</sup> Participant B.

<sup>98</sup> Lotto et al. (n79.)

framework is clearly limiting patient choice and doctors appear to be analogising pre and post birth scenarios to determine the legality of any treatment response. Again, we have evidence of the instrumental effect in post 24-week terminations:

*“Its background. Does not enter the discussion with the parents. Don’t say whether legal or illegal. For most surgery. The 24-week cut off for termination that would only become an issue if a late request for a reduction in an abnormality... not be possible but really never come across that. Parents will know from early on and because most are related to fertility treatments most come very early on [inaudible].”<sup>99</sup>*

When asked whether triplet reductions were typically carried out under ground C, **PB** responded:

*“there are those that fall under E as well in that .... the argument is substantially reducing the risk of severely .... what you're trying to do reduce is the 24 to 26 week premature triplets and maybe 26 to 28 weeks ones because those are the ones who will have a high risk of complications and serious handicap as a result of being severely premature there is a pretty substantial risk there is a risk of delivering in that critical period and if you do fall into that period there's a higher risk amongst that survivors of developing a handicap probably higher in multiples than singletons”<sup>100</sup>*

When **PB** was asked whether maternal risk considerations fed into decisions to reduce, this interesting response is given:

*“wouldn’t normally no, again every complicated pregnancy is more common in the multiple and the higher the multiple the more common it is but most mothers cope with perfectly well with twins with more twinges and so on. There is a higher risk of preeclampsia. Triplets is a noticeable physiological stress for quite a lot of mothers. Higher than that, you begin to run into quite common significant issues, just in terms of coping with caring, carrying that many babies”<sup>101</sup>*

Of course, we should remind ourselves that consideration of fetal welfare is not a lawful basis for termination.

The strict requirements of the law on information disclosure may present a dilemma for some consultants and again places emphasis on individual responsibility/ accountability:

*“Whether really what I am going to write down is for the parents and for their understanding and the shared decision-making process or whether going to write a legal document that absolves me of all responsibility and I think sometimes the legal..., sounds awful... gone too far to demonstrate that all risks.”<sup>102</sup>*

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<sup>99</sup> Participant C.

<sup>100</sup> Participant B.

<sup>101</sup> Participant B.

<sup>102</sup> Participant C.

## 9.14 Decision-making

This theme has 6 sub-categories, and each is addressed separately:

### 9.14.1 Clinical selection

If you do not reduce a multiple pregnancy:

*“there is a risk of spontaneous MFP loss and the risk of premature birth. They are the 2 big categories. You lose the pregnancy because mother miscarries at 15-17 weeks with babies or you actually have an early preterm at 28-30 weeks. Not really concerned at prematurity beyond 34-35 weeks because those babies tend to do very well anyway.”<sup>103</sup>*

However, if you do reduce the multiple pregnancy (from 3>2):

*“you reduce the risk of prematurity but you increase the risk of miscarriage slightly because you are doing an intervention and then yeah there is that balance again is pregnancy loss or miscarriage is one outcome... live births with handicaps is a completely different outcome. Cannot say 2 are equivalent. Different things. Comparing 2 different things. Completely”<sup>104</sup>*

When anomaly is not involved, the selection process is driven by location and access:

*“then you continue on with long with the lowest risk then the other principle that you use – the fetus you want to reduce you usually want it to be the first to away from the neck of the womb if possible so that ... but sometimes you can't because you can't get to it or whatever but you want to try to be as high as possible so that if you know has the stuff breaking down it doesn't set the whole pregnancy ...”<sup>105</sup>*

And fetal size/ chorionicity:

*“that goes into the whole assessment right , so if you have two which are normally sized but one that is abnormally sized and is struggling and very small, even though it may have a favourable risk, you would go for the the small one and the other thing with high orders you have to check one might be sharing one placenta and one might be on its own so you can't reduce the one of the two that are sharing in the placenta because if you reduce one you effect the other one so you've only got the one single. You could reduce three down to one it's known it's recognised”<sup>106</sup>*

**PB** records a similar practice:

*“There may be a clear-cut indication there is an anomaly or one is noticeably smaller or and if all else is equal then it is really around accessibility. And on no*

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<sup>103</sup> Participant C.

<sup>104</sup> Participant C.

<sup>105</sup> Participant A.

<sup>106</sup> Participant A.

*particular evidence base, I try to avoid avoid twin one/ triplet one, because that baby is nearest the cervix and thereby more at risk of ascending infection.”<sup>107</sup>*

Similarly, **PD** chooses the “one that's furthest away from the cervix, the one that is easiest to get to.”<sup>108</sup>

#### 9.14.2 Medical decision-making

**PC** helpfully summarises the term decision-making “in terms of communication and advice given to patients.”<sup>109</sup> This might frame the clinical encounter as a one-way exchange, but this is not consistent with other comments made by this participant.

Internal collaborative and peer review mechanisms appear to underpin good medical decision making for **PA**.<sup>110</sup> Similarly, **PB** says:

*“yes, we have a weekly meeting where we go through everything we seen this week, and everything that is due to come up next week. We will often have a discussion around some of the difficulty of management of some of the rarer patients or what some of the common things that we do. Common things we clearly do all the time so it's quite easy, but if there are rarer things that we are discussing and we will try and discuss them.”<sup>111</sup>*

The importance of enquiry and understanding patient requests is emphasised:

*“if you are reducing twins normal I would want to understand the reason underpinning the request. I would try to understand at least. I would offer a second opinion and even sometimes, an external second opinion because I think it is very hard sometimes.”<sup>112</sup>*

As to the need for openness and straight talking:

*“She is 45 the only pregnancy she will have and really unlikely that another pregnancy will be achieved. I am generally very open with parents. I tell them unlikely you will achieve another pregnancy. Do you feel this is likely to be your last chance? Last chance pregnancy. This plays into the decision.”<sup>113</sup>*

And creating time and space for decision-making:

*“as long as they need.... These are often the longest consultations ... honestly. We lock our office for an hour. Go for a cup of tea and come back. Quite often the end of a long conversation. Go home, sleep on it and come back tomorrow.”<sup>114</sup>*

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<sup>107</sup> Participant B.

<sup>108</sup> Participant D.

<sup>109</sup> Participant C.

<sup>110</sup> Participant A (n67).

<sup>111</sup> Participant B.

<sup>112</sup> Participant A.

<sup>113</sup> Participant C.

<sup>114</sup> Participant C. Cf GMC (n48), para 17-18, 20-32.

This fits with the gravity of these decisions, the draft GMC guidance on time and resource constraints,<sup>115</sup> and reflects the benefits of using specialist tertiary fetal medicine units.

For **PC**, collaboration with the parents is critical because “(t)hey have to carry that decision-making process for the rest of their life.”<sup>116</sup> **PB** also emphasises the need for collaborative decision-making in the context of late terminations but he appears to be talking about internal collaboration with colleagues.<sup>117</sup> However, the doctors ultimately control outcomes, timings and options as choice architects:

*“the parents are very clear after you’ve told them ‘yes’ I want a reduction, I still give them even if they push on the same day, I always give them that one night.”<sup>118</sup>*

*“Frankly, we are trying to steer the parents away from going down the reduction route. Really strong feelings about it.”<sup>119</sup>*

In terms of triplet or higher order pregnancies, the decision to reduce often comes down to historic losses<sup>120</sup> or the likelihood of parents coping post birth:

*“Our outcomes for our triplets tends to be very good. Often comes down to how parents cope with triplets. If they come holding their head in hands. This is really terrible news. So difficult for our family unit to cope and actually got 3 other kids ... or whatever ... might be the... rather than the medical. Very finally balanced.”<sup>121</sup>*

In cases of anomaly, the risk assessment and communication process can be very complex:

*“If you had a pair of babies with a major abnormality where parents had already some idea what the abnormality is and we confirmed that and they’ve already time to think about things and they will already come with a decision in their head. We don’t want a handicap baby and therefore we want a selective termination. Then I would explain what the effects on the co twin might be in order to make that balanced judgment. It is very individualised because, for example there are some abnormalities that are least ... expect a baby with the abnormality to die shortly after birth therefore does it make sense to put the co twin at risk from a selective reduction if that baby in a sense is not going to be exposed to long term handicap anyway. One might think just leave them in case of twins leave both twins alone. The reasons for termination which is to avoid long term handicap is not an issue because baby going to die anyway. On other hand there are abnormalities associated with pregnancy complication, where the whole pregnancy will definitely be at risk, for example, you might have a problem where brain has not developed at all, an encephaly where you might say well the baby is going to die anyway but why risk a miscarriage but the condition is also associated with additional fluid around*

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<sup>115</sup> GMC (n48), para 36-38.

<sup>116</sup> Participant C.

<sup>117</sup> Participant B (n97).

<sup>118</sup> Participant A.

<sup>119</sup> Participant C.

<sup>120</sup> Participant D.

<sup>121</sup> Participant C. Cf “quite common significant issues, just in terms of coping with caring, carrying that many babies”. (**PB**)

*the baby and the risk of pre-term birth. So really needs very careful consideration.*  
”<sup>122</sup>

### 9.14.3 Parental decision-making

Whilst “(m)aternal mortality (is) very rare”,<sup>123</sup> parents:

*“may choose to reduce triplets to 1 for example if significant burden on family maternal wellbeing you know but again not common at all most of the time ...it comes into consideration, certainly comes into parental consideration, whatever it is I don't my wife to be more unwell or whatever...”<sup>124</sup>*

In terms of the need for reflection and dialogue with other healthcare professionals:

*“I hope it will allow ... it is not so much to drive their position but for them to feel because people do regret their decision but they need to feel and if that was to unfortunately happen, they need to feel they have not just made a decision by speaking to one person”<sup>125</sup>*

Similarly, **PB** says that even when parents come with a firm decision to have a reduction, they “*would still say that they should go away and think about the data and come back*”.<sup>126</sup> Otherwise “*the parents sometimes later look back in regret because they feel they have been pulled into a sausage machine process*”.<sup>127</sup> This is regarded as good medical practice by the GMC.<sup>128</sup> However, parents display variable engagement in the discussion of reduction:

*“There will be group of parents who will not want to discuss at all and so I would open the discussion by saying this is an issue that some parents want to discuss, is it something you would want to hear about and they say no, I say fine we will support you with the triplets let's get on with it. If it is something they want to discuss I will discuss it and I may need to counterbalance some of the counselling they've had beforehand.”<sup>129/130</sup>*

**PE** makes a similar point in the context of engagement with informational sources.<sup>131</sup>

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<sup>122</sup> Participant C.

<sup>123</sup> Participant C. (added)

<sup>124</sup> Participant A.

<sup>125</sup> Participant A.

<sup>126</sup> Participant B.

<sup>127</sup> Participant B.

<sup>128</sup> GMC (n48), paras 23/ 36.

<sup>129</sup> Participant B.

<sup>130</sup> See also Participant D (n31)

<sup>131</sup> Participant E (n66).

#### 9.14.4 Ethical decision-making

**PA** highlights the potential ethical conflicts thrown up by certain fetal reduction procedures:

*“you know if you feel straight forward twin pregnancy there not sharing the same placenta and they're not going into the usual placenta related complications ... then I guess the ethical difficulty there is signing up to something completely flip this whole thing on its head and you could end up with no pregnancy and the difficulty is whether that the person or the couple or whatever have really has thought through everything. I guess that is where the ethical difficulties and of course you can never judge that in entirety right, it's easy where they got a very objective circumstantial situation around them that actually makes it easy to understand their decision, so for example, they just on their own, they've got no family support they've got no one, this or you know that is driving their positions it is easy.”<sup>132</sup>*

This suggests that the participant might be seeking objective parental justification for their request that is not necessarily connected to the legal framework. Again, this is justified on reflective grounds.

There were divergent views about the involvement of a formal ethics process in complex cases:

*“When I started here and I was the sole practitioner for [anonymized] years and therefore felt very exposed in terms of making the decisions I considered doing that and then realised I realised in the end I was going to carry the can. If the ethicists said yes and I said no”<sup>133</sup>*

However, some participants were more enthusiastic about formal ethics support:

*“we have a very good professor of medical ethics here it's very good who we talk to about these things sometimes. He is a very good provider of a framework. Thinking through the difficult stuff.”<sup>134</sup>*

**PC** acknowledged that ethical analogies could be helpful:

*“people use the lifeboat analogy in MFP. Got a lifeboat capacity of 12. Someone drowning in front of you. The 13<sup>th</sup> person drowning in front of you. If you haul them on everyone will drown or ... you have got to make decisions.”<sup>135</sup>*

There was awareness that professional ethical sources were being used for legal standard setting, although it was imperative that up to date versions were used for this

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<sup>132</sup> Participant A.

<sup>133</sup> Participant B.

<sup>134</sup> Participant D.

<sup>135</sup> Participant C.



purpose.<sup>136</sup> Finally, there was recognition of the need for professional organisations to provide clarity for the professional regulators in areas of uncertainty:

*“we will support our drs having difficulties with GMC to a reasonable degree. If someone acting unprofessionally, but if areas unclear try to help interaction with GMC. Had some success. Dr having difficulty may engage with us. May use our documents. Write reviews...”<sup>137</sup>*

#### 9.14.5 Decision difficulty

The shifting balance of risk in multiple pregnancy makes comprehension and choices challenging:

*“you would usually divide them into those two parts. Loss pre 23 weeks and loss post 23 weeks and preterm birth rate post 23 weeks ... the thing that is very difficult for people, you are much less likely to have a handicap baby although the absolute risk of a handicap baby is quite low and you're slightly more likely to lose the whole pregnancy at an early to middle stage. That is what people find difficult to deal with but that risk you going to adjust.”<sup>138</sup>*

Of course, you also need to factor the differing attitudes to risk for the doctor and parents into the equation.

#### 9.14.6 Decision aids

The participants describe the use of graphs,<sup>139</sup> pictures, abstracts, drawings,<sup>140</sup> and standardised/ personalised text<sup>141</sup> to support the decision-making and consent processes:

*“to see if patients would understand in a way that they would understand reasonably clearly and a paper has a couple of graphs that I find which you can show when babies tend to deliver if they are reduced when they tend to deliver if they're not reduced and so you can see that this is excess of pre 24 weeks if you select fetal reduction as opposed to a number of severely premature if you don't...”<sup>142</sup>*

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<sup>136</sup> Participant E.

<sup>137</sup> Participant E.

<sup>138</sup> Participant D.

<sup>139</sup> Participant B.

<sup>140</sup> Participant C.

<sup>141</sup> Participant D.

<sup>142</sup> Participant B.

*"I use pictures as well. You know depending on the parents' understanding. May give them an abstract and often with drawings as well. We are talking about proportions of things. Explaining risk. Do this quite a lot for other things."<sup>143</sup>*

*"in terms of the risks that we talk about would be usually in the ultrasound report. There will be a copy and paste thing that we would put into the ultrasound report about the risks that we would then sometimes alter that as it is a bit generic. If instance you had a very high maternal risk, we would add to it. If it was a monochorionic and it will be slightly different and again it would depend on the gestation and whether they're both babies are normal."<sup>144</sup>*

In the latest GMC draft guidance, it is envisaged that when a patient *"is likely to have difficulty retaining information"*, there should be an offer to record the discussion and any decisions made.<sup>145</sup> Participant E also observed the value and benefit of using shorter and focussed professional guidance which get across *"the key messages"*.<sup>146</sup>

## 9.15 Reform

This theme addresses suggestions for or examples of regulatory reform. **PB** thought it would be helpful to have *"some legal guidance about the term significant ... the term substantial"* in section 1(1)(d) AA 1967.<sup>147</sup> This participant also made adverse comments about the decision in *Montgomery v Lanarkshire Health Board*<sup>148</sup> because of existing vagueness in the AA 1967:

*"I think Montgomery complicates it. I think the issue is it would be helpful to know what is substantial because at the moment it is so woolly. Is a 1% risk substantial? Does it vary how nasty the condition is? Do you have to have a 50% risk for a relatively minor thing or a 1% risk of something really disastrous. Almost every baby I look after is about 1% at risk of something really nasty like autism but I could terminate everybody on those grounds."<sup>149</sup>*

Such perceptions could result in the over disclosure of risk with a view to limiting legal responsibility. However, not all the feedback on *Montgomery* was negative and the decision may have facilitated reflective behaviour by some doctors:

*"(Commenting on Montgomery) I think so ... yeah. I think it is the honesty which we approach things and how we write. Whether when you reach a collaborative approach. Whether really what I am going to write down is for the parents and for their understanding and the shared decision-making process or whether going to write a legal document that absolves me of all responsibility and I think*

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<sup>143</sup> Participant C.

<sup>144</sup> Participant D.

<sup>145</sup> GMC (n48), para 24.

<sup>146</sup> Participant E (n63).

<sup>147</sup> Participant B.

<sup>148</sup> [2015] UKSC 11.

<sup>149</sup> Participant B.

*sometimes the legal..., sounds awful... gone too far to demonstrate that all risks.*<sup>150</sup>

Perversely, requiring more from doctors might cause some professionals to feel less able to comply with this obligation, resulting in a greater number of referrals to tertiary or quaternary centres.<sup>151</sup> This could have positive outcomes if it concentrates relevant expertise:

*“People might be more up to date with literature. Is it a good or bad thing? Probably a good thing. If I need a complicated surgery on my heart once in my life. I would find out best place in UK. If I find it is in Newcastle, I would go to Newcastle ... This is a decision once in my life... Talking about packages of care ... healthcare ... Inconvenience of travel for a couple of hours. Good at everything. Good enough. Big discussion around healthcare. To me it is very clear. You should do it in centres of excellence. 4 or 5 places in country is fine.”*<sup>152</sup>

This statement speaks to the bigger picture and to the increasing significance of large specialist hospital teams. Whilst **PE** was generally positive about *Montgomery*, there was a qualification:

*“My one objection, my concern about ruling started to filter through is the retrospective application of it worries me a bit... worries my colleagues out there, we do not have a view yet”*<sup>153</sup>

Indeed, this concern about retrospective application has received inconsistent judicial treatment to date.<sup>154</sup>

**PC** offers some advice on things to avoid and on the appropriate focus for the regulatory framework:

*“yes so many variables has to be an individually tailored approach. Difficult to make rules when there are so many different anomalies. Whether they be very major, intermediate and minor, then the gestational age, ...”*<sup>155</sup>

*“there is a temptation to try and make things fits into neat boxes and protocols. Many things are amenable to that but I also believe strongly that some things are really difficult. Maybe this is one of those areas”.*<sup>156</sup>

***“Systems should be more geared at the enabler .... Truly not just HCP but really taking the views of parents. They are the ones that live with the decisions. The system has to be fit for them and not just the medical profession.”***<sup>157</sup>

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<sup>150</sup> Participant C.

<sup>151</sup> Participant C.

<sup>152</sup> Participant C.

<sup>153</sup> Participant E.

<sup>154</sup> Cf *Grimstone v Epsom and St Helier Hospitals NHS Trust* [2015] EWHC 3756 (QB) and *Webster (a child) v Burton Hospitals NHS Foundation Trust* [2017] EWCA Civ 62.

<sup>155</sup> Participant C.

<sup>156</sup> Participant C.

<sup>157</sup> Participant C (emphasis added).

This closing statement powerfully captures a perceived need for a change in attention and focus within the healthcare system. **PE** also considers that there is a need to secure comprehensive national data before further standard setting occurs:

*“as you know setting standards requires evidence and getting high quality evidence. Until now relied on getting the high quality evidence has relied on academic units. Often funded by a call to NIHR. Those are very focused. What we want is a much wider collection that effectively extracts information from all maternity information packages that all maternity units have around country. And uses that data for meaningful processes and outcomes. Last year, called national maternity and perinatal audit.”<sup>158</sup>*

The same participant highlights the importance of the form of regulation:

**“Question:** *You also highlighted another issue – with legislative changes you get some notice that law will change or could change. With courts no notice and give you short time to make necessary changes?*

**Answer:** *Any changes we make have got to have teeth. Teeth in not resisting using them. Can’t mandate but want to use them”<sup>159</sup>*

Without effective enforcement mechanisms, regulatory rules need recognition and acceptance (‘buy in’) from key stakeholders. However, even when sanctions are possible, voluntary engagement is more likely to achieve regulatory goals. In terms of singleton termination, the preferred option for **PE** was decriminalisation:

*“Regulate it in same way as any other procedure. Don’t need the plethora of signatures need under Act at moment. One of things (Institution) wants to see. Got to be driven by the right standards. I would hope NICE have a regulatory ambition in the framework. That would set the appropriate standards. Would the law allow member bodies or arms length body like the MRHA to regulate? Standards would need to be current and up to date. You and I know Political and religious pressures... more than anything else out there”<sup>160</sup>*

However, even if we decriminalise abortion, we would still need to agree upon the deregulated framework and options. There was acknowledgment that fetal reduction:

*“has evolved actually quite significantly in last decade or so, if not fully covered need to produce some guidance and standards for that and working with legislators and regulators would be the right thing to do.”<sup>161</sup>*

In terms of external bodies (eg courts) using professional ethical guidance to set standards:

*“One thing ask if setting standard use the most up to date one. Have come across organisations using an old standard. You said this. 15 years ago and*

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<sup>158</sup> Participant E. See RCOG, *National Maternity and Perinatal Audit* (RCOG 2017), < <http://www.maternityaudit.org.uk/Audit/Charting/Keyfindings1516> > accessed 8 May 2019.

<sup>159</sup> Participant E

<sup>160</sup> Participant E. This participant indicated that NICE abortion guidance was expected by the end of 2019 (see NICE, *Termination of Pregnancy – NICE Guideline – Draft for Consultation* (NICE April 2019)).

<sup>161</sup> Participant E.

*now saying this. Look at what is current standard. Don't think we would be prescriptive of other bodies. Most bodies that use them involve us. We quite like you to endorse what we are doing."*<sup>162</sup>

When pressed about the use of discursive guidance to set legal standards, **PE** said:

*"Historically almost the altruistic nature of these documents is open to multiple interpretations...With the directive point by point evidence based-green top or NICE guideline less open to that discursive interpretation or misinterpretation or different interpretation... Not a driver for us in cleaning up our warehouse of different types of guidelines. Making it easy to interpret, less flexibility in it. Ultimately, if you put a flexible interpretation on it our members will say to us, I had this situation didn't cover it or didn't help me make my decision, could go either way. We are trying to produce as if a peer review process there more fit for direct practice. One of the problems is that we will always have situations where issues in clinical practice that need some sort of steering. We do not sit there and... think GMC won't mind at all. Most important driver is safe effective patient care."*<sup>163</sup>

They accept that there needs to be flexibility and professional discretion in some areas, whilst acknowledging the difficulty when broad/ flexible rules are used in a rigid way.

## 9.16 Conclusions

In closing, we make four comments about medical decision-making in fetal reduction/ selective termination, and two thematic observations.

First, there is evidence that the views and comments of our participants fit with our earlier characterisation of doctors as 'choice architects'.<sup>164</sup> Secondly, notwithstanding the opportunity to frame and steer patient choices, there is general acceptance by the participants of the value of collaborative dialogue/ decision-making and active informed patient engagement. There is evidence that these doctors are keen to unearth patient values and rationales, even if the reasons for doing so may be variable and complex. Thirdly, the evidence suggests that these doctors rarely refuse to perform a fetal reduction or selective termination in practice. Whilst, they may attempt to resist or divert certain requests (eg healthy twin reductions), in most cases they will act according to the wishes of the parents, especially if there is a counter risk of whole pregnancy termination. However, the interview data suggests that requests for late ground E terminations<sup>165</sup> can be influenced by the threat of litigation/ prosecution.

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<sup>162</sup> Participant E.

<sup>163</sup> Participant E.

<sup>164</sup> See for eg, Participant C (n12, 47 and 50).

<sup>165</sup> As per Abortion Act 1967, s1(1)(d) and post 24 weeks.

Fourthly, and outside of these late terminations, there is evidence that the professional ethical and legal norms have a relatively weak influence on the practice of fetal reductions and selective terminations.

More generally, we observe two core themes surfacing from the interview data. The first and most notable is *individual accountability and responsibility*. It is evident that the legislative framework for pregnancy termination has a focussing and interpretive effect on professionals in areas of perceived uncertainty (eg ground E) and ethical tension (eg terminations post 24 weeks). The existence of uncertain or vague legal rules does not appear to trouble the doctors unduly when they perceive there is societal and peer support for their professional practices (ie terminations up to 24 weeks). The use of team-based decision-making processes are frequently used in these cases and may help reduce the discretionary nature/ variability of decision-making within an organisation.<sup>166</sup> These processes may also have a supportive function because the individual doctor will know that they are likely to have workplace and peer support in the event of future challenge or prosecution. However, it is also apparent that these processes do not remove a doctor's awareness of individual accountability and responsibility. There is a very real sense that these doctors bear the societal and legal burden of these decisions and an uncertain legal framework.<sup>167</sup> The question then turns on whether this burden, and these types of decision, should be borne by individual designated human agents

The other core theme is *professional resistance* - whether it be professional resistance to change, conflict, or patient demands. This resistance may simply be a product and evidence of the accountability and responsibility theme. Some professional resistance might encourage positive patient reflection but could also pressurise and impede access for some parents. However, in borderline or uncertain cases, the resistance may ensure legislative compliance, narrow forms of interpretation<sup>168</sup> and avoid medical treatment on demand. In all cases, the difficulty will be to establish whether this resistance is due the exercise of professional discretion or personal values.

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<sup>166</sup> Helena Serra, 'Gamble on the Uncertain. Negotiating Medical Decision-Making' (2016) 12(4) QSR 44.

<sup>167</sup> See Lee et al. (n41). Cf also the media and academic narratives claiming excessive medical leniency in the interpretation of the AA 1967 (Ellie, J. Lee, 'Constructing abortion as a social problem: "Sex selection" and the British abortion debate.' (2017) 27(1) *Feminism and Psychology* 15).

<sup>168</sup> Potentially important in areas of legal compromise (see Brownsword and Wale (n78)).

## Chapter 10 – Discussion and Conclusions

Contents:

- 10.1 Introduction
- 10.2 Data triangulation
- 10.3 Research question 1
- 10.4 Research question 2
- 10.5 Research question 3

### 10.1 Introduction

In this chapter, we draw together our findings from the interview data and our review of the academic literature/ research studies. We revisit each of the research questions and look again at the frameworks for regulating fetal reduction in multiple pregnancy.

### 10.2 Data triangulation

We have undertaken a data triangulation exercise looking for convergence between the interview (chapter 9) and existing research data (chapter 8). This exercise is intended to demonstrate and support the extent to which our findings relate to the interview data (confirmability).<sup>1</sup> We have identified examples of convergent sources in the footnotes wherever possible. The following points appear to be supported, corroborated or repeated in other research:

- The inherent difficulty of situationally complex decision-making.<sup>2</sup>
- The need for and use of consensus building within clinical teams in uncertain, complex, difficult and contentious areas.<sup>3</sup>
- Lack of clarity around ground E (AA 1967) continues to cause difficulties for healthcare professionals especially post 24 weeks.<sup>4</sup> This difficulty may be due

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<sup>1</sup> Norman K. Denzin, *Sociological Methods: A Sourcebook* (McGraw Hill 1978).

<sup>2</sup> Robert L. Klitzman, 'Reducing the number of foetuses in a pregnancy: providers' and patients' views of challenges', (2016) 31(11) *Human Reproduction* 2570.

<sup>3</sup> Helen Statham, Wendy Solomou and Jasper B. Green, 'Late termination of pregnancy: law, policy and decision making in four English fetal medicine units', (2006) 113(12) *BJOG: An International Journal of Obstetrics and Gynaecology* 1402; Robyn Lotto, Lucy K. Smith and Natalie Armstrong, 'Clinicians' perspectives of parental decision-making following diagnosis of a severe congenital anomaly: a qualitative study', (2017) 7 *BMJ Open* e014716.

<sup>4</sup> *Ibid.*

to interpretive uncertainty, the delegation of social judgement, the fear/ risk of individual accountability or a combination of factors.

- Lack of clarity around maternal rights/ interests rarely causes difficulty in terminations before 24 weeks.<sup>5</sup>
- Fetal reduction/ selective terminations raise some issues that are distinctive from terminations in singleton pregnancy.<sup>6</sup>
- Healthy twin reductions are problematic for some parents and healthcare professionals.<sup>7</sup>
- Inconsistency persists around the terminology – however the issue may be more theoretical than practical.<sup>8</sup>
- The importance of the professional framing of risks and benefits.<sup>9</sup>
- The societal influence upon the medical interpretation of the AA 1967.<sup>10</sup>
- The tension between vague/ broad and clear/ fixed standards.<sup>11</sup>
- The importance of preserving professional discretion and judgement.<sup>12</sup>
- Some professionals may be able and willing to work “*within a professional paradigm despite it being in conflict with their own personal opinions.*”<sup>13</sup>
- External scrutiny creates concern for individual accountability.<sup>14</sup> The perceived threat of scrutiny/ litigation may be out of proportion to the actual level of risk (eg in terms of sanction/ accountability).<sup>15</sup>
- The tertiary hospital setting creates space, expertise and less regional variation.<sup>16</sup>
- Artificial reproduction techniques continue to impact on the prevalence of multiple pregnancy and incidence of chorionicity.<sup>17</sup>

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<sup>5</sup> Lisa Crowe and others, 'Negotiating acceptable termination of pregnancy for non-lethal fetal anomaly: a qualitative study of professional perspectives', (2018) 8(3) *BMJ Open* 2018 e020815.

<sup>6</sup> R. Katie Morris. and Mark D. Kilby, 'Fetal Reduction', (2010) 20(11) *Obs, Gynae & Reprod Med* 341.

<sup>7</sup> Klitzman (n2); Jennifer Kelland and Rosemary Ricciardelli, 'Mothers of Multiple Perspectives on Fetal Reduction and Medical Abortion', (2014) 5(2) *J Motherhood Initiative for Research and Community* 126.

<sup>8</sup> Morris and Kilby (n6); Caroline M. Ogilvie, 'Multiple pregnancy, fetal reduction and selective termination', (2013) 26(6) *Reproductive Bio-Medicine Online (Elsevier Science)* 52; Claire-Marie Legendre and others, 'Differences between selective termination of pregnancy and fetal reduction in multiple pregnancy: a narrative review' (2013) (26(6) *Reproductive Bio-Medicine Online (Elsevier Science)* 542, 543.

<sup>9</sup> David W. Britt and Mark I. Evans, 'Sometimes doing the right thing sucks: Frame combinations and multi-fetal pregnancy reduction decision difficulty', (2007) 65 *Social Science & Medicine* 2342; Klitzman (n2).

<sup>10</sup> Statham et al. (n3).

<sup>11</sup> Lotto et al. (n3).

<sup>12</sup> Jonathan Montgomery, 'Conscientious Objection: Personal & Professional Ethics in the Public Square', (2015) 23(2) *Med L. Rev* 200; Klitzman (n2).

<sup>13</sup> Lisa Crowe and others, 'A survey of health professionals' views on acceptable gestational age and termination of pregnancy for fetal anomaly', (2018) 61(9) *European Journal of Medical Genetics* 493., 497.

<sup>14</sup> Lotto et al. (n3); Ellie Lee, Sally Sheldon Sheldon and Jan Macvarish, 'The 1967 Abortion Act fifty years on: Abortion, medical authority and the law revisited.' (2018) 212 *Social Science and Medicine* 26, <<https://doi.org/10.1016/j.socscimed.2018.07.010>>accessed 18 May 2019.

<sup>15</sup> Montgomery (n12), 206.

<sup>16</sup> Eg., TAMBA, *Twin Pregnancy and Neonatal Care in England, November 2017* (TAMBA 2017).

<sup>17</sup> Eg., Morris & Kilby (n6).



- Regulation can impact on clinical behaviours but not always in clear, expected, consistent or foreseen ways.<sup>18</sup>
- Professional regulation may be more impactful on the behaviour of junior than senior doctors.<sup>19</sup>
- There are significant time delays between the creation of national/ professional guidelines and their subsequent implementation within institutional regimes and professional practice.<sup>20</sup>
- Organisational and communication skills are important for effective shared decision-making.<sup>21</sup>
- There is perceived value in creating reflective space for professionals.<sup>22</sup>
- The variability of patient engagement in the decision-making process.<sup>23</sup> There is some evidence of parents using avoidance techniques to remove or circumvent difficult decision-making.<sup>24</sup>
- There is perceived difficulty in evaluating online information in terms of availability, use and quality.<sup>25</sup> However, accurate and accessible information sources and decision-making tools can help bridge the gap and facilitate the clinical encounter.<sup>26</sup>

Overall, there is a substantial degree of convergence between the interview data and previous research findings involving a range of relevant stakeholders. This suggests that our interview findings should be sufficiently trustworthy to carry forward into formal conclusions and recommendations. However, we cannot rule out divergence across regional practice, and given the importance of local culture, this may weaken the transferability of some of our interview findings.

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<sup>18</sup> Eg., Jane Fisher and others, 'Termination for fetal anomaly: Are women in England given a choice of method?' (2015) 35(2) *Journals of Obs & Gynae* 168.

<sup>19</sup> Oliver Quick, *A scoping study on the effects of health professional regulation on those regulated: Final report submitted to the Council for Healthcare Regulatory Excellence* (2011), 18.

<sup>20</sup> NCT and TAMBA, *Maternity Services and Multiple Births: A joint report by NCT and the Twins and Multiple Births Association* (NCT/ TAMBA 2015); TAMBA (n15)

<sup>21</sup> The Health Foundation, *Helping People Share Decision Making: A Review of Evidence Considering Whether Shared Decision Making is Worthwhile* (The Health Foundation 2012).

<sup>22</sup> PSA, *The regulator's role in professional identity: validator not creator* (PSA 2018).

<sup>23</sup> Lotto et al. (n3).

<sup>24</sup> Kelland & Ricciardelli (n7).

<sup>25</sup> Briege M. Lagan, Marlene Sinclair and W. George Kernohan, 'What is the impact of the Internet on Decision-Making in Pregnancy? A Global Study' (2018) 38(4) *Birth* 336.

<sup>26</sup> The Health Foundation (n21).

### 10.3 Research question 1

***To establish how and why Maternal and Fetal Medicine specialists make decisions (fetal reduction) in response to specific dilemmas (multiple pregnancy).***

We have identified a range of circumstances when these specialists will offer and undertake fetal reductions in multiple pregnancy. There is evidence of global variation but in Great Britain this typically occurs between the 11-14th week of the pregnancy. There are 100 or so cases annually and they are undertaken for a range of reasons including pregnancy preservation, improved fetal health and survival rates, socio-economic considerations and reduced health risks for the pregnant women. There are also those cases where the procedure is undertaken to remove anomalous fetuses or the risks posed to others by those entities (also described as selective termination/feticide). There is a very small pocket of cases undertaken much later in the pregnancy following discovery of fetal anomaly.

These procedures are undertaken in the shadow of the AA 1967 (often using the statutory ground E/ section 1(1)(d)), creating a fairly unique regulatory context and environment for the healthcare professionals operating in this field. They are subject to a range of socio-political-economic factors that do not affect other medical procedures to the same degree. The AA 1967 was amended in 1990<sup>27</sup> to reflect some of the specific underlying considerations linked to multiple pregnancy. However, the legislative amendments did not explicitly address fetal interests but introduced differential time limits related to the authorising ground. Although medical methods increasingly dominate early singleton terminations, fetal reduction remains a highly specialist surgical procedure.

### 10.4 Research question 2

***To establish how existing norms and frameworks influence and direct the decision-making and behaviours of these individuals.***

We now have a clearer sense of the connections and relationships between the moral, ethical and regulatory frameworks in our procedural context. The AA 1967 has

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<sup>27</sup> Human Fertilisation and Embryology Act 1990, s37.

subordinated, and to a large degree excluded individual moral values from day to day obstetric practice. There is technically scope for conscientious objection, but it is difficult to work in this field without being exposed to termination in some way. The effects of this change has been experienced differentially - depending on where you live (eg Scotland has more terminations undertaken in NHS hospitals) and who you work for (private or NHS hospital trust). Some professionals will be able to work within a professional paradigm which differs from their own personal beliefs, although leakage via unconscious bias/ practice is possible, especially when socio-economic considerations are the driver for parental requests. Public expectation of obstetric services and societal attitudes have shifted since 1967, but professional discretion remains an important and valuable aspect of delivering reproductive care and we exclude this feature of medicine at risk. We are mindful of participant C's assertion that it has "*got to be ok... (to say no to a patient request) so long as patient is properly looked after.*"<sup>28</sup>

The legal framework is generally a somewhat background consideration for healthcare professionals. However, in terminations post 24 weeks, it moves into the foreground and becomes a significant consideration for decision-making. Here, vague, opaque or flexible legal criteria contribute to uncertainty and sometimes defensive medical practices. Whilst this might be intentional, create caution and drive team related behaviours, it also offers a platform for variable access and inconsistent medical practices. Focus on individual responsibility may be important whilst doctors play a gatekeeping or entrusted role, but there is a potential disconnect from the team-based reality of modern reproductive services. We also question whether it is legitimate for Parliament to require an individual to undertake a gatekeeping activity based on loose standards with the threat of criminal accountability. On reflection, this seems an extremely onerous obligation for fallible human agents and has driven our later recommendations to narrow the qualifications for lawful termination in the first/second trimester (up to 24 weeks).

There has been some opposition to the dual certification process although this was not raised as a specific concern by our participants. Ex-post scrutiny does appear to influence medical practice in post viability cases, although it is unclear whether the general CQC inspection mechanisms are more or less influential than the freestanding certification and notifications provisions in the AA 1967 and associated regulations.<sup>29</sup> There does not appear to be any real concern about the exclusion of fetal interests as

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<sup>28</sup> Participant C (added).

<sup>29</sup> Including the Abortion Regulations 1991 (SI 1991/499); Abortion (Amendment) (England) Regulations 2002 (SI 2002/887); Abortion (Amendment) (Wales) Regulations 2002 (SI 2002/2879); Abortion (Amendment) (Wales) Regulations 2008 (SI 2008/1338); Abortion (Amendment) Regulations 2008 (SI 2008/735).

a lawful ground for termination, perhaps, because there will nearly always be a corresponding maternal ground. The legal framework addressing the standard and quality of care appears to be important, especially for independent providers reliant on NHS funding. Overall, international law has had very little impact on domestic law or medical practices in this area.

There is mixed evidence about the need for explicit recognition of maternal interests in the legislation. Whilst maternal consent is a necessary but insufficient condition for surgical termination, the medical interpretation is to treat the woman's wishes as decisive in most cases up to 24 weeks. Thereafter, recognition of maternal interests recedes, and decisions become focused on the legality of the procedure. The overarching legal framework is reinforced by the availability of public funding, executive acknowledgement and specialist fetal medicine centres, ensuring general public access to these procedures.

The professional frameworks have a more complex and nuanced relationship with medical practice in this context. Some NICE, GMC and RCOG guidance/ standards are directly relevant and influential to clinical practice in multiple pregnancy although there are limited sources directly applicable to our specific procedures (see Table 4A/ appendix F). The associated BMA guidance<sup>30</sup> has little relevance or significance for this group of professionals. There is evidence that it takes time to embed new national NICE standards and guidance. There is recent evidence that professional regulators and representative bodies are recognising the importance of the distinction between discursive guidance and directive rules. Overall, professional ethical norms have a fairly limited influence on the practise of fetal reduction and selective termination.

There is evidence that the doctors place more focus and regular emphasis on peer review and support. The legal framework appears to be more influential in borderline cases, although doctors often need to use their discretion to interpret what is acceptable and lawful. Here workplace systems and behaviours, peer to peer feedback and past experience drive decisions much more directly than professional ethical regulation.

Workplace and subspeciality cultures and bureaucracy are important in influencing medical practice in this and many areas of healthcare delivery. It is evident that shared decision-making mechanisms are starting to become embedded in many areas of healthcare, including tertiary fetal medicine, although some regional variation persists. Patients will have limited choice in tertiary delivery – they are likely to be referred from

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<sup>30</sup> BMA, *The Law and Ethics of Abortion: BMA Views* (BMA November 2014 (updated October 2018)).

a primary or secondary provider; may not have been actively engaged in the choice; and there are relatively few subspecialists and fetal medicine centres in any event. Parents may have to travel significant distances to see these professionals and this may limit the choice of centre or specialist in practical terms. Decisions often have to be made very quickly, under emotionally charged and difficult circumstances. The parents will know that they are going to see specialists – they are likely to have been informed during the initial consult and be aware that a specialist referral has been made. They will know that multiple pregnancy is atypical involving additional risk factors for the woman, her pregnancy and unborn babies. The outcomes from fetal reduction involve some uncertainty and the parents will probably look to the doctors for active guidance or reassurance. These considerations combine to influence the power dynamics/ relationships between patients and the treating professionals in these cases. Indeed, it is this cocktail of factors that make pregnant women especially vulnerable during their engagement with a tertiary centre and the decision-making processes leading to possible reduction of their pregnancy. There may be additional socio-economic, cultural or conception related factors that add to their vulnerability as patients.<sup>31</sup> These factors are partially offset by a culture that attempts to build in time and reflection for decision-making that may not always be available elsewhere in the NHS. There is evidence that longer term (post procedure) care may be of variable quality and this could be important because these stakeholders are a valuable asset for embedding future patient engagement in structural terms.

These are undoubtedly difficult, complex and highly variable cases, and this situational specificity ought to be reflected in the regulation of information exchange, the decision-making processes, the procedure and related patient care. There needs to be sensitivity to the relationships, circumstances and environments in which choices are framed. Going back to our earlier discussion of *Montgomery*,<sup>32</sup> it is apparent that a 'reasonable patient' in a tertiary fetal medicine centre contemplating reduction of a multiple pregnancy, will have subtly different needs than a person undergoing a hernia operation. Certainly, many of the medical/ patient concerns will be similar but the order of complexity and risk factors appear distinctive. It is here that tertiary centres have an important role to play beyond technical expertise – the medical specialists have experience and insight into the typical concerns of this small demographic of patients. This is an invaluable quality for supporting shared decision-making and embedding the delivery of patient centred care.

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<sup>31</sup> For discussion of vulnerability in pregnancy, see Sam Rowlands and Jeffrey Wale, 'Sterilisations at delivery or after childbirth: Addressing continuing abuses in the consent process', (2019) *Global Public Health* < <https://doi.org/10.1080/17441692.2019.1583265> > accessed 28 February 2019.

<sup>32</sup> *Montgomery v Lanarkshire Health Board* [2015] UKSC 11

The decision in *Montgomery*<sup>33</sup> can be read in different ways but appears to facilitate, rather than hinder a shift towards patient centred care. We should recognise that *Montgomery* predominantly regulates civil liability at an organisational level although it still appears to impact upon individual professional behaviours. Whilst legal decisions and rules, can be instrumental in achieving seismic shifts in behaviour, case law may not be the best way of achieving this. Legislative consultation affords key stakeholders an opportunity to contribute to the change, may reduce the degree of resistance and influence the speed of take up following implementation. Cultural engagement (at workplace and disciplinary level) and organisational factors (structural and individual) are also important to delivery. Specifically, there needs to be recognition that the reception to change is likely to vary at the junior and more experienced ends of the medical profession, requiring differential strategies for successful implementation at a national and local level. Effective patient centred care is more likely to be achieved by multiple strategies directed at a range of stakeholders. Ideally, regulatory strategies aimed at organisational and structural factors should be combined and balanced with mechanisms directed to individual healthcare professionals.

There is a complex relationship between the law and professional ethics. We have argued that the law should not seek to drive out differentials unless it is absolutely necessary to achieve early consistent compliance and coherent public narratives. *Montgomery*<sup>34</sup> may be one example where legal intervention was necessary. Differentials will be influenced by the performance of professional regulation, and space can produce helpful dialogue between law makers and the medical profession.<sup>35</sup> Although a synergistic relationship will often be helpful, law makers/ actors should look critically at professional rules/ standards and ask whether they are entirely suitable for developing clear legal principle. Discursive guidance from representative bodies is unlikely to satisfy this precondition. Consistent clarity about the mandatory and discretionary elements of professional guidance will also assist individual healthcare professionals.

Finally, we should be alert to the influence of public narratives upon medical practice - whether from legal initiatives, governmental bodies, regulators or the media. Inconsistent narratives can create contextual barriers that distort regulatory outcomes. Against this backdrop, we now turn our attention to the the third research question.

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<sup>33</sup> Ibid.

<sup>34</sup> Ibid.

<sup>35</sup> Penny Lewis, 'The Medical Exception', (2012) 65 *Current Legal Problems* 355, 375.

## 10.5 Research question 3

***To consider how future legal, ethical and professional rules/guidance might be framed, and how future clinical developments/research might be advanced.***

### **Legal**

In light of this discussion, how should we accommodate these difficult cases within the law? We are not persuaded that the criminal law has no role to play in the regulation of human pregnancy. A criminal framework is still necessary and justifiable for addressing non-consensual terminations and procedures posing a significant risk to individual safety.<sup>36</sup> We also need to recognise that there are divergent societal views about fetal interests, especially in the latter stages of pregnancy. Ultimately, the need for a criminal framework in early consensual low risk terminations may turn on whether criminalisation is deemed a necessary socio-political price for any legal compromise.

We have considered taking forward three basic models for the criminal regulation of individuals in the context of termination of pregnancy/ entity life. First, a single legal framework wide enough to cover fetal reduction and selective termination in multiple pregnancy. Secondly, a distinct and separate legal framework for these procedures. Thirdly, a hybrid solution, with additional rules for fetal reduction and selective termination. At the outset, we hypothesised that the second might be suitable, but have come to the view that the first solution is preferable under certain conditions. There is much to be said for clarity and simplicity - we should avoid overly qualified exceptions or legal exceptions heavily dependent on entity status. In sketching out this framework, we acknowledge that there will still be areas of possible resistance and uncertainty although it is intended that this space will have a function. We are not in favour of an unqualified right to terminate – such a position would run contrary to our recognition of possible fetal interests in the latter stages of pregnancy and to the value we place on continued professional discretion in this area of medical practice. What we propose, hopefully offers a more coherent legal position that also more accurately reflects current medical practice and contemporaneous considerations around the viability of pregnancy.

Of course, we should be prepared to defend this position. We are heavily influenced by gradualist and multiple property theoretical positions that recognise that an appropriate balance should be struck between maternal autonomy and possible fetal

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<sup>36</sup> This would include surgical (and some medical) terminations involving non medically qualified individuals and would arguably satisfy the requirements for intervention as per Art 8(2) ECHR.

interests in the latter stages of pregnancy. It is impossible to accommodate all moral views within the law but a more restrictive legal approach for most terminations is unlikely to receive widescale societal support and would come at a heavy cost for pregnant women. We consider that viability or sentience (circa 24 weeks) arguably strikes an appropriate balance and variation is not a significant issue where we are addressing legal protection within a specific jurisdiction. Implantation and birth - in the sense of independent existence - should remain a significant legal criterion.

Professional discretion is preserved but without the need for artificial or contrived legal grounds for terminations before 24 weeks. We do accept that maternal interests are likely to be seriously engaged, if for example, a pregnant woman receives a late diagnosis of anomaly and decides that she does not wish to continue with her pregnancy. Our proposals seek to achieve an appropriate balance although we acknowledge that maternal interests are qualified by the legal hurdles that we propose in the latter stages of pregnancy.

We have attempted to normalise the medical procedure as much as possible, by removing the need for dual certification where terminations are performed by doctors, but have maintained the obligation to keep records, with the need for extra information in cases post 24 weeks. We have made no express statutory provision for conscientious objection – as previously argued, objections are more appropriately managed at workplace level. We would continue to regulate the prescription or use of abortifacients by the Human Medicines Regulations 2012 (as amended), and medical providers in respect of safety/ care considerations. The retention of organisational criminal obligations in respect of patient safety/ care is important, and these regulations should address the place of administration/ treatment. Our tentative view is that patient safety considerations may merit initial evaluation in a UK clinical environment in the case of medical methods of termination. Pregnant woman should have a choice between medical and surgical methods unless there are clear medical considerations which count against such an option (this should be explained in any event). Healthcare providers should be required to ensure that all pregnant women have access to accessible information sources about their choices and non-directive counselling. A national informational programme should accompany any legal change and clarify the importance/ consequences of any time limit change. With these considerations in mind, we have sketched out a possible replacement criminal framework below:

- Repeal the ILPA 1929, AA 1967, and sections 58/ 59 of the OAPA 1861.<sup>37</sup>
- Enact a single criminal statute with 2 new indictable offences:

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<sup>37</sup> For our purposes, we are restricting application to England and Wales. Of course, there should be consideration of a possible unified legal framework across the UK.



- **Unlawful Termination** - covering termination of an established pregnancy or embryo/ fetal life post implantation and up to the 24th week of pregnancy.<sup>38</sup> The offence will cover any act, procedure or administration of a substance causing termination and intended to cause termination.<sup>39</sup> The prosecution bears the burden of proving that the pregnancy has not exceeded 23 weeks and 6 days. Attempt would be covered where the defendant believes that the woman is pregnant or is reckless as to whether she is pregnant and intends to cause termination. There would be a lawful ground for termination *if the relevant conduct<sup>40</sup> was consensual,<sup>41</sup> and the person causing (or attempting to cause) the termination (D) was at the material time a registered medical practitioner (or a registered healthcare professional<sup>42</sup> acting under the specific direction of a registered medical practitioner). D will bear the burden of proving (a) that they were either a registered medical practitioner or a registered healthcare professional acting under the direction of a registered medical practitioner at the time of the alleged offence and (b) consent. D (and any directing medical practitioner) must complete a written certificate with prescribed information relating to the patient, consent, pregnancy duration and the place/ methods of termination used.*

Note: pregnant women will not be committing either of these offences by consenting to a termination (or attempted termination) undertaken by a healthcare professional/ medical practitioner in accordance with a lawful ground.

- **Unlawful Child Destruction<sup>43</sup>** - covering terminations (as previously described) from 24 weeks and prior to independent existence from the pregnant woman. The offence will cover any act, procedure or administration of a substance that causes termination and intended to cause termination<sup>44</sup> The prosecution bears the burden of proving that the pregnancy was 24 weeks or more, but it will be a defence to this offence if D can prove that they honestly and reasonably believed that

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<sup>38</sup> I.e 23 weeks 6 days and using medical standards for timing.

<sup>39</sup> We would need to address how to treat the withdrawal of support or life sustaining technology.

<sup>40</sup> Any act, procedure or administration causing or intending to cause termination.

<sup>41</sup> The pregnant woman must give free and informed consent to the termination as per *Montgomery* (n32).

<sup>42</sup> Limited to registered nurses and midwives.

<sup>43</sup> We might want to debate whether the offence label might be better described as Unlawful Fetus Destruction.

<sup>44</sup> We would also cover attempt as per the Unlawful Termination Offence.

the pregnancy had not exceeded 23 weeks 6 days,<sup>45</sup> and they are otherwise able to satisfy the lawful ground for the Unlawful Termination offence.

In all other cases,<sup>46</sup> there would only be a lawful ground for *termination if the relevant conduct<sup>47</sup> was consensual, and the person causing (or attempting to cause) the termination (D) was at the material time a registered medical practitioner,<sup>48</sup> and D certifies in good faith<sup>49</sup> either that:*

- *their conduct was necessary to save the life of the pregnant woman; OR*
- *their conduct was necessary to prevent or significantly reduce the risk of serious injury or harm to the physical or mental health of the pregnant woman. D (and the court) may have regard to the pregnant woman's wishes about the continuance of the pregnancy and her actual or reasonably foreseeable circumstances and environment but for the termination; OR*
- *their conduct was necessary to prevent or significantly reduce the risk of (whole)<sup>50</sup> pregnancy loss.*

*It will not be an offence for a registered medical practitioner to take steps intended to prevent or reduce the risk of significant suffering to the unborn entity in circumstances where it is reasonably foreseeable that that entity will die before, at or shortly after birth. The court may have regard to accepted medical practice in these circumstances.*

*D and their employer will bear the combined burden of keeping a written record of certification for 6 years - punishable with a summary criminal offence. A defence will not be available to either offence unless contemporaneous certification is available to the court and it is signed by the registered medical practitioner/D. These records should be made available to the CQC on request.*

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<sup>45</sup> Reasonable belief would be determined as per *Bolam v Friern HMC* [1957] 2 All ER 118 and *Bolitho v City & Hackney HA* [1992] PIQR 334.

<sup>46</sup> In cases, where there is no question about the pregnancy having at least reached week 24, and where the relevant offence is Unlawful Child Destruction.

<sup>47</sup> As per footnote 40.

<sup>48</sup> We have excluded other HCPs.

<sup>49</sup> This requires an honest and reasonable belief (as per footnote 45) that the certified ground(s) factually exists.

<sup>50</sup> The inclusion of 'whole' can be debated although we would argue that it is unnecessary.

We have deliberately removed the ground E provision and any reference to anomaly as a lawful ground for termination. We recognise that if parents/ clinicians discover a fatal or serious fetal anomaly from 24 weeks, there will remain some uncertainty around the lawful termination of that entity. Steps can be taken to protect the life of the pregnant woman or pregnancy loss in the case of a multiple pregnancy. The second lawful ground provides scope for doctors to act where the continuation of the pregnancy would cause (or where there was risk of) mental or physical injury or harm to the pregnant woman.<sup>51</sup> The likelihood of injury/ harm occurring is not specified but the required magnitude (serious) is spelled out. D and the Court are entitled to have regard to maternal autonomy considerations including known wishes and contextual factors in the evaluation of the risk or degree of harm. D would have to demonstrate that their conduct was necessary to either prevent or significantly reduce the risk of serious harm or injury to the woman.

The penultimate provision relating to the prevention or reduction of suffering, does not make it clear whether the intended steps would extend to the termination of fetal life, but the court may have regard to accepted medical practice in these circumstances. This provision should hopefully encourage peer reflection and evidenced based decision-making that reflects the equivalent treatment of neonates. The explicit inclusion of an objective element in the good faith requirement in the second offence will also ensure that the Courts remain the ultimate arbiter albeit subject to medical considerations.

These draft offences do not remove all uncertainty – it is the price of greater coherency in the law and for driving cautious professional behaviours in the latter stages of pregnancy – but the intention is to reduce the overall divergence between legal and practice norms in this area. We recognise that coherent professional standards should accompany this legal change. This framework provides a new shadow against and in which obstetric professionals must operate. We have argued elsewhere that such arrangements should be subject to regular and positive legislative renewal.<sup>52</sup> What these proposals ought to achieve is a safe and more transparent framework that covers the vast majority of cases, reducing but not extinguishing the trusted role performed by doctors, nurses and midwives. Further, by reducing the hurdles for most pregnant women in consensual terminations carried out by qualified healthcare professionals, we hopefully limit the opportunities for challenge under Article 8 ECHR.<sup>53</sup> We fully

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<sup>51</sup> In doing so, we focus on maternal interests and have in mind the comments of the Supreme Court *In the matter of an application by the Northern Ireland Human Rights Commission for Judicial Review (Northern Ireland)* [2018] UKSC 27.

<sup>52</sup> Roger Brownsword and Jeffrey Wale, 'Compromise Medicalisation', in C. Stanton and others (eds), *Pioneering Health Care Law Essays: In honour of the work of Professor Margaret Brazier* (Routledge 2015).

<sup>53</sup> Cf Rosamund Scott, 'Risks, Reasons and Rights: The European Convention on Human Rights and English Abortion Law', (2016) 24(1) *Med L. Rev* 1.

recognise that these proposals would have an impact beyond the specific locus of this research, but the purpose has been to highlight how fetal reduction and selective termination might be accommodated in a single unitary legal framework. We also acknowledge that in the absence of a specified right to terminate, it is essential that the environmental, contextual and social circumstances should be such that women continue to have free and widely available access to termination services delivered by suitably qualified healthcare professionals.

We now turn our attention to the decision in *Montgomery*<sup>54</sup> and the role of shared decision-making. Fetal reduction (however defined) typifies the situational context in which shared decision-making should be encouraged and developed. *Montgomery* may introduce fresh and uncertain variables into the patient encounter but fetal reduction is neither exclusively legal, technical, pathogenic or ethical to warrant unqualified patient or professional autonomy. Indeed, these are thankfully rare scenarios that warrant a professional obligation to use reasonable endeavours to unearth information/ values from the patient. We recognise the danger of creating unnecessary hurdles to access but these are atypical, complicated and value laden clinical scenarios. We would also recommend legal clarification of the 'reasonable patient' limb of the *Montgomery* test. We are not convinced that further legal authority mechanisms are necessary to deliver improvements in decision-making – educational, incentive and organisational strategies seem more likely to be effective in this context.

### **Professional regulation**

Professional guidance and standards should be clear about whether there is scope for discretionary application or rules that 'must' be adhered to. This will make it easier for professionals to use these documents and help external bodies (including legal actors) to have a clearer benchmark for subsequent use. Legal actors should be discouraged from placing too much weight on documents created by self interested professional bodies (as opposed to those documents promulgated by statutory regulators). We recognise that professional regulators may not be entirely objective, but fragmentation should be avoided where possible.

We believe that professional regulators should consider standards addressing the neutral framing of risks and benefits. This should be part of wider informational, educational and organisational strategy aimed at supporting patients and professionals in the development of shared decision-making in appropriate medical contexts. Shared decision-making, relevant communication skills and the importance of framing should

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<sup>54</sup> n32.

also be embedded in medical education as a priority. There is merit to the development of dedicated national (NICE) guidance for fetal reduction/ selective termination, with particular emphasis on the 'reasonable patient' needs in terms of information exchange, support and choices. Recognised informational and decision-making tools aimed at parents should be developed.

We have already identified a range of local and national strategies for introducing and maintaining changes in professional behaviour. Positive framing and ground up development is preferable to blunt regulatory enforcement. There has to be the space for professional learning/ engagement and recognition of the wider organisational and resource consideration within the NHS.

### **System regulation**

System regulation ought to be at the heart of delivering patient safety and patient centred care. We agree that system regulators should not become too involved in the actual delivery of actual improvement – that is a job for the regulatee. Shared decision-making needs to be supported at an organisational/ workplace level and system regulation is likely to be important in managing local cultures. We have identified a number of specific priorities including adequate resourcing, continuity of staffing and a genuine commitment to securing active patient engagement.

### **Clinical developments**

The use of a tertiary fetal medicine model appears to have value in our context and in multiple pregnancy generally. Online consultation and informational sources are likely to facilitate access to these services and help bridge the gap following referral. Evidence suggests that bridging the consult and aftercare services may be especially important in this context.

Ectogenesis, prenatal testing and the development of remedial fetal surgery<sup>55</sup> are likely to shape this field in the near future. New invasive surgical techniques have already impacted on the clinical approach to the care of monochorionic multiple pregnancies. Prenatal testing will offer greater information but create new dilemmas and choices for parents. The access and timing arrangements and informational regimes around prenatal testing are likely to prove highly significant in any time limited termination framework.

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<sup>55</sup> See for example, BBC, Spina bifida: Keyhole surgery repairs baby spine in womb (17 May 2019), < <https://www.bbc.co.uk/news/health-48253477>> accessed 18 May 2019.

## **Research**

The priority for future research is the facilitation of active patient engagement both generally and in specific situational contexts. Additional studies concerning the development of online mechanisms for supporting patients and their decision-making would be worthwhile. Undertaking institutional comparisons of fetal medicine units may prove helpful in the development of the national guidance outlined above.

## Chapter 11 – Closing Remarks

This research has taken a narrow contextual focus (multiple pregnancy) and placed a spotlight on a specialist set of medical procedures (fetal reduction) operating in a unique regulatory environment complicated and influenced by a polarised range of socio-political factors. In doing so, we have been able to explore medical decision-making in a situationally centred context that might not have been available had we used a broader landscape or a different research lens. Specifically, it has enabled us to address the particular power dynamics of these clinical encounters.

In this work, we have pursued three central lines of inquiry: first, to understand more about the nature of fetal reduction, its frequency, and the legal ground(s) for termination on which doctors typically rely; secondly, to assess the extent to which legal, ethical and professional norms guide and constrain this particular kind of decision-making; and, thirdly, to evaluate the adequacy of these norms and to explore possible solutions.

With regard to the first line of inquiry, the evidence suggests that fetal reduction (however defined) is a relatively rare event (fewer than 150 each year) and that, by way of contrast with everyday singleton terminations where the justifying ground is usually descriptively medical, it is fetal abnormality that is often given as the justifying ground. Further, these procedures combine a range of technical, legal and ethical considerations that cannot be neatly segmented into exclusive domains of ownership.

In relation to the second line of inquiry, analysis shows that the legal, ethical, and professional norms offer little explicit guidance or help in relation to fetal reduction. In relation to the general question of termination, ethical norms suffer from a high level of contestation and a plurality of views, the key norms in the abortion legislation are both unclear and no longer properly connected to the practice of terminations, and professional norms are only marginally more adequate. Given the indeterminacy of these norms, it is no surprise that the empirical evidence indicates that doctors are only weakly guided by them in making their decisions about fetal reduction. In practice, doctors are guided by the views of their peers and by the sense that, in the final analysis, they will be held accountable and will need to be able to justify their actions. We recognise that our characterisation of doctors as ‘choice architects’ may be controversial, but evidence supports this is an apt description of what actually transpires given the specific power dynamics and relational aspects of fetal medicine. This general position is reinforced by a legal framework that places a substantive

burden on the shoulders of doctors in terms of securing lawful access to these procedures.

Responding to the third line of inquiry, we make several observations and recommendations, some have specific situational relevance, and some have more general application. We observe the value and acknowledge the importance of tertiary fetal medicine as a model and system for the delivery of specialist care and the acquisition of specialist knowledge, skills and expertise. More specifically, we recommend that the fetal abnormality ground for termination is so problematic that it should be removed from the abortion legislation. We fully recognise that this proposal (and our wider recommendations for reform) would have an impact beyond fetal reduction in multiple pregnancy, but our purpose has been to highlight how these procedures might be accommodated in a single unitary legal framework.

While recognising that there is a legitimate place for professional medical discretion, we also recommend that professional and ethical norms should emphasise the importance of shared decision-making and patient-centred care in relation to these procedures. Given our characterisation of doctors as 'choice architects', regulatory strategies should endeavour to create an appropriate power balance in the clinical choice environment that is sensitive to the general and specific needs of this subset of patients. Policy makers and regulators should also be alert to the possible impact of global variations in practice and legal norms.

Given our findings, and while recognising the limitations of qualitative research, we believe that this thesis contributes new insight and the kind of evidence necessary to shape regulation, clinical developments and future research in this field.



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## **Appendices**

A – Data Collection Instruments

B – Research Quality

C – Theme Definitions

D – Research Ethics

E – Clinical and Qualitative Research Studies

F – Recommendations, Codes and Guidance

G – Copyright Permissions



**Bournemouth  
University**

## Participant Information Sheet

### **The title of the research project**

Regulating medical decision making: A qualitative study of fetal reduction in multiple pregnancy

### **Invitation**

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **What is the purpose of the project?**

This research concerns the medical procedure known as ‘fetal reduction in multiple pregnancy’<sup>1</sup> and seeks to obtain a better understanding of decision making in the context of the existing moral, ethical, regulatory and legal frameworks.

The central research questions are:

- 1) To establish how and why medical professionals make particular decisions (fetal reduction) in response to a particular dilemma (multiple pregnancy).
- 2) To establish how existing norms and frameworks (personal/ ethical/ regulatory/ legal) influence and direct the decision making/ behaviours of these individuals.

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<sup>1</sup> For our purposes, the working definition is ‘the interruption of the development of one or more probably normal fetuses in multiple pregnancy’ (Legendre et al. 2013, p 543).

3) To consider how future legislative, ethical and professional rules/ guidance might be framed and how future clinical developments and research might be advanced.

### **Why have I been chosen?**

You and other participants have been recruited in your professional capacity as maternal and fetal medicine specialists.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a participant agreement form. You are free to withdraw up to the point where the data is processed and becomes anonymous, so that your identity cannot be determined. You can withdraw without giving reason and without there being any negative consequences.

### **What do I have to do and what will happen to me if I take part?**

You will be involved in this research during 2017/18. Your participation will be limited to one (or possibly two) formal interviews. The interviews are not time limited but will typically be of 1-2 hours duration. We plan to undertake these interviews in person but can undertake them by SKYPE or similar medium where requested. You will be asked open questions but you will also be given the opportunity to expand on any issue at your discretion. Your participation is voluntary but you are requested to participate in the interview as fully as you can. The interviews will be recorded by digital audio media and through hand written field notes (see below). You will be interviewed by a lecturer and postgraduate researcher from Bournemouth University (Jeffrey Wale). His research profile can be found at:

<http://staffprofiles.bournemouth.ac.uk/display/jwale#publications>

### **How will the recordings be used?**

The audio recordings and handwritten notes of the interviews will be used for transcription and analysis only. No other use will be made of them without your written permission. No one (save for Jeffrey Wale) will be allowed access to the

original recordings/ notes without your written permission. You do give permission for members of the research project team to have access to your anonymised transcribed responses. Your name will not be linked with the research materials, and you will not be identified or identifiable in the outputs that result from the research.

For the avoidance of doubt, the research project team consists of the researcher (Jeffrey Wale) and his three supervisors (Dr Max Lowenstein, Associate Professor Sascha-Dominik Bachmann and Professor Roger Brownsword).

**What are the possible disadvantages and risks of taking part?**

Participation in this research will involve your time and engagement. Fetal reduction is a controversial procedure and societal views on its moral permissibility are polarised. Publication of any material relating to permissibility and decision making are made against a background where some individuals and groups hold strong and deeply held views that oppose these procedures.

**What are the possible benefits of taking part?**

Whilst there are no immediate benefits for the participants in the project, it is hoped that this work will help inform how future legislative, ethical and professional guidance might be framed and how future clinical developments and research might be advanced.

**Will my taking part in this project be kept confidential and what will happen to the results of the research project?**

You will not be able to be identified in any subsequent reports or publications relating to this research. Any identifying data will be extracted at the transcription stage and prior to write up and publication. Anonymised data collected during the course of this project might be used for additional or subsequent research and/or for conference presentations but anonymity will be maintained. All the information that we collect about you during the course of the research will be kept in accordance with the Data Protection Act 1998. All hard copy data collected will be stored in a secure location and any digital data will be encrypted and held securely on the University password protected secure network. Audio recordings and field notes will be deleted/ destroyed once the interviews have been transcribed and anonymised. All identifying data



relating to this project will be destroyed after 5 years from the conclusion of the research project in any event. The research is likely to be concluded by the end of 2018 and the results will be disseminated (in summary form) to each participant of the study. The results will be formally written up and will hopefully be published in due course.

### **What type of information will be sought from me?**

You will be asked to comment on the research subject (fetal reduction in multiple pregnancy) and on matters directly related to the research questions. You will not be asked for any data or information that relates to specific individual patients or individuals. This project does not intend to and will not capture data/information on any specific patient, parent, embryo or fetus.

### **Who is funding the research?**

This research has no external funding and is supported by Bournemouth University and the researcher, Jeffrey Wale. This project was granted ethics approval by Bournemouth University on 24 February 2014.

### **Contact for further information**

The research contact is Jeffrey Wale, Bournemouth University, Weymouth House, Fern Barrow, Poole, Dorset, BH12 5BB. Telephone: 01202 962245 Email: [jwale@bournemouth.ac.uk](mailto:jwale@bournemouth.ac.uk). The primary research supervisor is Dr Max Lowenstein, Bournemouth University, Weymouth House, Fern Barrow, Poole, Dorset, BH12 5BB. Email: [mloenstein@bournemouth.ac.uk](mailto:mloenstein@bournemouth.ac.uk)

### **Complaints**

If you have any concerns regarding this study, please contact Professor Iain MacRury by email at [researchgovernance@bournemouth.ac.uk](mailto:researchgovernance@bournemouth.ac.uk).

Thank you for taking the time to read through the information.

**31 March 2017**



## Participant Agreement Form

**Full title of project:** *Regulating medical decision making: A qualitative study of fetal reduction in multiple pregnancy*

**Name, position and contact details of researcher:** *Jeffrey Wale, Lecturer, Bournemouth University, Weymouth House, Fern Barrow, Poole, BH12 5BB, Email: [jwale@bournemouth.ac.uk](mailto:jwale@bournemouth.ac.uk)*

**Name, position and contact details of supervisors:**

*Dr Max Lowenstein, Bournemouth University, Weymouth House, Fern Barrow, Poole, Dorset, BH12 5BB, Email: [mloenstein@bournemouth.ac.uk](mailto:mloenstein@bournemouth.ac.uk);*

*Associate Professor Sascha-Dominik Bachmann, Bournemouth University, Executive Business Centre, Email: [sbachmann@bournemouth.ac.uk](mailto:sbachmann@bournemouth.ac.uk);*

*Professor Roger Brownsword, Kings College London, Email: [roger.brownsword@kcl.ac.uk](mailto:roger.brownsword@kcl.ac.uk)*

Please  
Initial or  
Tick Here

I have read and understood the participant information sheet for the above research project.	
I confirm that I have had the opportunity to ask questions.	
I understand that my participation is voluntary.	
I understand that I am free to withdraw up to the point where the data is processed and becomes anonymous, so my identity cannot be determined. I can withdraw without giving reason and without there being any negative consequences	
Should I not wish to answer any particular question(s), I am free to decline.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the outputs that result from the research.	
I understand that taking part in the research will include being recorded (audio) but that these recordings will be deleted once transcribed.	
I agree to take part in the above research project.	

\_\_\_\_\_  
\_\_\_\_\_

Name of Participant

Date

Signature

---

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Name of Researcher

Date

Signature

*This form should be signed and dated by all parties after the participant receives a copy of the participant information sheet and any other written information provided to the participants. A copy of the signed and dated participant agreement form should be kept with the project's main documents which must be kept in a secure location until the date for destruction.*

[Insert Date]

Dear Sir/ Madam

**Research Project: Regulating medical decision making: A qualitative study of fetal reduction in multiple pregnancy**

I am writing to introduce my research and to ask if you would be willing to be a participant in the aforementioned research project.

I enclose a participant information sheet and agreement form that contains further detail about the research project and the required involvement of participants. The research is being undertaken using semi structured interviews and the expected duration of these interviews is between 1-2 hours.

This research will not capture any patient identifying data and participants are being interviewed in their professional capacity as doctors and not as employees or officers of the National Health Service.

I can travel to see you at a suitable UK based location at a mutually convenient time.

Do let me know if you require any further information or clarification about this research project.

I hope that you will consider being a participant and look forward to hearing from you.

Yours faithfully

**Jeffrey Wale**  
LLB (Hons), PGCE, FHEA, Solicitor\*  
LLB Programme Leader  
Department of Law  
Bournemouth University

## **Interview Plan**

### **Introduction**

Welcome & basic introductions

Nature of a semi structured interview - voluntary

Duration: 1-2 hours

Recorded

Use of data/anonymity/confidentiality

Benefits/disadvantages/risks

Funding of research

### **Context**

Fetal reduction in multiple pregnancy

### **Aims of research (the research question)**

1. How / why make decisions
2. How norms / frameworks influence decision-making & behaviour.
3. How legal, ethical & professional guidance/rules might be framed & clinical developments/research advanced

Sampling & selection

### **Preliminaries**

Questions                      Sign participant agreement form

Participation                      Additional questions/issues

### **Materials**

Participant Information Sheet X2

Participant agreement form X2

Skype/alternative contact details (as required)

### **Other Resources**

Digital audio recorder

Notepad/pen

Computer Skype link (as required)

Soundproof room

### **Follow up**

Check audio recording

Duration of research

Outcome

Communication of findings

### **Contact details**

Including supervisors

## Background questions ('Tell me about')

Current practice: numbers of MFPR/Selective terminations

Experience & past practice

Future plans

## Main Questions (open)

Legal & regulatory environment	Understanding
Professional guidance, standards & ethical codes	Understanding
Personal beliefs- Opinions/Values/Feelings	Influencing
Training	Influencing
Professional practice	Influencing
Other Health Care Professionals	Influencing
Institutional – practice & process	Influencing
Professional guidance/standards/codes	Influencing
Professional regulation & discipline	Influencing
Legislative Framework	Influencing
Patients	Influencing
Ranking influence	Understanding/ Influencing
Legal status of fetus	Understanding
Status of fetus	Influencing
Clinical issues & basis for MFPR	Understanding/ Influencing
Ethical issues & MFPR	Understanding/ Influencing
Role of patient	Understanding/ Behaviour
Pre-reduction sampling/scanning	Understanding/ Influencing/ Behaviour
Approach to risk assessment in MFPR	Understanding/ Behaviour
Selection & techniques	Understanding/ Behaviour
Technological & clinical developments	Understanding/ Influencing / Behaviour
Current issues	Understanding/ Influencing / Behaviour

Research	Understanding/ Influencing / Behaviour
Own behaviour in MFPR	Understanding

## **Clarifying Questions**

Follow up: 'please clarify', 'please expand', "can you tell me anything else?"

Probing: 'can you give me examples'

Specifying: 'what happened when you said'

Interpretation: 'what do you mean by'

## **Closing Questions**

Any other questions/ points/ issues

**Jeff Wale 27/3/2017**

### **Summary of Findings and Recommendations for Interview Participants:**

1. Analysis shows that the legal, ethical, and professional norms offer little explicit guidance in relation to fetal reduction.
2. In relation to the general question of termination, ethical norms suffer from a high level of contestation and a plurality of views.
3. The key norms in the abortion legislation are both unclear and no longer properly connected to the practice of terminations, and professional norms are only marginally more adequate.
4. In light of 3, it is no surprise that the evidence indicates that doctors are only weakly guided by these norms in making their decisions about fetal reduction. In practice, doctors are guided by the views of their peers and by the sense that, in the final analysis, they will be held accountable and will need to be able to justify their actions. There is also the need to respect the wishes of the pregnant woman, whenever possible.
5. There is clear tension between clear/ fixed and vague/ broad rules or standards. The use of consensus/ team-based decision-making can be helpful in areas of uncertainty.
6. Legal and practice uncertainty persists in relation to ground E (Abortion Act 1967, s 1(1) (d)). This provision should be replaced including fresh legal rules for terminations post 24 weeks.
7. Organisational responsibility should play a more significant role in any associated criminal framework because it better reflects the contemporary delivery of healthcare. The criminal legal framework for individuals (including the Abortion Act 1967) should be amended to remove unnecessary qualifications, and to reflect contemporary medical practice in consensual terminations up to 24 weeks (ie consensual terminations performed by doctors in good faith (and certain registered healthcare professionals under the direction of doctors) should be lawful).
8. While recognising that there is a legitimate place for professional medical discretion, relevant professional and ethical norms should emphasise the importance of shared decision-making and patient-centred care.
9. The need for distinctive legal provision for terminations in singleton and multiple pregnancies is closely linked to the nature and breadth of the associated legal framework. Separate legal provision is unnecessary if the authorising framework is sufficiently broad/ inclusive.
10. Any inconsistency in terminology (between fetal reduction and selective termination) may be a theoretical, rather than a practical issue. However, the term 'reduction' emphasises the positive over narrative transparency.
11. The law should not seek to drive out all differences in professional and practice norms, unless it is absolutely necessary and for a clearly defined purpose.
12. Professional ethical sources should be explicit about any mandatory and discretionary element. These sources should also endeavour to frame risks and benefits with appropriate balance.



13. Law makers should exercise considerable care in developing legal standards/ norms from professional ethical norms (especially when derived or produced by a professional representative body).
14. Legal development via case law (as opposed to statutory law) is generally unhelpful for medical practice (especially if it introduces or requires significant changes in medical practice).
15. Conscientious objection is better managed at an occupational (workplace) level rather than through the use of statutory conscience clauses in this area.
16. National NICE guidance requires support, co-ordination and resources to improve implementation timescales.
17. Tertiary Fetal Medicine centres provide a valuable model and resource for supporting parents through complex multiple pregnancies. They also offer the kind of situationally specific knowledge, expertise and skills that facilitate patient centred care. These centres can also assist the communication of information/ risks etc and the conceptualisation of the 'reasonable patient' (as envisaged in *Montgomery v Lanarkshire Health Board* [2015] UKSC 11). However, specialist tertiary centres may also have the capacity to increase patient vulnerability and medical deference. Strategies are therefore required to combat these risks and to facilitate shared decision-making processes.
18. Future research may be helpful in the following areas:
  - a. Online mechanisms for supporting effective shared-decision making.
  - b. Effective mechanisms for facilitating active patient engagement.
  - c. Comparison of fetal medicine delivery across institutions looking for variables and best practice.

Jeffrey I. Wale April 2019.

## **Summary Reflective Account by Researcher**

### **1. Participant Pool**

1 pilot interview was undertaken before my transfer/ upgrade in 2015. This individual was contacted directly.

32 possible participants (19 male and 13 female) plus relevant professional bodies were contacted directly by letter. There was also an open invite to BMFMS members. Interested participants made contact and they selected their preferred interview medium. All bar one participant selected an interview in person.

### **2. Data Collection Instruments**

The pilot interview and preliminary research on fetal reduction/ selective termination helped shape the draft interview plan (appendix A).

### **3. Participant interviews**

The main participants were interviewed between the 9 June 2017 and the 26 July 2018. The interview with participant A (9 June 2017) took several aborted attempts during the day because they were very busy and had a number of emergency admissions. However, we were eventually able to complete an uninterrupted interview in the late afternoon. This participant appeared to be very open and keen to answer all questions fully. They were also willing to expand upon points.

Participant B arrived late because of peer consultation but we were able to complete an uninterrupted interview in the afternoon (17 July 2017). The participant was initially a little defensive but opened up and expanded on points as the interview progressed.

Participant C was interviewed during their lunch break (22 February 2018). They appeared very open, helpful and were keen to expand/ develop points.

Participant D was seen after some delay on the arranged appointment time. This participant was also interviewed during their lunchbreak. Initially their answers to questions were short and concise with little expansion. This position did change a bit as the interview progressed.

Participant E was interviewed by SKYPE on the 26 July 2018. The medium actually worked reasonably well but we did have one glitch where we needed to re-establish contact. The recording of this interview was clear. This participant was very open and appeared keen to develop points.

It is acknowledged that the framing of the interview questions were subtly influenced by the responses of previous interviewees, although the researcher

attempted to cover all of the areas on the interview plan. All participants were given the opportunity to expand on any point.

#### **4. Transcription**

Transcription took place between March and August 2018. All digital recordings were transcribed and typed up by the researcher. The digital recordings were slowed down (where necessary) to assist the transcription process and headphones were used to prevent interruptions/ noise interferences/ breaches of anonymity.

#### **5. Coding and Theming**

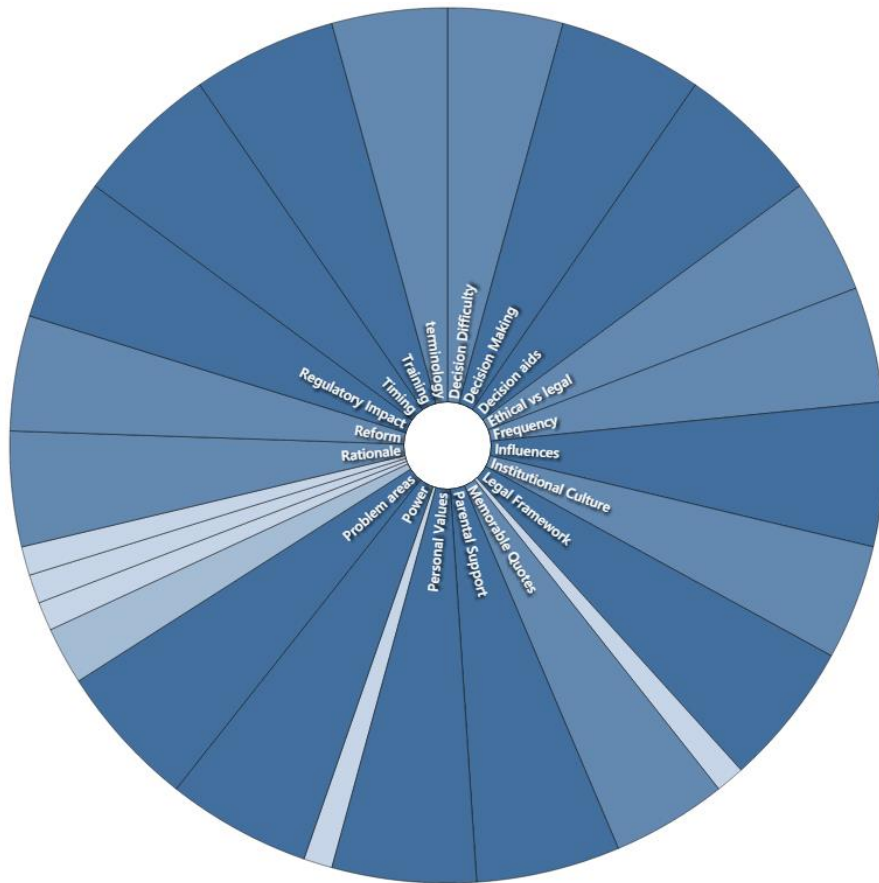
NVivo was used to code the interview transcripts. The researcher attended two half day training sessions on this software before it was used in practice for coding. In addition, the researcher attended a number of training sessions on the qualitative coding process.

During the coding process, various analytical routines were run in NVivo to assist in the identification and sorting of themes. We have included some frequency charts and a word cloud produced during the theming process at the end of this document.

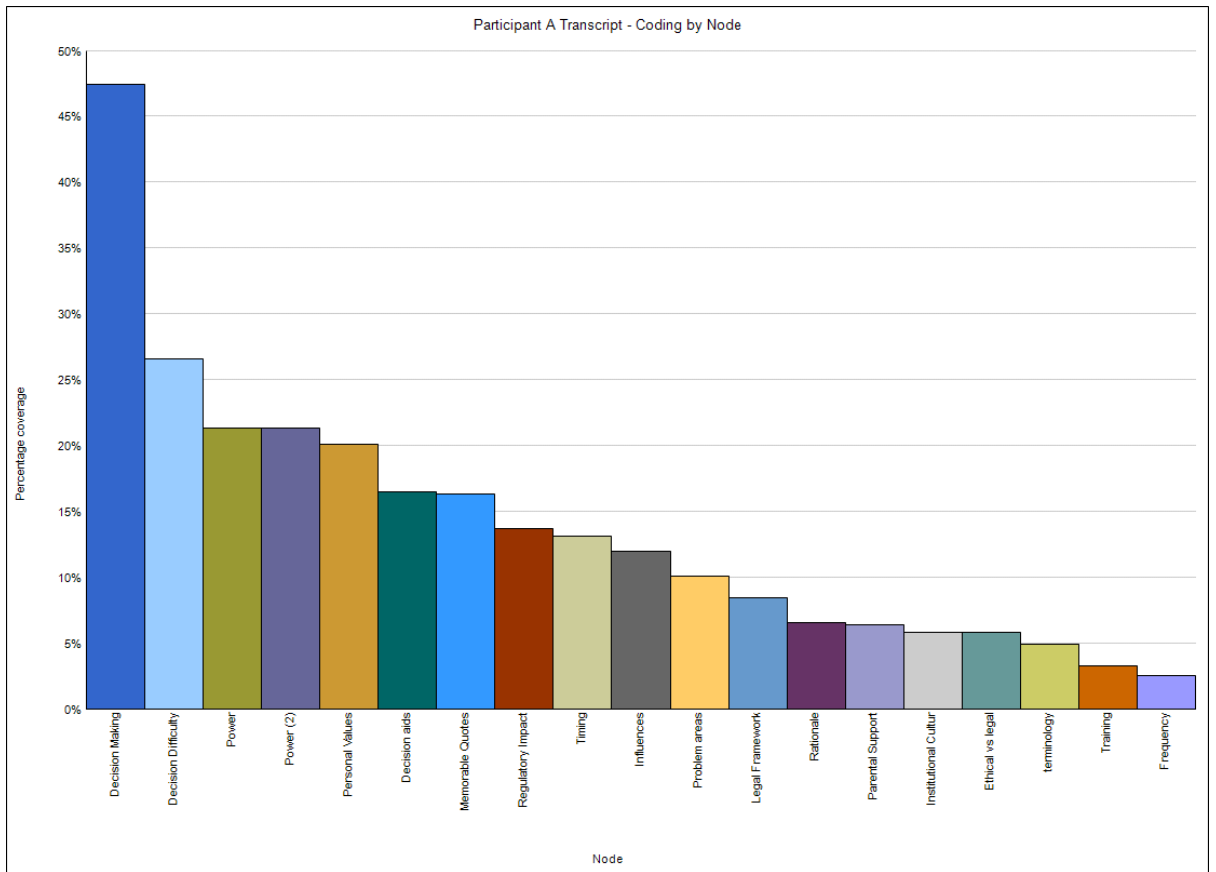
#### **6. Triangulation by Data and Investigator**

The first supervisor was asked to undertake some coding/theming on a single participant transcript. The feedback was used by the researcher to re-evaluate all the transcripts, the theming of codes and the write up of interview data (chapter 9). In addition, the interview data was triangulated with the findings from range of stakeholder research studies (chapter 8). The results of this process were useful and helped develop/ reinforce our conclusions (chapter 10).

**Example Frequency Coding/ Theming Charts and Diagrams**



**Figure 3 – Frequency Coding – All Participants**



**Figure 4 – Frequency Coding – Participant A**

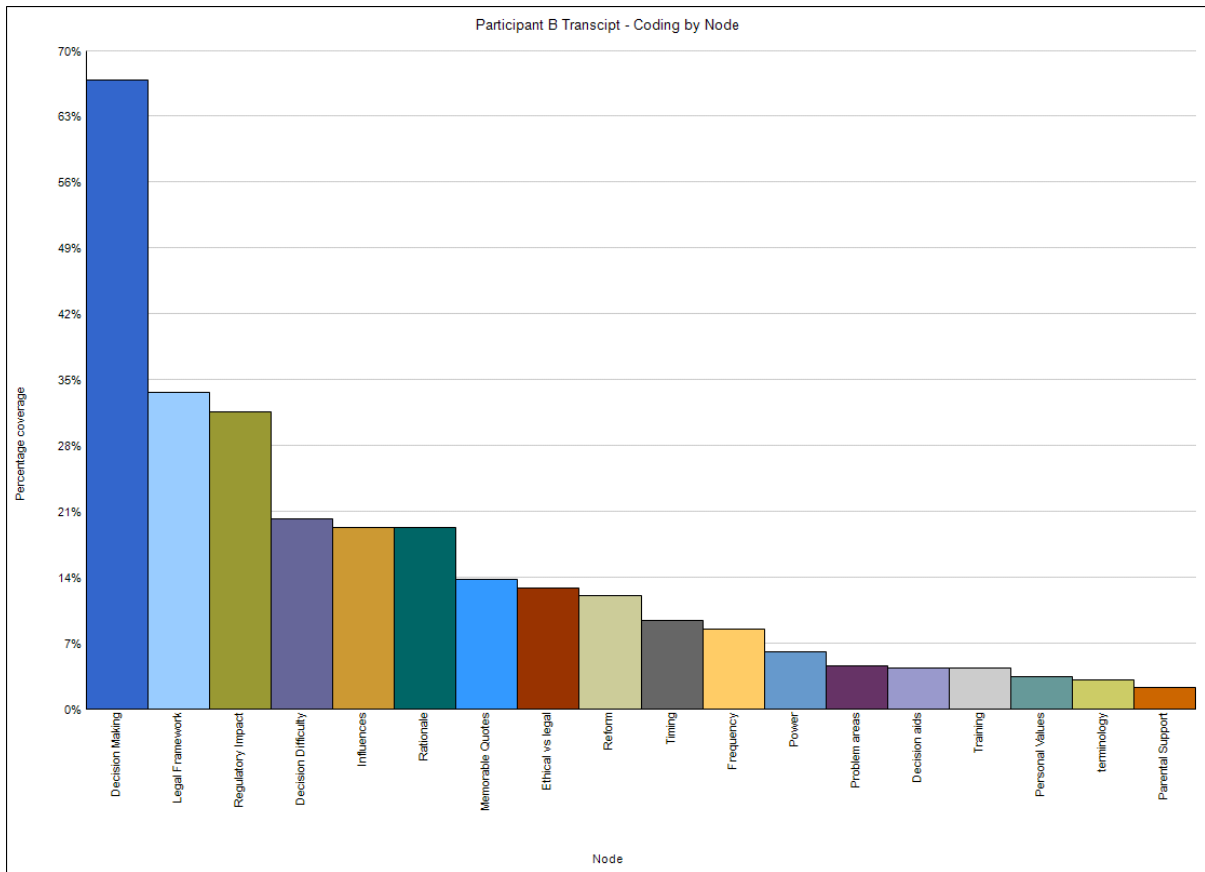
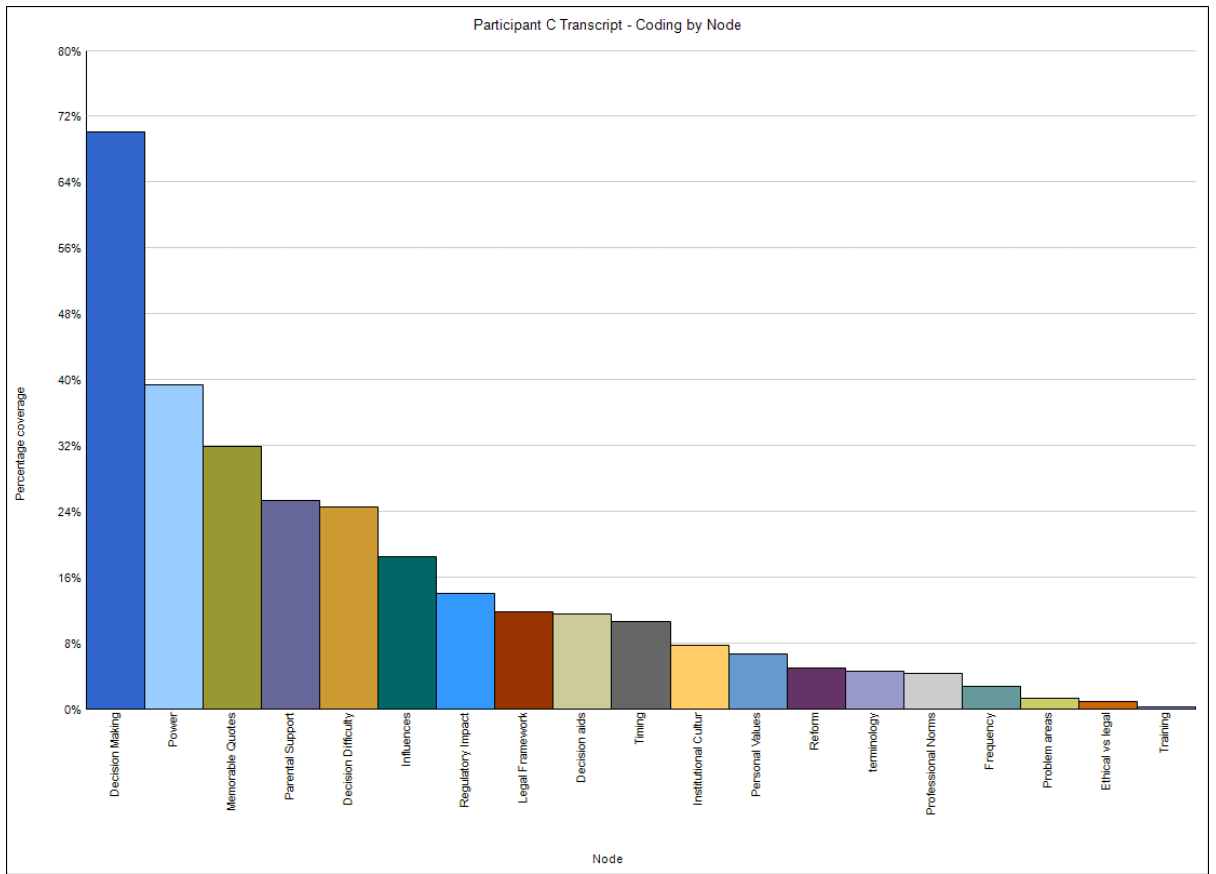


Figure 5 – Frequency Coding – Participant B



**Figure 6 – Frequency Coding – Participant C**

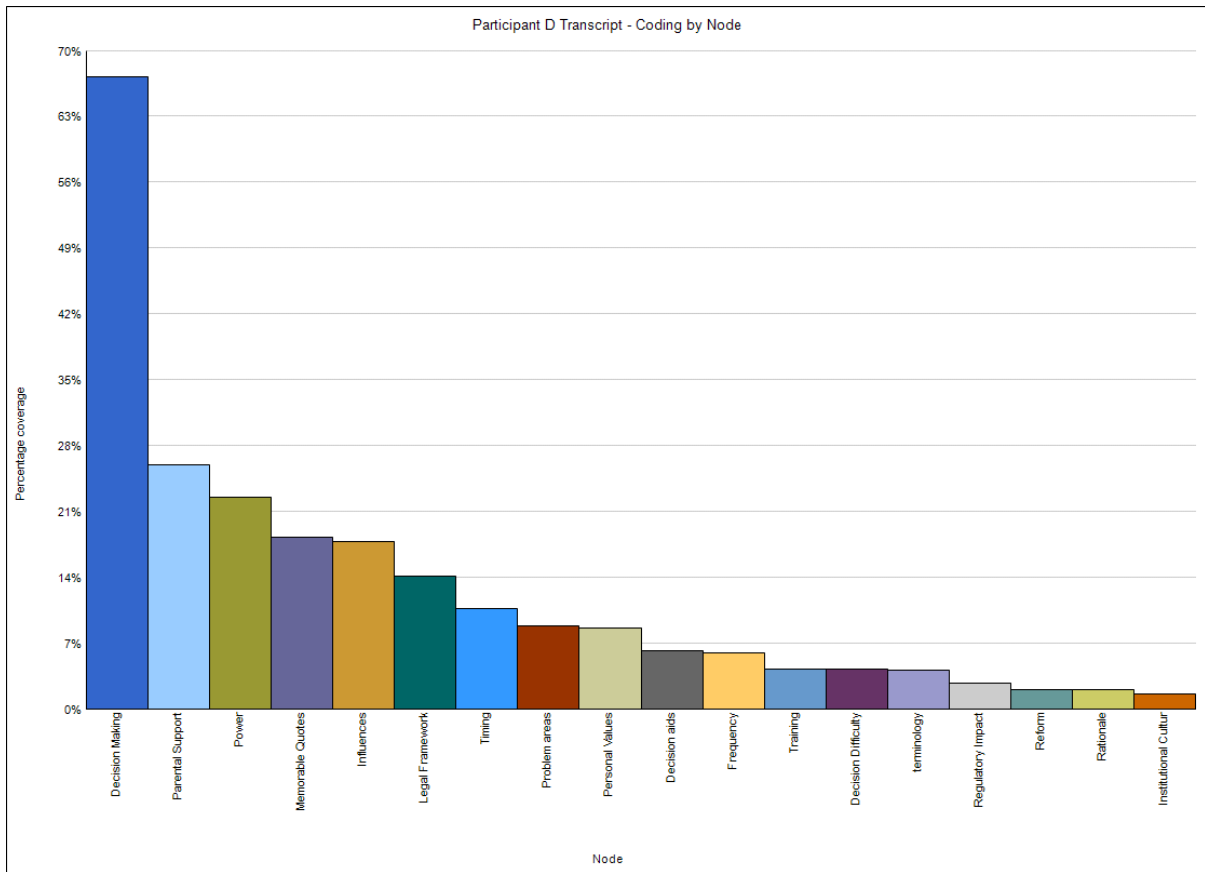
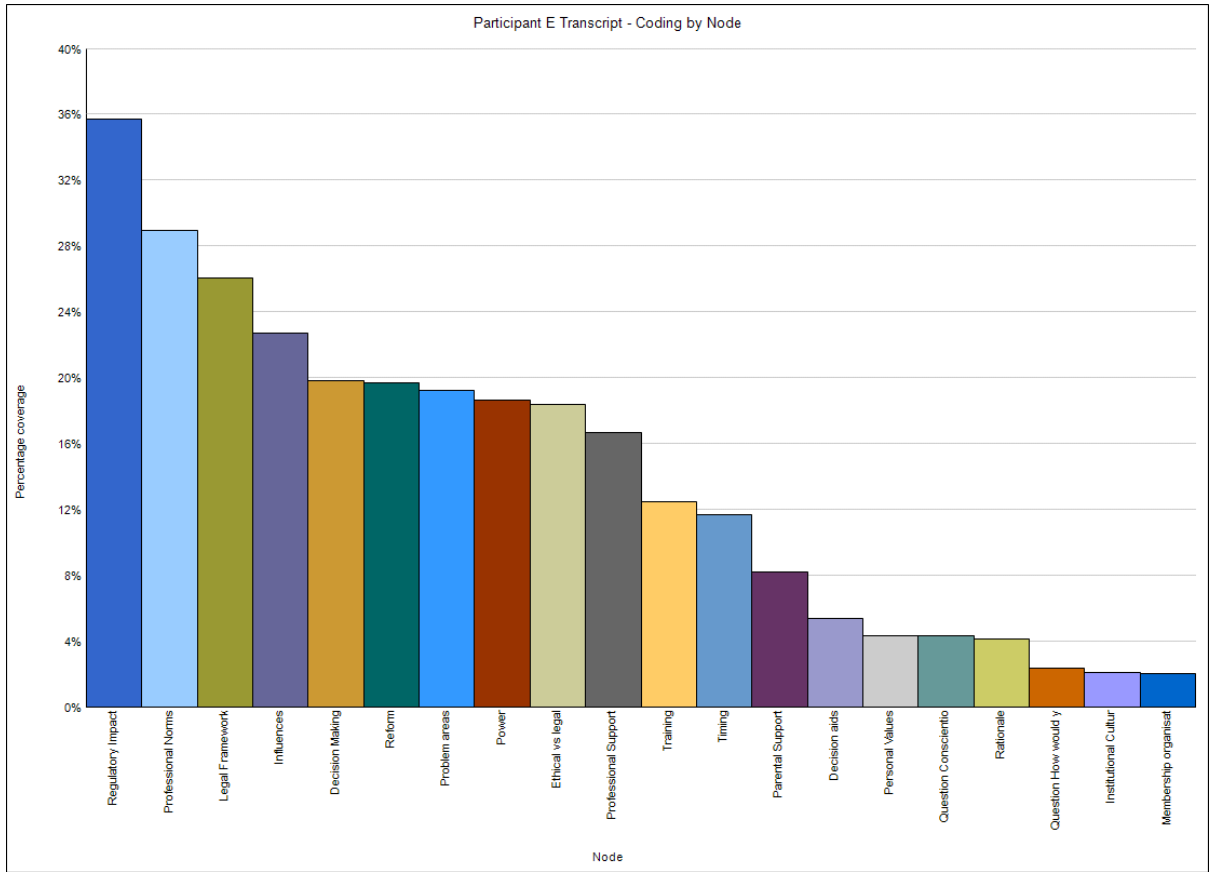


Figure 7 – Frequency Coding – Participant D





**Figure 8 – Frequency Coding – Participant E**



## Appendix C – Theme Definitions

Table 1A -Theme Definitions

Primary Theme	Sub Theme	Definition
<b>Decision-Making</b>		Decision-making as a process or system for identifying, prioritising and selecting options/ choices where they exist. Includes:  -contributions to the choices of one self and of others. -choices that may or may not prompt or result in action on the decision maker's part. -the basis for any preferences.
	Clinical Selection	Decision-making around selections to reduce/ terminate.
	Medical Decision-Making	Decision-making from the perspective of the healthcare professionals.
	Parental Decision-Making	Decision-making from the perspective of the parental stakeholders.
	Ethical Decision-Making	Ethical decision-making.
	Decision Difficulty	Identifies those decisions/ choices which present (or are perceived to present) the decision-maker with a significant degree of hardship, obstacle, hurdle, deliberation, obfuscation or other impediment.
	Decision Aids	Devices, mechanisms, aids, systems or processes used to facilitate dialogue/ communication between the HCP/ parents and intended to facilitate/ support the parental decision-making process.
<b>Influences</b>		Those factors, values or norms that have an effect or impact on the behaviour or decisions of someone or something. May also describe the effect.



<b>Legal Framework</b>		The relevant legal rules, codes or mechanisms that influence, restrict, modify or direct behaviours and decisions.
<b>Personal Values</b>		The personal values and beliefs (that fall outside professional and legal norms or rules) that influence, restrict, modify or direct behaviours and decisions.
<b>Ethical vs Legal</b>		Addresses areas of conflict or potential conflict between ethical and legal frameworks and norms.
<b>Power</b>		Control, authority, rights and influence over people, things, outcomes or decisions.
<b>Training</b>		Giving or receiving education or information related to knowledge, competency and skills.
<b>Problem Areas</b>		Areas generating issues/ complex decision-making. May indicate deficiency, shortcomings or flaws in an area, decision or decision-making process
<b>Parental Support</b>		Processes, advice and other mechanisms to facilitate, enhance, aid or support parents/ parental decision-making. Includes matters related to the development of self-sufficiency.
<b>Timing</b>		Relevant period(s) eg, during the pregnancy.
<b>Frequency</b>		Temporal repetition/ how often something happens
<b>Terminology</b>		The terms and language used for a technical area, process or application.
<b>Reform</b>		Suggestions, recommendations or statements relating to regulatory or other reform.
<b>Culture</b>		Practice impact of local (workplace and disciplinary) culture.

<b>Individual Accountability &amp; Responsibility</b>		Awareness and impact of (possible) personal liability, culpability and responsibility on decision-making and actions.
<b>Professional Resistance</b>		Professional resistance to change, conflict or demands.

**(Table 1A)**

## Appendix D – Research Ethics

Go straight to content.



**Is my study research?**

**i** To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

IRAS Project ID (if available):

You selected:

- **'No'** - Are the participants in your study randomised to different groups?
- **'No'** - Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?!
- **'Yes'** - Are your findings going to be generalisable?!

**Your study would be considered Research.**

You should now determine whether your study requires NHS REC approval.

**[Follow this link to launch the 'Do I need NHS REC approval?' tool.](#)**

For more information please visit the [Defining Research](#) leaflet

**[Follow this link to start again.](#)**

[Print This Page](#)

NOTE: If using Internet Explorer please use browser print function.

[About this tool](#) [Feedback](#) [Contact](#) [Glossary](#)

Go straight to content.



Do I need NHS REC approval?

**i** To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

IRAS Project ID (if available):

Your answers to the following questions indicate that **you do not need NHS REC approval for sites in England**. However, **you may need other approvals**.

You have answered **'YES'** to: Is your study research?

You answered **'NO'** to all of these questions:

**Question Set 1**

- Is your study a clinical trial of an investigational medicinal product?
- Is your study one or more of the following: A non-CE marked medical device, or a device which has been modified or is being used outside of its CE mark intended purpose, and the study is conducted by or with the support of the manufacturer or another commercial company (including university spin-out company) to provide data for CE marking purposes?
- Does your study involve exposure to any ionising radiation?
- Does your study involve the processing of disclosable protected information on the Register of the Human Fertilisation and Embryology Authority by researchers, without consent?
- Is your study a clinical trial involving the participation of practising midwives?

**Question Set 2**

- Will your study involve research participants identified from, or because of their past or present use of services (adult and children's healthcare within the NHS and adult social care), for which the UK health departments are responsible

Go straight to content.



Do I need NHS REC approval?

**i** To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

IRAS Project ID (if available):

Your answers to the following questions indicate that **you do not need NHS REC approval for sites in Wales**. However, **you may need other approvals**.

You have answered **'YES'** to: Is your study research?

You answered **'NO'** to all of these questions:

**Question Set 1**

- Is your study a clinical trial of an investigational medicinal product?
- Is your study one or more of the following: A non-CE marked medical device, or a device which has been modified or is being used outside of its CE mark intended purpose, and the study is conducted by or with the support of the manufacturer or another commercial company (including university spin-out company) to provide data for CE marking purposes?
- Does your study involve exposure to any ionising radiation?
- Does your study involve the processing of disclosable protected information on the Register of the Human Fertilisation and Embryology Authority by researchers, without consent?
- Is your study a clinical trial involving the participation of practising midwives?

**Question Set 2**

- Will your study involve research participants identified from, or because of their past or present use of services (adult and children's healthcare within the NHS and adult social care), for which the UK health departments are responsible



## Appendix E – Clinical and Qualitative Research Studies

**Table 2A - Clinical Case Studies (CCS) and Literature Reviews (LR)**

YEAR	Author	Study type	Numbers	Method/Timing	Conclusions/ results	Issues/ other
1988	Berkowitz et al. <sup>1</sup>	CCS	MFPR 3+ >2 (1 in a single case)	TC aspiration & TA injection	Criteria: 11-12 weeks, inject PC, use TA, selection: avoid sac over internal OS & spare 2	
1989	Osborn. <sup>2</sup>	LR	MFPR where 1 fetus abnormal or 4+		Timing: 10-12 weeks, selection: position, ease of location, fundal size & size of embryo. Spare 2 (dependent on height of women)	Screening, Use of U/S (& issues of attachment), termination of healthy fetus against background of fertility treatment, nursing implications.
1990	Itskovitz et al. <sup>3</sup>	CCS	MFPR	TV U/S guided reduction (aspiration at 7-8 w & intra thoracic injection at 9-11w)	TV better than TA & TC approaches	
1991	Ko et al. <sup>4</sup>	CCS	MFPR to 2	10-14 weeks	Acceptable method of preventing high perinatal mortality & morbidity in MP	
1993	Desai et al. <sup>5</sup>	CCS	MFPR	TC aspiration or TA needling using black & white U/S		
1993	Check et al. <sup>6</sup>	CCS	MFPR 3+> 2	8 weeks	MFPR is a reasonable therapeutic option	

<sup>1</sup> R L Berkowitz and others, 'Selective reduction of multifetal pregnancies in the first trimester', (1988) 318(16) *The New England Journal of Medicine* 1043.

<sup>2</sup> M R Osborn, 'Selective reduction in multiple gestation', (1989) 3(1) *The Journal of Perinatal & Neonatal Nursing* 14.

<sup>3</sup> J Itskovitz and others, 'First trimester selective reduction in multiple pregnancy guided by transvaginal sonography', (1990) 18(4) *Journal of Clinical Ultrasound* 323.

<sup>4</sup> T M Ko and others., 'Selective reduction of multiple pregnancies in the first trimester or early second trimester', (1991) 90(5) *Journal of The Formosan Medical Association = Taiwan Yi Zhi*, 493

<sup>5</sup> S K Desai, G N Allahbadia and A K Dalal, 'Selective reduction of multifetal pregnancies in the first trimester using colour Doppler ultrasonography' (1993) 8(4) *Human Reproduction* 642.

<sup>6</sup> J H Check and others, 'The effects of multiple gestation and selective reduction on fetal outcome', (1993) 21(4) *Journal of Perinatal Medicine* 299.

1995	Brambati & Tului <sup>7</sup>	LR	MFPR		Suggest testing of fetus to be spared before reduction. FR is most effective therapeutic option for reducing risk in MP	
1998	Dechaud et al. <sup>8</sup>	LR	MFPR	1 <sup>st</sup> trimester	TV approach seems safest. TC> high fetal loss & should be excluded	
2001	Lipitz et al. <sup>9</sup>	CCS	MFPR 3>2	11-12 w & 13-14w by TA injection	Early 2 <sup>nd</sup> trimester MFPR from 3 may allow more selective termination of abnormal fetuses w/o adverse effect	
2003	Webb <sup>10</sup>	CCS	Monochorionic twins (1 with abnormality)			Differential reasoning between mother & HCP
2003	Rochon & Stone <sup>11</sup>	LR	MFPR to singletons (notes recent increase)		Options now available for selective reduction of a monochorionic pair	
2004	Evans et al. <sup>12</sup>	LR	MFPR		MFPR 3+> 2 shows dramatic improved outcomes. 2>1 more common esp 40+ women. Evidence combining MFPR with CVS testing.	
2005	Evans & Britt <sup>13</sup>	LR	Increase in MFPR in 40+ women		3>2 clearly improves outcome. 2> 1 now a reasonable consideration but no expert consensus	Effective counseling against conflicting data. Data suggests mortality lowest for twins and morbidity for singletons

<sup>7</sup> B Brambati and L Tului, 'First trimester fetal reduction: its role in the management of twin and higher order multiple pregnancies', (1995) 1(4) *Human Reproduction Update* 397.

<sup>8</sup> H Dechaud and others, 'First-trimester multifetal pregnancy reduction: Evaluation of technical aspects and risks from 2,756 cases in the literature', (1998) 13(5) *Fetal diagnosis and therapy* 261.

<sup>9</sup> S Lipitz, 'A comparative study of multifetal pregnancy reduction from triplets to twins in the first versus early second trimesters after detailed fetal screening', (2001) 18(1) *Ultrasound in Obstetrics & Gynecology* 35.

<sup>10</sup> J, Webb, 'A case of selective feticide', (2003) 11(2) *British Journal of Midwifery* 103.

<sup>11</sup> M Rochon and J Stone, 'Invasive procedures in multiple gestations', (2003) 15(2) *Current Opinion in Obstetrics and Gynecology* 167.

<sup>12</sup> Mark I. Evans, D Ciorica and David W. Britt, 'Do reduced multiples do better?' (2004) 18(4) *Best practice & research clinical obstetrics & gynaecology* 601.

<sup>13</sup> Mark I. Evans and David W. Britt, 'Fetal Reduction', (2005) 29 *Seminars Perinatol* 321.

2009	Wimalasundera <sup>14</sup>	LR	MFPR		Evidence 4+>2 undisputed. 3>2 still significantly reduces risk. Can do MFPR in MC twins.	MFPR in non-trichorionic triplets possible but complex & complications
2010	Balasubramanyam <sup>15</sup>	CCS	FR		67% women did not regard FR as of moral concern.	
2011	Skiadas et al. <sup>16</sup>	CCS	MFPR in trichorionic & triamniotic triplets.	Comparative study of SR of 1 fetus & spontaneous reduction before 12w.	Similar benefits & outcomes.	
2011	Antsaklis et al. <sup>17</sup>	LR	MFPR	1 <sup>st</sup> trimester by TA injection guided by U/S of PC into fetal heart	Selection: reduce MC twins, primary criteria is proximity to abdominal wall (reduce furthest from cervix). Other criteria: obvious abnormality, significantly smaller crown rump and abnormal nuchal translucency.	Controversy in reduction in triplets & twins.  Need patient info & guidelines based on expert consensus.
2011	Talwar et al. <sup>18</sup>	CCS	MFPR 3>2 (94%)	MFPR at 7-8 weeks (92%) by TV U/S guided needle injection	Reduced perinatal morbidity & may be associated with reduced perinatal mortality.	

<sup>14</sup> R C Wimalasundera, 'Selective reduction and termination of multiple pregnancies', (2010) 15(6) *Seminars in fetal & neonatal medicine* 327.

<sup>15</sup> S, Balasubramanyam, 'Knowledge and Attitudes of Women towards Multiple Embryo Transfer, Fetal Reduction and Multiple Pregnancy', (2010) 1(1) *International Journal of Infertility & Fetal Medicine* 31.

<sup>16</sup> C C Skiadas and others, 'Spontaneous reduction before 12 weeks' gestation and selective reduction similarly extend time to delivery in in vitro fertilization of trichorionic-triamniotic triplets', (2011) 95(2) *Fertility and Sterility* 596.

<sup>17</sup> A Antsaklis and E Anastasakis, 'Selective reduction in twins and multiple pregnancies,' (2011) 39(1) *Journal of Perinatal Medicine* 15.

<sup>18</sup> P Talwar and others, 'Embryo reduction: our experience', (2011) 67(3) *Medical Journal Armed Forces India* 241

2011	Cameron <sup>19</sup>	LR	MFPR & ST	TA needle injecting PC or TV/TC aspiration (TV associated with higher loss rate)	Selection criteria: measure nuchal translucency, reduce those with abnormality, select furthest away from cervix & reduce MC twins.	Controversy 3>2 and 3>1
2012	Kuhn-Beck et al. <sup>20</sup>	CCS	MFPR 3>2 or 3>1	MFPR of triplets in trichorionic and triamniotic pregnancy	Reviews outcome of trichorionic triamniotic triplets reduced to twin (136) or singletons (44) at 10-12 weeks gestation. Outcome: reduction to 1 rather than 2 led to significantly higher term delivery rate without significant differences in fetal loss rate or take-home baby rate.	
2013	Legendre et al. <sup>21</sup>	LR			Considers differences between selective termination for fetal abnormality and fetal reduction in MP.	
2013	Ogilvie <sup>22</sup>	LR			Responds to Legendre	

<sup>19</sup> A Cameron, *Fetal medicine for the MRCOG and beyond* (2nd ed, RCOG Press 2011).

<sup>20</sup> F Kuhn-Beck and others, 'Fetal reduction of triplet pregnancy: One or two?' (2012) 32(2) *Prenatal Diagnosis* 122.

<sup>21</sup> C M Legendre and others, 'Differences between selective termination of pregnancy and fetal reduction in multiple pregnancy: a narrative review' (2013) 26(6) *Reproductive Bio-Medicine Online* (Elsevier Science) 542.

<sup>22</sup> C M Ogilvie, 'Multiple pregnancy, fetal reduction and selective termination', (2013) 26 (6) *Reproductive BioMedicine Online* (Elsevier Science) 52.

2013	Drugan et al. <sup>23</sup>	CCS	MFPR in triplet pregnancy	<p>No reduction vs MFPR to twins.</p> <p>34 opted to continue with triplet pregnancy and 46 for MFPR to twins.</p>	<p>Outcome: mean gestational age for triplets 32.3 weeks and 35.6 weeks for twins. Severe prematurity (before 32 weeks) in 37.5% of triplets and 7% of twins. The rate of neonatal morbidity and death was significantly higher in the unreduced triplet group.</p>	<p>MFPR reduces risk of severe prematurity and neonatal morbidity of triplets plus saving in costs. MFPR should be offered in triplet gestations.</p>
2013	Li et al. <sup>24</sup>	CCS	MFPR in triplet pregnancy with monochorionic twins	<p>Group A (9 MFPR to reduce one monochorionic twin) Group B (26 MFPR for both MC twins)</p> <p>NB: Control A for Group A included another 18 cases of TC triplet reduction to twins. Control B for Group B included 35 cases of TC triplet reductions to singletons. Reductions all at same period (6-8 weeks)</p>	<p>Group A had significantly more low birth weight newborns than control A</p> <p>Group B had similar pregnancy outcomes and neonatal conditions as control B</p> <p>Early abortion rate was lower in Group A than B</p> <p>Late abortion rate was higher in Group A than B</p> <p>Groups A &amp; B did not differ significantly in premature labor rate, term birth rate, gestation at delivery and take-home baby rate.</p> <p>Rate of very low and low birth weight significantly higher in Group A than B.</p>	<p>To retain a singleton or twin in a triplet pregnancy with MC twins?</p> <p>Retaining a singleton is always the best choice when deciding about using MFPR to improve pregnancy outcomes.</p> <p>Where patient strongly desires to keep twins, MFPR in one MC twin was feasible by aspirating embryonic parts early in gestation (6-8 weeks) with no drug injection. Pregnancy outcomes are similar with twin reduction in TC triplet pregnancy.</p>

<sup>23</sup> A Drugan and others, 'Fetal Reduction in Triplet Gestations: Twins still fare better, (2013) 15(12) *Lsr Med Assoc J* 745.

<sup>24</sup> Rang Li and others, 'Retain singleton or twins? Multifetal pregnancy reduction strategies in triplet pregnancies with monochorionic twins, (2013) 167(2) *Eur J Obstet Gynecol Reprod Biol* 146.

2014 a	Haas et al. <sup>25</sup>	CCS	MFPR 2>1 vs no reduction	2>1 compared with twin pregnancy.  63 reduced from 2>1 (dichorionic/diamniotic) vs 62 not reduced (dichorionic/diamniotic).	MFPR of twins is associated with lower risk of prematurity and superior perinatal outcomes. Consider where risks exceptionally high.	
2014 b	Haas et al. <sup>26</sup>	CCS	MFPR in triplet pregnancies	3>2 vs 3>1 74 trichorionic pregnancies – early TV MPFR at 6-8 weeks.	Reduction of triplet pregnancies to singleton rather than twin gestations is associated with improved outcomes (later delivery/higher birth weight).	
2016	Satti et al. <sup>27</sup>	CCS	MFPR in 64 triplet pregnancies	15 reductions vs 49 no reduction.	No significant differences in maternal BMI, gestational age at birth, incidence of pre-term birth rate and live birth rate post viability BUT Significant difference in maternal age (older in reduction gp) and average birth weight (higher in reduction gp).	
2016	Gupta et al. <sup>28</sup>	CCS	DC TA Triplet reduction using a saline cardiac tamponade		Potassium Chloride cannot be used in a MC pregnancy – it can endanger both fetuses. This is a novel way of reducing fetuses with common placentas without adverse effects on co-twin.	

<sup>25</sup> J Haas and others, 'Perinatal outcome after fetal reduction from twin to singleton: to reduce or not to reduce', (2014) 103(2) *Fertility & Sterility* 428.

<sup>26</sup> J Haas and others, 'Pregnancy outcome of early multifetal pregnancy reduction: triplets to twins versus triplets to singletons', (2014) 29 *Reproductive Biomedicine Online* 717.

<sup>27</sup> Mohamed Satti and others, 'Selective Fetal Reduction Versus Expectant Management in Triplet Pregnancies After IVF-ET' (2016) *Obstetrics & Gynecology* 127: 64S.

<sup>28</sup> Ashutosh Gupta and others, 'Diachorionic Triamniotic Triplets – Saline Cardiac Tamponade for Fetal Reduction: A Novel Approach', (2016) (3(4) *Journal of Fetal Medicine* 167. See also Devika Gunasheela and others, 'Outcomes of Transvaginal multifetal pregnancy reduction without injecting potassium chloride', (2017) 6(1) *IJRCOG* ISSN 2320-1770.

2017	Zipori et al. <sup>29</sup>	LR	MFPR of triplet pregnancies	3>2 vs unreduced twin pregnancies	22 Studies. Comparable perinatal outcomes save re caesarian section rate.	
2017	Liu et al. <sup>30</sup>	CCS	302 ART conceived multiple pregnancies in China	4/3>2 vs no reduction of twin pregnancies.  152 triplet or quads reduced to twins (RT) 150 non-reduced twin pregnancies (NRT)  Used TA FR Also, comparison between FR at different stages of gestation.	Pregnancy loss rates were 14.5% (RT) and 6.7%(NRT).  Loss rate at weeks 16-24 were significantly higher than 12-13 week groups.	Increased risk of pregnancy loss in RT group but performing MFPR before 16 weeks could reduce the risk of loss significantly.
2017	Tse et al. <sup>31</sup>	CCS	MFPR in 52 triplet pregnancies in Hong Kong	3>2 vs 3>1 vs no reduction  22 reduced to twins and 4 to singletons.	Mean gestation:  No reduction: 32.6 3>2: 35.2 3>1: 39.6	50% of triplet pregnancies elected to undergo FR.
2017	Chaveeva et al. <sup>32</sup>	CCS	DC triplet pregnancies reduced to DC twins by laser ablation of pelvic vessels of one of MC twins	3>2  FR undertaken using intrafetal laser ablation in 61 DC triplet pregnancies at 11 to 14 (+3) weeks gestation.	MC co-twin died in 28 cases within 2 weeks. Of those, 27 had a liveborn singleton.  In the DC group of 33 (1e with live DC twins left), there was one miscarriage at 16 weeks, one neonatal death after delivery at 26 weeks and then 31 live births at a median gestational age of 35.3.	Approximately 50% of these procedures resulted in the death of the MC co-twin.

<sup>29</sup> Yaniv Zipori and others, 'Multifetal reduction of triplets to twins compared with non-reduced twins: a meta-analysis', (2017) (35(1) *Reproductive BioMedicine Online* <<https://doi.org/10.1016/j.rbmo.2017.04.001>> accessed 29 May 2018.

<sup>30</sup> Yan Liu and others, 'Effect of selective second- trimester multifetal pregnancy reduction and its timing on pregnancy outcome' (2017) 10(3) *Int J Clin Exp Med*: 5533.

<sup>31</sup> W T Tse and others, 'Triplet pregnancy with fetal reduction: experience in Hong Kong', (2017) 23(4) *Hong Kong Medical Journal* 326.

<sup>32</sup> P Chaveeva and others, 'Intrafetal laser ablation for embryo reduction from dichorionic triplets to dichorionic twins', (2017) *Ultrasound in Obs and Gynae* <<https://doi.org/10.1002/uog.18834>> accessed 29 May 2018..

2017	Razaz et al. <sup>33</sup>	CCS	MFPR in triplet or twin pregnancy in Canada	>2 / 1 vs no reduction  95 underwent FR (45 to twin and 50 to singleton)	No significant difference in rate of serious morbidity or perinatal death (save in ART induced pregnancies)  <u>But</u> FR (in both groups) was associated with substantial improvements in several other perinatal outcomes such as preterm birth and low birth weight.	
2018	Abdelhafez et al. <sup>34</sup>	CCS	Triplet (ART) pregnancies	Reduction to twins vs those managed with cervical cerclage  53 TV FR vs 65 cervical cerclage	Pregnancy duration significantly longer with FR (and incidences of delivery between 32-34 weeks gestation significantly lower with FR).  Miscarriage and live birth rates were comparable.	TV FR of 3>2 leads to improved obstetric outcomes as it decreases prematurity and related morbidity and mortality without increase in miscarriage rate.
2019	Liu et al. <sup>35</sup>	CCS	Triplet pregnancies	3 groups – MFPR to singleton (22 TC/22 DC), MFPR to twins (610 TC/ 50 DC) and expectant mothers (40 TC/ 17 DC)).	The groups with MFPR had better pregnancy and perinatal outcomes. The singleton group had higher birth weight and elder gestational age in DC and TC pregnancies.	For DC triplets, reduction to singleton is recommended . But if keeping MC twins, reduction of single fetus = acceptable outcomes.

<sup>33</sup> Neda Razaz and others, 'Perinatal outcomes in multifetal pregnancy following fetal reduction', (2017) 189(18) *CMAJ*: E652.

<sup>34</sup> Mohamed S. Abdelhafez, Mahmoud M. Abdelrazik and Ahmed Badawy, 'Early fetal reduction to twin versus prophylactic cervical cerclage for triplet pregnancies conceived with assisted reproductive techniques' (2018) 57(1) *Taiwanese J of Obs and Gynae*: 95.

<sup>35</sup> Yaqiong Liu and others, 'Clinical outcomes of multifetal pregnancy reduction in trichorionic and dichorionic triplet pregnancies: A retrospective observation study', (2019) 58 *Taiwanese Journal of Obstetrics & Gynecology* 133.



2019	Meng et al. <sup>36</sup>	CCS	MFPR in MC pregnancies using microwave ablation	40 twins 5 triplets	12 cases (26.7%) of post procedural fetal loss.  33 women delivered at a median gestational age of 37.6 weeks.  No evidence of injury/ neurological anomaly in surviving co-twin.	Microwave ablation appears safe and effective in complicated MC pregnancies.
2019	Kim et al. <sup>37</sup>	CCS	MFPR to twins or singleton	181 transvaginal embryo reductions (ER) at a mean of 7.6 weeks & 115 transabdominal fetal reductions (FR) at mean of 12.9 weeks.	The incident of procedure related loss, miscarriage rate and overall loss rate was lower in the FR group.	The FR procedure is a better and safer approach to reduce morbidity and mortality in multiples.

(Table 2A)

<sup>36</sup> Xinlu Meng and others, 'Forty-five consecutive cases of complicated monochorionic multiple pregnancy treated with microwave ablation: a single-center experience', (2019) *Prenatal Diagnosis* DOI.org/10.1002/pd.5423.

<sup>37</sup> M S. Kim and others, 'Procedural and obstetric outcomes after embryo reduction' (2019) 53(2) *Ultrasound in Obstetrics and Gynecology* 214.

**Table 3A – Qualitative Research<sup>38</sup>**

Author/Year	Method	Analysis	Participants	Purpose
Statham et al., 2006 <sup>39</sup>	Semi-structured interviews	Thematic	15 HCP in English NHS fetal units	Decision making re late abortions on grounds of abnormality
Lipp, 2007 <sup>40</sup>	Literature review of existing research	Unknown	Nurses and midwives in UK	Healthcare attitudes to abortion
Britt & Evans, 2007 <sup>41</sup>	Semi-structured interviews	Comparative	54 women contemplating multi-fetal reduction in a US Centre	Decision difficulty in different conceptual frameworks
Graham et al., 2009 <sup>42</sup>	Semi-structured interviews	Thematic	HCP and parents in 3 NHS fetal units	Feticide in late terminations
Gallagher et al., 2010 <sup>43</sup>	Semi-structured interviews	Thematic	9 nurses in 3 clinics in UK	Global themes: “attitudes towards abortion” and coping (roles, patients, late abortions)
Nicholson et al., 2010 <sup>44</sup>	Structured interviews	Interpretive phenomenological	7 gynae nurses working in TOP services in England	Challenges for staff working in TOP.

<sup>38</sup> Also note the ESRC funded research project by Sheelagh McGuinness and the British Pregnancy Advisory Service: ‘The experience of doctors who provide abortion services in the UK’.

<sup>39</sup> Helen Statham, Wendy Solomou and Jasper B. Green, ‘Late termination of pregnancy: law, policy and decision making in four English fetal medicine units’, (2006) 113(12) *BJOG: An International Journal of Obstetrics and Gynaecology* 1402.

<sup>40</sup> Allyson Lipp, ‘A review of termination of pregnancy: prevalent health care professional attitudes and ways of influencing them’, (2007) 17(13) *Journal of Clinical Nursing* 1683.

<sup>41</sup> David W. Britt and Mark I. Evans, ‘Sometimes doing the right thing sucks: Frame combinations and multi-fetal pregnancy reduction decision difficulty’, (2007) 65 *Social Science & Medicine* 2342.

<sup>42</sup> Ruth H. Graham and others, ‘The role of feticide in the context of late termination of pregnancy: a qualitative study of health professionals’ and parents’ views’, (2009) 29 *Prenat Diagn* 875.

<sup>43</sup> Katie Gallagher, Davinia Porock and Alison Edgley, ‘The concept of nursing in the abortion services’, (2010) 66 *Journal of Advanced Nursing* 849.

<sup>44</sup> J Nicholson, P Slade and J Flethcher, ‘Termination of pregnancy services: Experiences of gynaecological nurses’, (2010) 66(10) *Journal of Advanced Nursing* 2245.

<b>Kirkman et al., 2011<sup>45</sup></b>	Semi-structured interviews	Discourse	Pregnant women contemplating abortion in Australia	Patient perception of fetal status
<b>Lagan et al., 2011<sup>46</sup></b>	13 online focus groups	A version of thematic analysis	92 women from Australia, New Zealand and the US who had accessed the internet for pregnancy related information over a 3-month period.	To understand internet use in pregnancy and its role in relation to decision-making
<b>Astbury Ward et al., 2012<sup>47</sup></b>	Semi -structured interviews	Unknown	17 Pregnant women undergoing abortion in 2 UK NHS Trust clinics	Experiences influenced by perceived social attitudes
<b>Menezes et al., 2013<sup>48</sup></b>	Semi-structured interviews	Thematic	40 HCP in Australian fetal units	Emotional response of working with couples viz risk of fetal abnormality
<b>Kelland &amp; Ricciardelli, 2014<sup>49</sup></b>	Interviews	Thematic	41 Canadian mothers of multiples (twins and triplets)	To explain how decision-making is based on medical and non-medical reasoning.

<sup>45</sup> Maggie Kirkman and others, 'Abortion is a difficult solution to a problem: A discursive analysis of interviews with women considering or undergoing abortion in Australia', (2011) 34(2) *Women's Studies International Forum* 121.

<sup>46</sup> Briege M. Lagan, Marlene Sinclair and W. George Kernohan, 'What is the impact of the Internet on Decision-Making in Pregnancy? A Global Study' (2018) 38(4) *Birth* 336.

<sup>47</sup> Edna Astbury-Ward, Odette Parry and Ros Carnwell, 'Stigma, Abortion, and Disclosure – Findings from a Qualitative Study', (2012) 9 *IJ Sex Med* 3137.

<sup>48</sup> Melody A. Menezes and others, 'Taking Its Toll': The Challenges of Working in Fetal Medicine. (2013) 40(1) *Birth: Issues in Perinatal Care* 52.

<sup>49</sup> Jennifer Kelland and Rosemary Ricciardelli, 'Mothers of Multiple Perspectives on Fetal Reduction and Medical Abortion', (2014) 5(2) *J Motherhood Initiative for Research and Community* 123.

<b>Richards et al., 2015<sup>50</sup></b>	Semi-structured	Thematic	14 UK mothers who had experienced pregnancy loss and had a surviving twin	To obtain mothers' perspectives on the perinatal loss of a twin.
<b>Purcell et al., 2016<sup>51</sup></b>	Semi-structured interviews	Thematic	37 HCP involved in abortion provision in NHS hospitals in Scotland	Focus on the role of emotional labour, the temporality of abortion work and changes in provision.
<b>Klitzman., 2016<sup>52</sup></b>	Semi-structured telephone interviews	Grounded theory	17 physicians, 10 other health providers and 10 patients all involved in ART in US	To obtain perspectives on the challenges of fetal reduction in multiple pregnancy.
<b>Richards et al., 2016<sup>53</sup></b>	Semi-structured interviews	Thematic	26 HCPs working within a single UK NHS hospital	To obtain HCP perspectives in respect of caring for parents who had lost a baby from a twin pregnancy either during pregnancy or in the neonatal period.

<sup>50</sup> Judy Richards and others, 'Mothers' perspectives on the perinatal loss of a co-twin: A qualitative study' (2015) 15 *BMC Pregnancy & Childbirth*: 143.

<sup>51</sup> Carrie Purcell and others, 'The changing body work of abortion: A qualitative study of the experiences of health care professionals', (2016) *Sociology of Health and Illness* ISSN 0141-9889:1.

<sup>52</sup> Robert L. Klitzman, 'Reducing the number of foetuses in a pregnancy: providers' and patients' views of challenges', (2016) 31(11) *Human Reproduction* 2570.

<sup>53</sup> Judy Richards and others, 'Health professionals' perspectives on bereavement following loss from a twin pregnancy: A qualitative study' (2016) 36 *Journal of Perinatology* 529.

<b>Lotto et al., 2016<sup>54</sup></b>	Semi-structured interviews	Constant comparative	18 parents in 4 UK fetal medicine units (10 women and 8 partners)	Experiences of parents in 4 UK fetal medicine units following a decision to terminate a pregnancy affected by severe congenital anomaly.
<b>Lafarge et al., 2017<sup>55</sup></b>	Semi-structured interviews	Thematic	15 HCP in 3 English Hospitals	Are HCP perspectives of women's coping with termination for fetal anomaly congruent with maternal accounts?
<b>Meaney et al., 2017<sup>56</sup></b>	Semi-structured interviews	Phenomenological	9 Irish (ROI) parents who had experienced perinatal loss in twin pregnancy with a diagnosis of congenital abnormality.	Exploring parental perspectives of loss following diagnosis of congenital abnormality.

<sup>54</sup> Robyn Lotto, Natalie Armstrong and Lucy K. Smith, 'Care provision during termination of pregnancy following diagnosis of a severe congenital anomaly - A qualitative study of what is important to parents', (2016) 43 *Midwifery* 14.

<sup>55</sup> Caroline Lafarge and others, 'Pregnancy termination for fetal abnormality: Are health professionals' perceptions of women's coping congruent with women's accounts?', (2017) 17(1) *BMC Pregnancy and Childbirth* 60.

<sup>56</sup> Sarah Meaney, Paul Corcoran and Keelin O'Donoghue, 'Death of One Twin during the Perinatal Period: An Interpretative Phenomenological Analysis', (2017) 20(3) *Journal of Palliative Medicine* < <https://doi.org/10.1089/jpm.2016.0264> > accessed 29 May 2018.

MacFarlane et al., 2017 <sup>57</sup>	Semi-structured interviews	Content and thematic	14 adult women who had obtained abortion care in Istanbul on/ after 1 January 2009.	To assess recent experiences in light of political rhetoric and threatened legislative changes restricting abortion in Turkey.
Lotto et al., 2017 <sup>58</sup>	Semi-structured interviews	Constant comparative	22 HCP across 4 tertiary UK fetal medicine centres.	To obtain HCP perspectives of parental decision-making (re severe congenital anomaly).
Crowe et al., 2018 <sup>59</sup>	Semi-structured interviews	Thematic	23 UK HCP perspectives of termination for non-lethal fetal anomaly.	To obtain HCP perspectives around the issue of termination of pregnancy for non-lethal anomaly.
Lee et al., 2018 <sup>60</sup>	Semi-structured interviews	Thematic	14 UK HCP involved in abortion provision & policy/ service development.	To obtain perspectives of practice & law.

(Table 3A)

<sup>57</sup> Katrina A. MacFarlane and others, "It was as if society didn't want a woman to get an abortion": a qualitative study in Istanbul, Turkey', (2017) 95(2) *Contraception* 154.

<sup>58</sup> Robyn Lotto, Lucy K. Smith and Natalie Armstrong, 'Clinicians' perspectives of parental decision-making following diagnosis of a severe congenital anomaly: a qualitative study', (2017) 7 *BMJ Open* e014716.

<sup>59</sup> Lisa Crowe and others, 'Negotiating acceptable termination of pregnancy for non-lethal fetal anomaly: a qualitative study of professional perspectives', (2018) 8(3) *BMJ Open* e020815, <<http://bmjopen.bmj.com/content/bmjopen/8/3/e020815.full.pdf>> accessed 31 May 2018.

<sup>60</sup> Ellie Lee, Sally Sheldon Sheldon and Jan Macvarish, 'The 1967 Abortion Act fifty years on: Abortion, medical authority and the law revisited.' (2018) 212 *Social Science and Medicine* 26, <<https://doi.org/10.1016/j.socscimed.2018.07.010>> accessed 18 May 2019

## Appendix F – Recommendations, Codes and Guidance

**Table 4A – Recommendations, Codes and Guidance**

Body	Instrument/ Comment	Recommendations/ Instruction
<b>International Bodies</b>		
<b>FIGO</b>	<p><b><i>Ethical Recommendations on Multiple Pregnancy and Multifetal Reduction.</i></b><sup>61</sup></p> <p>Multiple pregnancy involves great danger for the woman's health and her fetuses, which are likely to be delivered prematurely with a high risk of either dying or suffering damage.</p> <p>Multifetal reduction is not medically considered as terminating that pregnancy but rather as a procedure to secure its best outcome.</p>	<p>Clinical priority should be by way of careful planning and monitoring of infertility treatment for the reduction or avoidance of multiple pregnancies. However, where such pregnancies arise, it may be considered ethically preferable to reduce the number of fetuses rather than to do nothing.</p> <p>Information provided must include the risks to mothers and fetuses with and without fetal reduction, including miscarriage. Whether the couple decide to maintain or to reduce high order multiple pregnancies, they should be assured that they will receive the best available medical care.</p>

<sup>61</sup> FIGO Committee for the Ethical Aspects of Human Reproduction and Woman's Health, 'Ethical Recommendations on Multiple Pregnancy and Multifetal Reduction', (2006) 92 *Int J of Gynecologists and Obstetricians* 331.

<p><b>ACOG</b></p>	<p><b><i>Committee Opinion on Multi Fetal Pregnancy Reduction.</i></b><sup>62</sup></p> <p>Fellows should be aware that multifetal pregnancies increase both maternal and perinatal morbidity and mortality. High-order multifetal pregnancies present higher risks than do twin pregnancies.</p> <p>Nondirective patient counseling should be provided to all women with high-order multifetal pregnancies. Resources for providing such counseling include maternal-fetal medicine specialists, neonatologists, mental health professionals, child development specialists, support groups, and clinicians with expertise in multifetal pregnancy reduction.</p> <p>Respect for autonomy – only the patient can weigh the relative importance of the medical, ethical, religious, and socioeconomic factors and determine the best course of action for her unique situation.</p> <p><i>“Selective reduction is somewhat different from that of multifetal pregnancy reduction. In multifetal pregnancy reduction, the fetus(es) to be reduced are chosen on the basis of technical considerations, such as which is most accessible to intervention. In selective reduction, fetuses are chosen on the basis of health status.”</i><sup>63</sup></p>	<p>Fertility treatments have contributed significantly to the increase in multifetal pregnancies. Strategies to limit multifetal pregnancies, especially high-order multifetal pregnancies, should be practiced by all physicians who treat women for infertility.</p> <p>Fellows should be knowledgeable about the medical risks of multifetal pregnancy, the potential medical benefits of multifetal pregnancy reduction, and the complex ethical issues inherent in decisions regarding the use of multifetal pregnancy reduction. They should be prepared to react in a professional and ethical manner to patients who request or decline to receive information, or intervention, or both.</p> <p>Recognises the ethical concerns around reduction on the basis of fetal sex and in twin to singleton pregnancies.</p>
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<sup>62</sup> American College of Obstetricians and Gynecologists *Committee Opinion on Multi Fetal Pregnancy Reduction* (2017.) <<https://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Ethics/Multifetal-Pregnancy-Reduction> >accessed 21 June 2017.

<sup>63</sup> Ibid.



<b>Representative Bodies</b>	<b>Instrument/ Comment</b>	<b>Recommendations/ Instruction</b>
<b>British Medical Association</b>	<b><i>Law and Ethics of Abortion.</i></b> <sup>64</sup>	“ <i>Selective termination to be justifiable where the procedure is recommended for medical reasons ... Where there are no medical indications for aborting particular fetuses, the choice should be a random one.</i> ” <sup>65</sup>
<b>Royal College of Obstetricians and Gynaecologists</b>	<p><b><i>Fetal Awareness: Review of Research and Recommendations for Practice.</i></b><sup>66</sup></p> <p><b><i>Termination of pregnancy for fetal abnormality.</i></b><sup>67</sup></p> <p><b><i>Multiple pregnancy: the management of twin and triplet pregnancies in the antenatal period (NICE Clinical Guideline).</i></b><sup>68</sup></p> <p><b><i>The care of women requesting induced abortion.</i></b><sup>69</sup></p> <p><b><i>Monochorionic Twin Pregnancy Management 2016 (Green Top Guideline 51).</i></b><sup>70</sup></p>	<p>Selective feticide “<i>will only be lawful if one of the four statutory grounds is satisfied. Most specialists in this area believe that the continuation of multiple pregnancies could involve a greater risk to the woman than the termination of one of the foetuses and Ground 1(1)(a) is usually relied upon in pregnancies of under 24 weeks of gestation.</i>”<sup>71</sup></p> <p>NB. EXPRESSLY EXCLUDES EMBRYO REDUCTION FROM REMIT (no relevant changes are proposed in the 2019 consultation).</p> <p>“<i>Prior to invasive testing or in the context of twins discordant by abnormality, selective reduction should be discussed and made</i></p>

<sup>64</sup> BMA, *The Law and Ethics of Abortion: BMA Views* (BMA November 2014 (updated October 2018)).

<sup>65</sup> *Ibid.*, 9.

<sup>66</sup> RCOG, *Fetal Awareness: Review of Research and Recommendations for Practice* (RCOG 2010a).

<sup>67</sup> RCOG, *Termination of pregnancy for fetal abnormality* (RCOG 2010b).

<sup>68</sup> RCOG, *Multiple pregnancy: the management of twin and triplet pregnancies in the antenatal period (NICE Clinical Guideline)* (RCOG 2011a); NICE CG129. See also NICE, *Twin and Triplet Pregnancy (CG129 Guideline Update) – Draft for Consultation* (NICE 2019).

<sup>69</sup> RCOG, *The care of women requesting induced abortion* (RCOG 2011b).

<sup>70</sup> RCOG, *Monochorionic Twin Pregnancy Management (Green Top Guideline 51)* (RCOG 2016).

<sup>71</sup> RCOG (n67), 5 (emphasis added).

		<p><i>available for those requesting the procedure after appropriate counselling.</i><sup>72</sup></p> <p><i>“Selective feticide by intravascular injection is not an option in (MC) pregnancies because of the presence of placental anastomoses. The potential risks of intrafetal/umbilical cord ablative procedures should be discussed prospectively, including the risk of co-twin loss and neurological morbidity.”</i><sup>73</sup></p> <p><i>“The consensus views ...recommend that selective reduction should be discussed in all high order pregnancies”</i>.<sup>74</sup></p>
<p><b>Royal College of Nursing</b></p>	<p><b><i>Termination of Pregnancy: An RCN nursing framework.</i></b><sup>75</sup></p>	<p><i>“When a woman has a triplet or higher order pregnancy, all the issues associated with fetal reduction should be discussed in depth to ensure she is able to make a fully-informed decision”</i>.<sup>76</sup></p> <p>Guidance appears to differentiate fetal reduction (also described as embryo reduction or selective reduction) from selective feticide <i>“if a fetus in a multiple pregnancy has major abnormalities”</i>.<sup>77</sup></p> <p>The guidance assesses the risk of losing the pregnancy after a fetal reduction at <i>“about 5% for triplets, 8% for quadruplets and 11% for quintuplets”</i><sup>78</sup> but oddly makes no allowance for gestational stage.</p>

<sup>72</sup> RCOG (n70), e8. See also e7, 25, 27 and 33.

<sup>73</sup> Ibid.

<sup>74</sup> Ibid., e32.

<sup>75</sup> Royal College of Nursing (RCN), *Termination of Pregnancy: An RCN nursing framework* (RCN 2017).

<sup>76</sup> Ibid., 10.

<sup>77</sup> Ibid., 11.

<sup>78</sup> Ibid.

<b>Professional Regulators</b>	<b>Instrument/ Comment</b>	<b>Recommendations/ Instruction</b>
<b>General Medical Council</b>	<p><i>Good Medical Practice.</i><sup>79</sup></p> <p><i>Confidentiality: Good Practice in Handling Patient Information.</i><sup>80</sup></p> <p><i>Decision making and consent: Supporting patient choices about health and care, Draft guidance for consultation.</i><sup>81</sup></p>	<p><i>“Serious or persistent failure to follow this guidance that poses a risk to patient safety or public trust in doctors will put your registration at risk” but “there is no automatic link between failure to follow this guidance and action against your registration...because the guidance sets out the principles of good practice, not thresholds for taking action”.</i><sup>82</sup></p> <p><i>“Doctors have an ethical and legal responsibility to involve patients as much as possible in making decisions about their own health and care”.</i><sup>83</sup></p>

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<sup>79</sup> Updated April 2019.

<sup>80</sup> 2017.

<sup>81</sup> 2018

<sup>82</sup> Ibid., 3.

<sup>83</sup> Ibid., 4.

<b>System Regulators</b>	<b>Instrument/ Comment</b>	<b>Recommendations/ Instruction</b>
<p><b>Department of Health and Social Care (formerly Department of Health)</b></p>	<p><b><i>Guidance in relation to requirements of the Abortion Act 1967.</i></b><sup>84</sup></p> <p><b><i>Procedures for the Approval of Independent Sector Places for the Termination of Pregnancy.</i></b><sup>85</sup></p> <p><b><i>Matching Department of Health Abortion Notifications and Data from the National Down's Syndrome Cytogenetic Register and recommendations for improving notification compliance.</i></b><sup>86</sup></p>	<p>This does not explicitly address fetal reduction.</p> <p>This has little relevance for fetal reduction per se.</p> <p>This addresses notification compliance issues. Fetal reductions and selective terminations are subject to greater scrutiny by the DHSC at the ex post stage, although the specific focus/ concern, appears to be on selective late terminations on the grounds of anomaly.<sup>87</sup></p>

<sup>84</sup> Department for Health, *Guidance in relation to requirements of the Abortion Act 1967* (DOH 2014a).

<sup>85</sup> Department for Health, *Procedures for the Approval of Independent Sector Places for the Termination of Pregnancy* (DOH 2014b).

<sup>86</sup> Department for Health, *Matching Department of Health Abortion Notifications & Data from the National Down's Syndrome Cytogenetic Register & recommendations for improving notification compliance* (DOH 2014d).

<sup>87</sup> See Department of Health, *Detailed guidance note for completing the abortion notification form HSA4 for abortions performed in England & Wales* (DOH 2013a); Department of Health, *Guidance Note for completing abortion notification form HSA 4 (England & Wales)* (DOH 2013b); Department of Health, *Summary Guidance note for completing the abortion notification form HSA4 for Abortions performed in England & Wales* (DOH 2013c).

<p><b>National Institute for Health and Care Excellence (NICE)</b></p>	<p><b>NICE Quality Standard (QS46)<sup>88</sup></b></p> <p><i>(Core statements for the treatment of women with a multiple pregnancy):</i></p>	<ul style="list-style-type: none"> <li>• Women with a multiple pregnancy have the chorionicity<sup>90</sup> and amnionicity<sup>91</sup> of their pregnancy determined using ultrasound and recorded between 11 weeks 0 days and 13 weeks 6 days.</li> <li>• Women with a multiple pregnancy have their fetuses labelled using ultrasound and recorded between 11 weeks 0 days and 13 weeks 6 days.</li> <li>• Women with a multiple pregnancy are cared for by a multidisciplinary core team.</li> <li>• Women with a multiple pregnancy have a care plan that specifies the timing of appointments with the multidisciplinary core team appropriate for the chorionicity and amnionicity of their pregnancy.</li> <li>• Women with a multiple pregnancy are monitored for foetal complications according to the chorionicity and amnionicity of their pregnancy.</li> <li>• Women with a higher-risk or complicated multiple pregnancy have an obstetrician from a tertiary level foetal medicine centre involved in their care.</li> <li>• Women with a multiple pregnancy have a discussion by 24 weeks with one or more members of the multidisciplinary core team about the risks, signs and symptoms of preterm labour and possible outcomes of preterm birth.</li> <li>• Women with a multiple pregnancy have a discussion by 32 weeks with one or more members of the multidisciplinary core team about the timing of birth and possible modes of birth so that a birth plan can be agreed.</li> </ul>
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<sup>88</sup> NICE Quality Standard (QS46): *Multiple pregnancy: twin and triplet pregnancies*

<<https://www.nice.org.uk/guidance/qs46/resources/multiple-pregnancy-twin-and-triplet-pregnancies-2098670068933>> accessed 11 April 2017.

<sup>90</sup> Number of placentas.

<sup>91</sup> Number of amniotic sacks.

	<b>NICE Guidance (CG129)<sup>89</sup></b>	<p>Referrals to tertiary fetal medicine centres in the following circumstances:</p> <ul style="list-style-type: none"> <li>• monochorionic monoamniotic twin pregnancies</li> <li>• monochorionic monoamniotic triplet pregnancies</li> <li>• monochorionic diamniotic triplet pregnancies</li> <li>• dichorionic diamniotic triplet pregnancies</li> <li>• pregnancies complicated by any of the following: <ul style="list-style-type: none"> <li>○ discordant fetal growth</li> <li>○ fetal anomaly</li> <li>○ discordant fetal death</li> <li>○ feto-fetal transfusion syndrome.</li> </ul> </li> </ul>
<b>NHS</b>	<p><b>Standard Contract for Fetal Medicine<sup>92</sup></b></p> <p><b>NHS RightCare Shared Decision-Making Programme<sup>93</sup></b></p>	<p>Provides for the creation of specialist fetal medicine services that will handle invasive procedures relating to termination of pregnancy (including multifetal pregnancy reduction, feticide (selective or otherwise).</p> <p><i>“Shared Decision Making is where individuals and clinicians work together to understand and decide what tests, treatments, management or support packages are most suitable bearing in mind the persons individual circumstances. It brings together the individual’s expertise about themselves and what is important to them together with the clinician’s knowledge about what is known about the benefits and risks of the available options.”</i></p> <p>Challenges include low health literacy and the professional perspective.</p>

<sup>89</sup> NICE Clinical Guideline (CG129) *Multiple pregnancy: antenatal care for multiple pregnancy: antenatal care for twin and triplet pregnancies twin and triplet pregnancies* (short version of the RCOG 2011a), <<https://www.nice.org.uk/guidance/cg129/resources/multiple-pregnancy-antenatal-care-for-twin-and-triplet-pregnancies-35109458300869>> accessed 11 April 2017. For latest, see NICE, *Twin and Triplet Pregnancy (CG129 Guideline Update) – Draft for Consultation* (NICE 2019) and NICE, *Termination of Pregnancy – NICE Guideline – Draft for Consultation* (NICE April 2019).

<sup>92</sup> NHS England E12/S/a 2013 p6

<sup>93</sup> NHS England, Shared Decision Making Programme <<https://www.england.nhs.uk/rightcare/useful-links/shared-decision-making/>> accessed 20 June 2018.

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## **ABBREVIATIONS**

**AA 1967** – Abortion Act 1967

**ACOG** – American College of Obstetricians and Gynecologists

**BJOG** – An International Journal of Obstetrics and Gynaecology

**BMA** – British Medical Association

**BMJ** – British Medical Journal

**BMFMS** - British Maternal and Fetal Medicine Society

**CCS** – Clinical Case Study

**CDCLA** – Congenital Disabilities (Civil Liability) Act 1976.

**CICA** – Criminal Injuries Compensation Authority

**CQC** – Care Quality Commission

**DA** – Diamniotic pregnancy

**DC** – Dichorionic pregnancy

**DOH** – Department of Health

**DHSC** - Department of Health and Social Care

**ECHR** – European Convention on Human Rights 1950 (Council of Europe)

**ECtHR** – European Court of Human Rights

**ER** – Embryo reduction

**FIGO** – International Federation of Gynecology and Obstetrics

**FR** – Fetal reduction

**GMC** – General Medical Council

**HCP** – Healthcare professional

**HCProv** – Healthcare provider

**HFEA** – Human Fertilisation and Embryology Act(s)

**ILPA 1929** – Infant Life (Preservation) Act 1929

**IUGR** - Intrauterine growth restriction

**LR** – Literature Review

**MC** – Monochorionic pregnancy

**MFPR** – Multi fetal pregnancy reduction

**MP** – Multiple pregnancy

**MPTS** - Medical Practitioners Tribunal Service

**NDSCR** – National Down Syndrome Cytogenetic Register

**NICE** – National Institute for Health and Care Excellence

**NIHR** – National Institute for Health Research

**NHS** – National Health Service

**OAPA 1861** – Offences Against the Person Act 1861

**OUP** – Oxford University Press

**PSA** – The Professional Standards Authority

**RCOG** – Royal College of Obstetricians and Gynaecologists

**RCP** - Royal College of Physicians

**TA** – Transabdominal

**TAP** – Triamniotic pregnancy

**TC** – Transcervical

**TCP** – Trichorionic pregnancy

**TFA** – Termination for fetal anomaly

**TOG** – The Obstetrician and Gynaecologist

**TOP** – Termination of pregnancy

**TTTS** – Twin to twin transfusion syndrome

**TAPS** – Twin anaemia polycythemia sequence

**TRAPS** – Twin reversed arterial perfusion sequence.

**TV** – Transvaginal

## GLOSSARY

**Abortion** – this term is used to describe non-spontaneous terminations of pregnancy.

**Amniocity** – the number of amniotic sacs. Shared amniotic sacs are called monoamniotic. Two amniotic sacs are called Diamniotic and three are called Triamniotic and so on.

**Bodily autonomy** – “*the freedom to act upon choices made by a person with decision-making capacity which relate to the human body*”.<sup>1</sup>

**Decision-making** - a process resulting in the selection of a course of action (choices) from several alternative possibilities. In our context, this includes the process of communicating choices to others.

**Dichorionic twin pregnancy** – each embryo has its own placenta.

**Dichorionic/ diamniotic twin pregnancy** – each embryo has their own placenta and amniotic sac.

**Embryo or fetal reduction** – a specific term used to denote the termination of one or more embryos or fetuses usually in a multiple pregnancy.

**Monochorionic twin pregnancy** – these have monozygotic (identical) twin embryos sharing the same placenta.

**Monochorionic/ diamniotic twin pregnancy** – the twins share a placenta but have separate amniotic sacs.

**Monochorionic/ monoamniotic twin pregnancy** – the twins share a placenta and amniotic sac.

**Monochorionic multiples** - where the placenta is shared by more than two twins.

**Morbidity** – a state of illness, disease, anomaly, impairment or ill health.

**Mortality** – another term for death.

**Regulation** – we have framed this broadly as an attempt to alter the behaviour of others with the intention of producing certain outcomes or goals.

**Transabdominal** – across the abdominal wall or through the abdominal cavity.

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<sup>1</sup> This is replicated from Elizabeth Wicks, *The State and the Body: Legal Regulation of Bodily Autonomy* (Hart 2016), 4.

**Transcervical** – through the cervical opening of the uterus.

**Transvaginal** – across or through the vagina.

**Trichorionic pregnancy** – triplet pregnancy and each embryo has their own placenta.

**Trichorionic / triamniotic pregnancy** – triplet pregnancy and each embryo has their own placenta and amniotic sac.

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