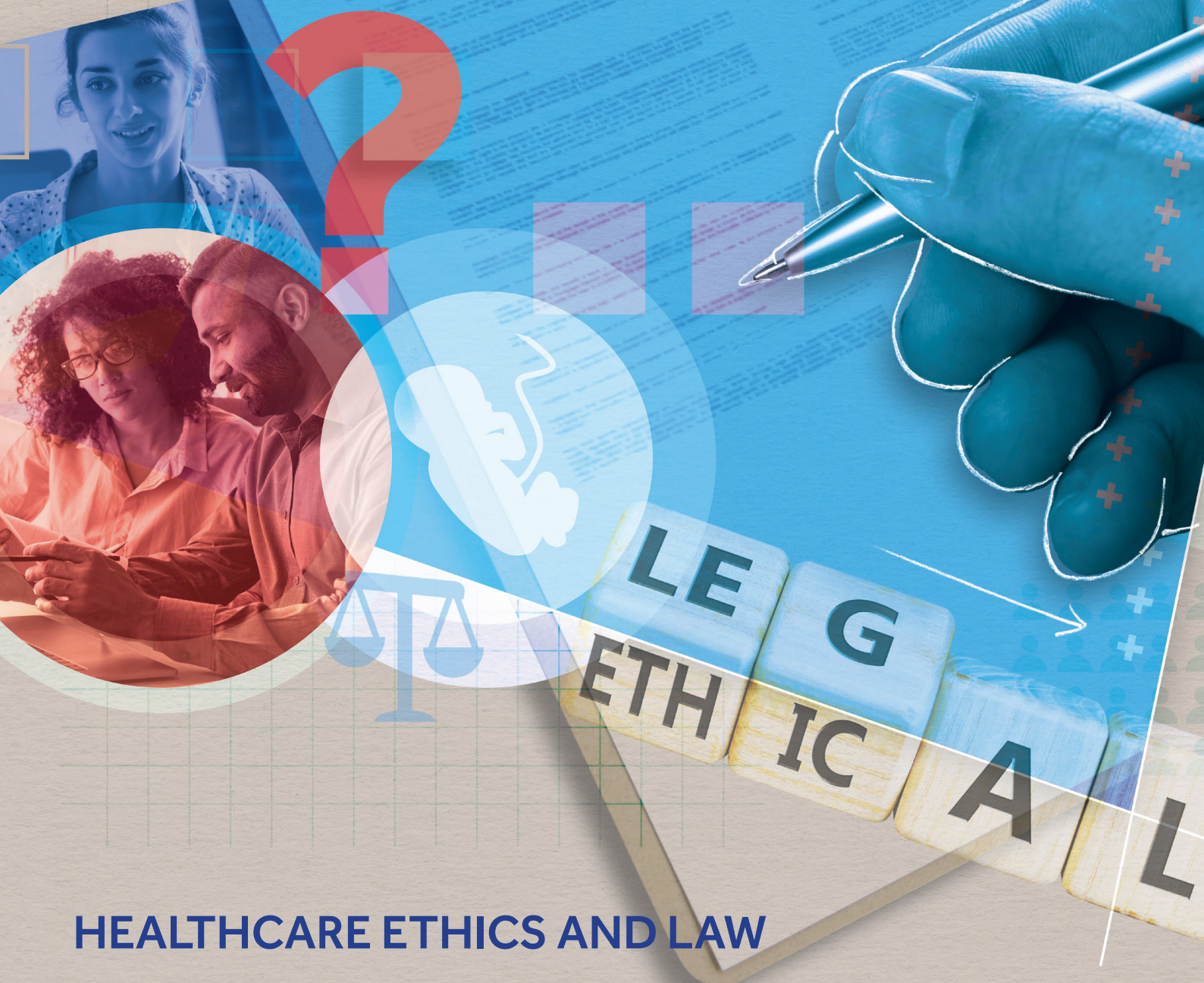


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INFORMED CONSENT



HEALTHCARE ETHICS AND LAW

Philosophical Bioethics: Autonomy and Pregnancy

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Philosophical Bioethics

SECTION 8

Autonomy and pregnancy

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Essential reading

Before completing this section you should read:

- H. Draper, 'Women, Forced Caesareans and Antenatal Responsibilities' *Journal of Medical Ethics* (1996) 22 [6] pp 327-333 [available **online** via University library]
- B. Steinbock, 'Maternal-Fetal Conflict: Pregnant Drug Addicts' in D. Bromham et al (eds), *Ethics in Reproductive Medicine* (Springer, 1992), pp 49-50 [available **online** via University library]



NB: Remember, as always, in order to get the most out of this Section and understand the issues it addresses in more depth you should do your own research into the subject focusing particularly on papers in ethical journals and books with an ethical focus.

Introduction

So far in this Course Unit we have explored the 'tools' of bioethics – critical thinking etc. – and some of the central concepts of bioethics such as what makes life valuable, the moral status of the fetus/embryo, the principle of respect for autonomy etc. In this Section we are going to explore an issue which is in the news a great deal and that combines many of the issues we have already looked at in this course unit. The issue of maternal¹-fetal conflict covers many different ethical issues including:

- When is abortion ethically defensible?
- Is it ethically acceptable to put pressure on pregnant individuals to accept testing and screening for disorders in their fetus?

- Is it ethically acceptable to punish individuals for behaviour in pregnancy which might cause harm to the child they bring to birth?
- Is it ethically acceptable to force pregnant individuals to accept treatment for the sake of the child they will bring to birth?

As we have seen, the principle of respect for individual autonomy, if taken seriously as it is in current English law, means that competent adults can usually choose to refuse any tests or treatments and act in ways that others may see as harmful. However, there are those who argue that pregnancy can change this situation at least in some circumstances. We will explore this claim in this Section.

¹ We will use the word 'maternal' to refer to any pregnant individual as is the convention in this literature, however, we recognise that an individual who identifies as any gender or non-binary might be pregnant.



The problem of maternal-fetal conflict for ethics and law

What moral obligations do pregnant individuals have towards the fetuses they carry and should these moral obligations be enforced or encouraged by law and policy?

This question is a very difficult one ethically and legally as it involves weighing the interests of an individual with the interests of the child she intends to bring to birth. Even those of us who hold that abortion is ethically permissible may have serious problems with the notion that those who become pregnant do not have any moral obligations to protect the children they bring to birth.

Obligations to protect future children can be compatible with upholding a right to abortion

It is a commonly held view that pregnant individuals clearly have a moral obligation to protect their future children, or fetuses they intend to bring to birth, from harm during pregnancy. On this view pregnant individuals have a moral obligation not to harm their future children by inflicting harm or failing to prevent harm to these children in their fetal state. This is because harm caused to a fetus we intend to bring to birth will be likely to reduce the welfare of a child we will cause to exist later down the line. As Brazier explains:



mothers-to-be have especial responsibility to their children in utero. The absolute dependency of the future child on its mother increases, not diminishes her moral responsibility for its welfare. She can no more morally justify causing injury to that child than to any of her born children, or any other woman's children.²

However such a moral obligation can be confusing and may be mistakenly interpreted as being incompatible with access to legal abortion. The acknowledgement of such moral obligations may also be seen as precursor to legal obligations in this area which would be very worrying for many. The reason this may be a worry is that a legal obligation to protect fetuses would revolutionize the way that we treat pregnancy and the interests of pregnant individuals, restricting access to abortion and curtailing rights to refuse treatment in pregnancy. Such legal restrictions of rights in pregnancy are things, as Brazier argues, that '[w]omen rightly fear (...) not out of a lack of concern for their future child but because of the potential

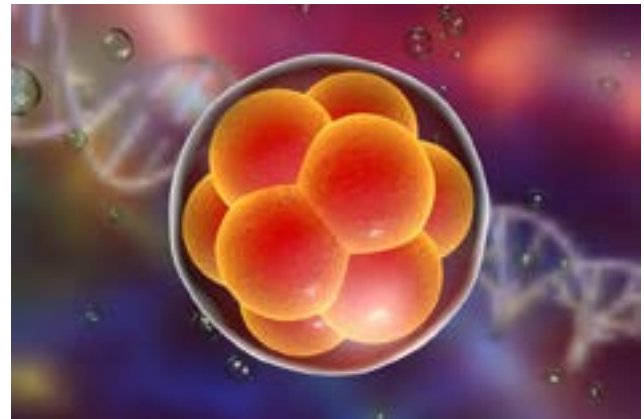
² M. Brazier, 'Parental responsibilities, foetal welfare and children's health in C. Bridge (ed), *Family Law Towards the Millennium: Essays for PM Bromley* (Butterworths 1998) p. 272 emphasis in original [see entry in library [catalogue](#)]



impact on their liberty and privacy during and prior to a pregnancy'.³ If a legal obligation for fetal protection were established, given that a fetus can be harmed particularly in early pregnancy when an individual may not even be aware they are pregnant, then the law would be effectively demanding that 'fertile, sexually active women of childbearing age should act at all times as if they were pregnant'⁴. Such a moral obligation would suspend any rights individuals had over their own bodies for the length of their pregnancy and allow any behaviour that might be seen as harmful to the fetus to be questioned and challenged and even legal steps taken to ensure pregnant individuals fulfil these legal obligations of fetal protection.

However, moral obligations to prevent harm to our future children while they are in their fetal state do not necessarily entail a moral obligation to protect all fetuses. The reason for this can be found in the rationale that usually justifies access to abortion in those jurisdictions where access to legal abortion is sanctioned.

Legal access to abortion is usually justified on the basis of the perceived moral status of the fetus. On this view of moral status that justifies legal abortion, the early fetus is considered to be a very different creature to the child he or she will become. The fetus is something that does not yet have the ability to be able to value its existence. Thus, the justification used for abortion is that it



does not involve the destruction of a self-conscious individual who can be aggrieved at this stage by the termination of their life and thus is morally acceptable. Bonnie Steinbock explains this stance, arguing that

*before becoming conscious and sentient, the fetus has no interests at all, and so no interest in continued existence. Without an interest in continued existence, the preconscious fetus is not harmed or wronged by being killed. Since abortion is not a wrong to the preconscious fetus, and the preconscious fetus has no right to life, the state should stay out of abortion decisions.*⁵

However, once prospective parents have made the decision to bring a fetus to birth obligations become different. While this view of the moral status of the fetus may allow us to terminate this human life at this very early stage, this stance does not sanction harm inflicted on the fetus if a decision to bring this fetus to birth has been made. This is because once this decision has been made to bring

³ Ibid p.273

⁴ S.A.M. McLean, *Old Law, New Medicine* (Pandora Press, 1999) p. 66 [see entry in [library catalogue](#)]

⁵ B. Steinbock, *Life Before Birth - The Moral and Legal Status of Embryos and Fetuses* (New York: Oxford University Press, 1992), p. 127 [available [online](#) via the University library]



this fetus to birth, it is possible to harm at the fetal stage, the self-conscious individual this fetus will become sometime after birth. Harm inflicted on a fetus who will be brought to birth will harm someone, it will harm the child that the fetus will become. Thus, harm inflicted on the fetus is morally reprehensible if it will affect a self-conscious born individual later in development. So as, Steinbock argues, while it is not wrong to kill the fetus, it is wrong to harm a fetus which will not be aborted but brought to birth. She explains:

The moral situation changes when a woman decides not to abort, but to carry her baby to term. For once this decision is made, the fetus is not simply a potential child, but a child-who-will-be-born. Once born that child will have interests, including an interest in a healthy and painless existence. That interest can be adversely affected by his or her mother's behaviour during pregnancy. If she neglects her own health, if she has an inferior diet, if she smokes or drinks too much or uses illegal drugs, if she takes risks with the health of her future child. Insofar as these risks are unnecessary or unreasonable, taking them is morally wrong, a violation of parental duty.⁶

The current law is generally consistent with this view. It is an established principle in English law that it is live birth that confers legal personality⁷, thus before birth a fetus is not a legal person and does not have the

legal protection that legal persons enjoy. The law also holds that all those capable of making healthcare decisions should be free to do so even if that person is pregnant at the time or even in labour. Lady Butler-Sloss established this in the Court of Appeal saying:

"[...] a competent woman who has the capacity to decide may, for religious reasons, other reasons, or for no reasons at all, choose not to have medical intervention, even though [...] the consequences may be the death or serious handicap of the child she bears or her own death [...] The fetus up to the moment 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 caesarean section operation. The court does not have the jurisdiction to declare that such medical intervention is lawful to protect the interests of the unborn child even at the point of birth."⁸

However, despite the law being clear on a) the lack of legal status of the fetus and b) a pregnant individual's right to refuse treatment there are often instances where this notion of moral obligations to future children appears to influence legal cases and legislation and things are not as clear cut as they may first seem. For instance, the *Infant Life Preservation Act, 1929* confers protection on the 'child capable of being born alive' by creating the offence of killing a viable fetus which is known

⁶ Ibid p.128

⁷ See for example, *Paton v Trustees of the Birth Pregnancy Advisory Service* [1979] 2 All ER 987 [available [online](#)]

⁸ *Re MB (an adult: medical treatment)* [1997] 8 Med LR 217



as child destruction. While child destruction cases are rare there have been a number of such cases since 2007.⁹ Further, under the criminal law the fetus is given some legal protection. Following the case of Attorney-General's Reference (No. 3 of 1994)¹⁰ where a man attacked his pregnant girlfriend causing the premature birth and death of her fetus, the House of Lords endorsed earlier judgments that a charge of murder or manslaughter can be sustained where a fetus is injured *in utero* then born alive and later dies as a result of those injuries.

Thus, while it might seem uncontroversial to many of us that pregnant individuals do have moral obligations towards the children they will bear, this is a very difficult area for both ethics and law. Turning moral obligations to future children into legal obligations or allowing them to influence policy is hugely problematic. Firstly, it is very difficult to establish clearly what exactly these ethical responsibilities are. Are pregnant individuals, for instance, under a moral obligation to minimise every risk to their future children however small? Addiction or circumstances may also make it very difficult for individuals to change their harmful behaviour. If law

and policy is enacted that enforces moral obligations to protect fetuses from harm where does this leave the rights of pregnant individuals? Is it acceptable for those who are pregnant to be forced to have medical treatment against their will even if they pass all tests for mental capacity and understanding? Should healthcare professionals and even the pregnant individual's partners have a say over what happens to their bodies in pregnancy and is this approach likely to have the effect it aims to have? Could it be that treating pregnant individuals in this way may make them less likely to be co-operative with any treatment options and have a detrimental effect on the future child particularly if an individual faces criminal sanctions?

Because of the importance and complexity of these issues it becomes imperative to explore what we have reason to believe are the moral obligations of pregnant individuals and how these moral obligations should be represented in law and policy if at all. This Section helps you to begin to explore these ethical issues around maternal-fetal conflict in order that you can come to your own position on these issues that you can defend.

⁹ *R v Maisha Mohammed* (2007), *R v Carl Anthony Whant* (2012) EWCA Crim 2457, Elizabeth Prochaska *The Guardian*, 21 September 2012, **Sarah Catt, abortion and the legal rights of pregnant women**, Jamie Grierson, *The Guardian* 17 December 2015, **Man convicted of killing unborn baby by kicking pregnant ex-girlfriend**

¹⁰ [1998] AC 245 (HL)



Optional Further Reading



For a great overview of the legal issues in this area read:

- M. Brazier and E. Cave, *Medicine, Patients and the Law* (Manchester: Manchester University Press, 2016) Chapter 11 [available **online** via University library]
- S. Fovargue and J. Miola, 'Are we still "policing pregnancy"?' in C. Stanton, S. Devaney, A. Farrell, A. Mullock (eds.) *Pioneering healthcare law: essays in honour of Margaret Brazier* pp. 243-254 (Oxford: Routledge, 2016) [available as an **ebook** via University library]

Compulsory medical treatment in pregnancy

As we have already discussed in detail in this course unit, the principle of respect for autonomy is a central principle of modern medical ethics and is often considered the most important principle in this area. However, as we have also discussed it can be argued that there are justifiable exceptions to this right to individual autonomy in medical decision-making. These exceptions usually relate to the interests of third parties. So while it is accepted that a competent adult can refuse medical treatment – even life-saving medical treatment – when to do so will only risk her life, such actions are viewed differently where other lives are at stake. The protection of others' physical wellbeing or autonomy sometimes dictates that an individual's autonomous choices should not be respected.

This is, as we have seen, the rationale behind established public health measures which in extreme circumstances allow provision to detain or enforce treatment on those with

dangerous infectious diseases, in order to protect the wider public from infection. It is also the motivating factor behind attempts to override the autonomous choices of pregnant individuals in order to prevent harm to any future child. Where this conflict exists between individual autonomy and the interests of third parties policy development will often be highly problematic. In such situations it is often impossible to uphold the individual autonomy of one individual without undermining the interests and/or autonomy of others. Difficult decisions have to be made in order to arrive at policy that provides the most just solution to this conflict.

So in the case of pregnancy we are left with the difficult situation where the adult with capacity would normally have the unqualified right to refuse any treatment or medical 'touching', but to do so may risk the life or wellbeing of the person her fetus will become.

Many of the high profile cases in which this dilemma is evident involve attempts to legally enforce caesarean section deliveries in labour.



NB: While much of the discussion in this area involves legal cases this Course Unit focuses on the **ethical** implications of these cases rather than the legal implications.

The legal aspects of these issues will be explored in the legal Course Units.



Activity 1: Case Study

Consider the following case study

In 1987, Angela Carder was diagnosed as having terminal cancer of the lung. She was twenty-five weeks pregnant and it was expected that she would only survive a week.

Angela had lived under the shadow of cancer since she was thirteen, but had thought herself to be in remission when she planned her pregnancy. Whilst insisting that her own comfort must be the primary consideration, she agreed in principle to consent to any treatment that might enhance the survival prospects of her baby. Her husband, parents and physician were in full agreement with these wishes.

Almost a week later, she refused her consent for caesarean section and the hospital decided to seek legal advice. Angela believed that it was unlikely that such an immature fetus would survive, and that if it did it would be likely to suffer multiple disabilities. Emmet Sullivan, the judge appointed to the case, decided that the pivotal issue was the fetus's chances of survival and what was in its best interests granted its mother's terminal condition. He ordered the caesarean section to take place. Angela still refused to consent so Sullivan again listened to both counsels but reaffirmed his original decision.

Less than one hour later and with the section planned to occur within fifteen minutes, Angela's counsel argued that the operation would foreshorten her life and was not therefore in her best interests. Against this it was argued that she had no interests and she was dying.

Sullivan cut across the ensuing argument by asking who had the best chances of surviving, the mother or the child. The answer was that the baby did and so he again ordered the operation to take place. The non-viable fetus died two hours after the caesarean was performed.



Activity 1, continued

Angela died two days later. At no point in the proceedings did Sullivan speak to Angela personally. In 1990, two appeal hearings later, the District of Columbia Court of Appeal reversed Sullivan's decision, not for the benefit of Angela, but to avoid setting a precedent for future cases.¹¹

Was the coercion of Angela Carder ethically justifiable? Explain your answer.

¹¹ H.Draper, 'Women, Forced Caesareans and Antenatal Responsibilities' *Journal of Medical Ethics* (1996) 22 [6] pp. 327-333 [available [online](#) via University library]



Activity 1, continued

Suppose the details of the case were different; perhaps the treatment required was a blood transfusion, the woman was not terminally ill, or the woman was over 30 weeks pregnant. What impact would these different circumstances have on your opinion of whether coercion is justifiable? Again, explain your answer.



Activity 1, continued

Research this issue of attempts to force caesarean sections on pregnant individuals who do not consent to them [there are a number of commentaries both legal and ethical in this area which you may wish to read - use the further reading below to guide you]. Do you think that it is possible to create policy to deal with this issue adequately? Explain your answer.



Activity 1, continued

The numbers of caesarean sections performed in hospitals is increasing due not only to recommendations by health professionals to accept this option but often they are requested by pregnant individuals either in what they believe to be the best interests of their child or for their own best interests (e.g. to preserve their pelvic floor).¹² If we should respect a pregnant individual's autonomy should we respect their choice to give birth by caesarean section? Explain your answer.

¹² James Gallagher, 'Women can choose Caesarean birth' *BBC News Online* November 2011[available online at: www.bbc.co.uk/news/health-15840743]



Activity 1, continued

Regarding whether a pregnant individual has the right to choose to have a caesarean section, it has been argued that 'Decisions should be made in the best interests of the patient. The patient has the right to decline to take one's advice, but, in my view, does not have the right to ask the doctor to perform a procedure which the doctor considers unwarranted by the evidence and which is not in the patient's best interests.'¹³

Do you agree? Is there good reason for respecting an individual's autonomous choice to refuse a caesarean section even if it causes harm to them or their child, while refusing another individual their choice for an elective caesarean section because we do not think it is in their best interests? What is this reason?

¹³ W. Savage, 'Caesarean Section: Who chooses?' in D. Dickenson (ed.), *Ethical Issues in Maternal-Fetal Medicine* (Cambridge: Cambridge University Press, 2002), p. 266 [available as an **ebook** via University library]



Further Reading on forced Caesarean Sections



For an interesting legal analysis of the issues see:

- S. Fovargue and J. Miola, 'Are we still "policing pregnancy"?' in C. Stanton, S. Devaney, A. Farrell, A. Mullock, (eds) *Pioneering healthcare law: essays in honour of Margaret Brazier* pp. 243-254 (Oxford: Routledge, 2016) [available as an **ebook** via University library]
- M. Brazier and E. Cave, *Medicine, Patients and the Law* (Manchester: Manchester University Press, 2016) Chapter 11 [available **online**]
- S. Fovargue and J. Miola, 'Policing Pregnancy: Implications of the Attorney-General's Reference (No. 3 of 1994)' *Medical Law Review* (1998) 6 [3] pp. 265-295 [available **online** via University library]

Ethical commentary:

- W. Savage, 'Caesarean Section: Who chooses?' in D. Dickenson (ed.), *Ethical Issues in Maternal-Fetal Medicine* (Cambridge: Cambridge University Press, 2002), p. 263 [**ebook** available via University library]

Pregnancy and routine antenatal screening

While forced caesareans provide a very dramatic and clear example of non-consensual treatment in pregnancy, it can be argued that other areas of antenatal care involve infringement of the pregnant individual's autonomy in an attempt to protect future children. One such area is the routine testing in pregnancy for conditions such as Down's Syndrome.

Antenatal genetic testing

Genetic testing in pregnancy is well established. There are routine and elective tests available for a number of genetic disorders.

At present, prenatal diagnostic testing is offered in pregnancy to individuals who are deemed to be at increased risk of genetic disorders or congenital abnormality based on family history of a genetic disorder, the result of an ultrasound scan or maternal age. In addition to this, most pregnant individuals in developed countries are routinely tested for other genetic disorders, commonly chromosomal disorders such as Down's syndrome and Turner's syndrome, as part of established antenatal screening programmes.



With increased understanding of the human genome and of the genetic factors involved in a range of diseases, and with many existing genetic tests becoming safer and cheaper to administer, there is clear potential for a dramatic increase in prenatal genetic diagnosis.

What are the ethical issues here?

The main ethical issue with antenatal genetic testing goes back to the principle of respect for autonomy.

As we have seen, it is generally accepted that individuals should be allowed to choose whether or not they have diagnostic tests especially those that may indicate potentially serious conditions. While there may be temptations on the part of healthcare professionals to test for conditions without explicit and voluntarily given informed consent, such temptations are usually deemed unacceptably paternalistic.



While there are those who argue that we need information about any genetic disorders that might be available to make an informed choice, in general the individual's right to autonomy and the legal framework that enshrines this right, upholds the individual's right to refuse any medical testing or treatment, even if this refusal is viewed as unwise by others.

However, genetic testing in pregnancy is a bit different. It can be argued that making these tests routine or even offering them to specific groups of individuals means that the nature of the consent given is very different from the 'opt in' test most of us would experience when deciding to have a genetic test.





Activity 2

What's wrong with routine antenatal testing for Down's Syndrome? Read the blog at the link below and answer the questions that follow: blog.law.manchester.ac.uk/routine-antenatal-testing-for-downs-syndrome/

Are you convinced by the argument that routine tests are coercive? Why/why not?

Do you think that routine testing for Down's Syndrome is ethically justifiable? Explain and defend your answer.



Activity 2, continued

It has been argued that where genetic disorders in fetuses are non-treatable and unlikely to render a child's life unworthwhile (i.e. dominated by suffering) then the information gained by antenatal testing is only useful for the potential parents - it cannot be used to prevent harm to the resultant child. As a result, it is argued that antenatal testing of this kind should not be routine but opt-in and require the same kind of voluntary consent as other genetic tests that provide useful information for adults. Do you agree? Why/why not?



Non-invasive prenatal testing (NIPT)

Non-Invasive prenatal testing (NIPT) is a blood test done at around 9 or 10 weeks into a pregnancy. This test provides a relatively accurate test for genetic conditions and variations and is currently being used in the NHS to identify conditions such as cystic fibrosis and achondroplasia where there is a family history of these conditions.

In 2021 this new test was made available on the NHS in pregnancy as a second stage screening test for Down's, Edward's and Patau's syndromes removing the need for previous diagnostic tests for these conditions that carry a risk infection and miscarriage.^{14 15}

How does it work?

The Nuffield Council on Bioethics explain how this new test works:

Small amounts of DNA, often referred to as 'cell free DNA' (cfDNA), circulate in everybody's blood. From an early stage in pregnancy, this includes DNA from the placenta, which is very similar to the fetal DNA. By analysing these cfDNA



*fragments, it is possible to find out genetic information about the fetus. The amount of fetal cfDNA in the woman's blood increases as the pregnancy progresses. NIPT can be carried out from about 9 or 10 weeks of pregnancy, which is when there is usually enough fetal cfDNA in the woman's blood to get an accurate reading.*¹⁶

The introduction of NIPT to existing NHS screening in pregnancy, particularly for Down's Syndrome, has created a great deal of controversy.¹⁷

Nuffield Council on Bioethics report on NIPT: ethical issues

In March 2017 the Nuffield Council of Bioethics launched their report on Non-Invasive Prenatal testing (NIPT).¹⁸ This Report focuses on making recommendations for how

¹⁴ A. Mackie, 'NIPT to be evaluated as a new part of NHS screening pathway for Down's syndrome, Edwards' syndrome and Patau's syndrome' available on the UK Government website: <https://phescreening.blog.gov.uk/2021/06/01/nipt-to-be-evaluated-as-a-new-part-of-nhs-screening-pathway-for-downs-syndrome-edwards-syndrome-and-pataus-syndrome/>

¹⁵ Public Health England, 'Screening for Down's syndrome, Edwards' syndrome and Patau's syndrome: NIPT' [available online]

¹⁶ Nuffield Council of Bioethics, Non-invasive prenatal testing: ethical issues (Nuffield Councils of Bioethics, March 2017) p.2 available at: nuffieldbioethics.org/wp-content/uploads/NIPT-ethical-issues-full-report.pdf

¹⁷ See for example, the campaign group 'Don't Screen us out' dontscreenusout.org/

¹⁸ Nuffield Council of Bioethics, op. cit.



NIPT should be introduced in the NHS and by private providers. The report emphasises the need to protect and enable individual choice using NIPT rather than allowing this test to be used to influence individuals to terminate pregnancies based on directive advice and

information. The report wants to see these tests as individual tests that may enhance the choices of individuals rather than ways of screening out disability and other undesired traits including gender.



Activity 3

Read the following blog which is a response to the Nuffield Council Report and answer the questions that follow:

blog.policy.manchester.ac.uk/posts/2017/03/downs-syndrome-bioethics/

In the blog it is suggested that introducing the NIPT Down's test will make routine screening and testing for Down's even more difficult to justify. It is suggested that:

- As this test is a non-invasive blood test and has no risk of miscarriage it may prove even harder for pregnant individuals who wish to refuse the test to do so.
- It is predicted that the new test will lead to nearly 200 more fetuses being identified as having Down's Syndrome each year which, in the current climate, may well result in more individuals feeling pressured to make a choice to terminate.
- The heralding of this new test as something that will improve screening and identify more fetuses with Down's Syndrome may send a message to those with disabilities that they have a lower status in society and that this is an attempt to screen out people like them.
- There is a concern that this new test will become a routine part of antenatal care and that, as this is a simple blood test rather than an invasive test, the standard of consent for this test will decrease further.



Activity 3, continued

What do you think about these claims? Do you think we should be concerned about the way that NIPT was introduced? Explain and justify the answer you give. To help you here do have a look at other readings and resources provided below that will provide you with other viewpoints than the one that Becki presents.



Activity 3, continued

Routine (opt out) testing for HIV in pregnancy has been established in the UK since 1999. Since then, HIV testing coverage has remained high (more than 99%).¹⁹ Unlike in Down's Syndrome, measures can be taken to prevent HIV being transmitted to newborns if HIV infection is identified in pregnant women - women can take antiretroviral drugs, have a caesarean birth and not breastfeed.

Does this make routine testing and the inevitable pressure to be tested more justifiable in the case of HIV? Explain and justify your answer.

¹⁹ UK Health Security Agency 'HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report. (The annual official statistics data release (data to end of December 2020) [available [online](#)]



Further optional resources



It is worth reading the Nuffield Council Report if you are interested in these issues as this is a very comprehensive and well written report. Summaries of the report are also available:

- Nuffield Council of Bioethics, Non-invasive prenatal testing: ethical issues (Nuffield Council of Bioethics, March 2017) p.2 available at: <http://nuffieldbioethics.org/wp-content/uploads/NIPT-ethical-issues-full-report.pdf>
- L. S. Chitty et al. 'Uptake, outcomes, and costs of implementing non-invasive prenatal testing for Down's syndrome into NHS maternity care: prospective cohort study in eight diverse maternity units' *BMJ* (2016) 354 :i3426 [available **online** via University library]
- R.V. van Schendel et al. 'NIPT-based screening for Down syndrome and beyond: what do pregnant women think?' *Prenatal Diagnosis* (2015) 35, 598–604 [available **online** via University library]
- S. Boseley, 'NHS to offer safer Down's syndrome test to pregnant women' *The Guardian*, 29 October 2016 available online at: www.theguardian.com/society/2016/oct/29/safer-downs-syndrome-test-nhs-pregnant-women-nipt
- H. Devlin, 'Fears over new Down's Syndrome test may have been exaggerated, warns expert' *The Guardian*, 4 November 2016 available online at: www.theguardian.com/society/2016/nov/04/new-prenatal-test-for-downs-syndrome-will-not-lead-to-more-terminations-nipt
- G. Kellogg, L. Slattery, L. Hudgins and K. Ormon, 'Attitudes of Mothers of Children with Down Syndrome Towards Noninvasive Prenatal Testing' *Journal of Genetic Counselling* (2014) 23 [5] pp.805-813 [available **online** via University library]
- A. de Jong, I. Maya and J.M.M. van Lith, 'Prenatal Screening: Current Practice, New Developments, Ethical Challenges' *Bioethics* (2015) 29, 1–8 [available **online** via University library]
- L. Page-Christiaens, and K. Hanns-Georg *Noninvasive Prenatal Testing (NIPT) : Applied Genomics in Prenatal Screening and Diagnosis* (London, UK: Academic Press) 2019 [**ebook** available via University library]
- A. Kater-Kuipers et al. 'Ethics of Routine: a Critical Analysis of the Concept of 'routinisation' in Prenatal Screening' (2018) *Journal of Medical Ethics* 44.9, 626–631 [available **online** via University library]



Further optional resources, continued



- A. Kater-Kuipers, I. D. de Beaufort, R. H. Galjaard, E.M. Bunnik, 'Rethinking counselling in prenatal screening: An ethical analysis of informed consent in the context of non-invasive prenatal testing (NIPT)'. *Bioethics* (2020) 34, 671– 678 [available **online** via University library]
- www.thesafetest.co.uk/ [accessed July 2023]

Further optional media



You might also find it interesting to watch a BBC documentary on this issue, for which Becki was the ethics consultant:

- A World Without Down's Syndrome?, 21:00 05/10/16, BBC2, England, 60 mins <https://learningonscreen.ac.uk/ondemand/index.php/prog/0DA04B5A>

(You will need to log in with your University username and password. Access is only available to those of you in the UK but if you search YouTube you should be able to find a copy of the documentary there.)

Optional further reading



- R. Bennett, 'Antenatal Genetic Testing and the Right to Remain in Ignorance', *Theoretical Medicine and Bioethics* (2001) 22 [5] 461-471 [available **online** via University library]
- R. Bennett, 'Routine antenatal HIV testing and informed consent: an unworkable marriage?' *Journal of Medical Ethics* (2007) 33, 446-448 [available **online** via University library]
- E. Parens, 'The Thorny Ethics of Prenatal Testing', *TIME*, 5 February 2014 [available online at <http://time.com/4584/genetic-testings-brave-new-world/>]
- D. Balkissoon, 'The more you know: The ethics of prenatal testing', *Today's Parent*, 19 November 2014 [available online at <http://www.todaysparent.com/pregnancy/ethics-prenatal-testing/>]
- A. de Jong, W. J Dondorp, C. E. M. de Die-Smulders, S. G. M. Frints and G. M. W. R. de Wert, 'Non-invasive prenatal testing: ethical issues explored', *European Journal of Human Genetics* (2010) 18, 272-277 [available **online** via University library]



Maternal-Fetal Conflict

There are many other factors which may cause harm to the fetus during pregnancy. Consider the following examples of possible harm:

A 1988 survey of 36 hospitals across America indicated that 11% of women were using drugs in pregnancy, resulting in 375,000 drug exposed infants annually [...] New evidence is emerging about the danger that cocaine can pose to fetal health. As recently as 1982, medical texts on high-risk obstetrics maintained that cocaine had no deleterious effects on fetuses. More recent studies indicate that the effects of fetal exposure to cocaine include retarded growth in the womb and subtle neurological abnormalities, leading to extraordinary irritability during infancy, and learning disorders later. In extreme cases, cocaine can cause loss of the small intestine and brain-damaging strokes. Cocaine-exposed babies face a tenfold increase in the risk of cot (crib) death. Some of the worst effects occur during the first 3 months of pregnancy, when the woman may not even know she is pregnant. Some researchers think even a single cocaine 'hit' during pregnancy can cause fetal damage.

[...]

Heavy drinking during pregnancy – especially binge drinking – is particularly risky. It can cause fetal alcohol syndrome (FAS), which is often marked by severe facial deformities and mental retardation.



One study showed that even moderate drinking – defined as one to three drinks daily – during early pregnancy can result in a lowering of as much as five IQ points. Perhaps most important, there is no established 'safe' level of alcohol consumption. While there is no evidence that a rare single drink during pregnancy does damage, there is no guarantee that it does not.²⁰

The number of ways in which maternal behaviour can put fetuses (or the children these fetuses become) at risk is seemingly unlimited. Obvious harmful behaviour includes the use of illegal and legal drugs such as cocaine, alcohol and tobacco, but other behaviours such as failing to attend for antenatal care, overworking, living in an industrial area where pollutants are high, living with a heavy smoker and even skiing may be equally harmful to fetal development.

With this in mind and the added complication that not all these harmful behaviours may be autonomously chosen, what are the moral obligations of pregnant individuals and how far is society justified in intervening on behalf of the children these fetuses will become?

²⁰ B. Steinbock, 'Maternal-Fetal Conflict: Pregnant Drug Addicts' in D. Bromham, et al, *Ethics in Reproductive Medicine* (London: Springer, 1992), pp. 49-52 [available **online** via University library]



Activity 4

Consider the following questions:

There is evidence that other factors such as smoking, drug and alcohol use in pregnancy affect the wellbeing of resulting children. Do you think that pregnant individuals should be tested for alcohol and drug use in pregnancy? Is drug or alcohol an analogous case to HIV testing? Why or why not?



Activity 4, continued

What impact does the seriousness of the possible harm or the invasiveness and effectiveness of the treatment have on pregnant individual's moral obligations towards their as yet-to-be born children?



Activity 4, continued

What impact does addiction have on the possible moral obligations of pregnant individuals?



Activity 5

Read the paper detailed below and answer the questions that follow:

- S. Bewley, 'Restricting the Freedom of Pregnant Women' in D. Dickenson, (ed), *Ethical Issues in Maternal-Fetal Medicine* (Cambridge: Cambridge University Press, 2002) pp. 131-146 [available as an **ebook** via University library]

Bewley asks (p.135) whether pregnant individuals have a different special relationship to their child than parents have to their born children. For instance, she points out that kidney donations between parent and child are not enforced. Do you think that pregnant individuals have more moral obligations than parents? Give reasons for this.



Activity 5, continued

In her framework to examine action taken against pregnant individuals (figure 8.1) Bewley argues that 'It is permissible to use offers and non-coercive threats when women can stop harmful behaviour (although threats need extra justification over offer), whereas coercion is only permissible, if at all, when women cannot stop freely. It thus becomes crucial which drug takers are or are not free'²¹. Do you think that this framework is a good one in principle? Why/why not? Could we determine whether drug takers are 'free or unfree' to stop their harmful behaviour?

²¹ S. Bewley, 'Restricting the Freedom of Pregnant Women' in D. Dickenson (ed.), *Ethical Issues in Maternal-Fetal Medicine* (Cambridge: Cambridge University Press, 2002), p. 140 (**ebook** available via University library)



Activity 5, continued

Why might it be morally acceptable to intervene to prevent harmful behaviour where an individual is incapable of stopping this behaviour herself and it is not morally acceptable to intervene to prevent harmful behaviour if the individual is capable of stopping themselves but refuses to do so?

What do you think about the framework and qualifications (pp. 143-144) that Bewley puts forward to justify intervening with pregnant women's actions? Do you think that non-consensual caesarean sections or mandatory antenatal genetic testing could be justified by this framework?



Optional further reading



- D. Campoamor, 'The WHO alcohol-pregnancy warning for childbearing women overlooks men, as usual' *Think*, 21 June 2021 (available [online](#))
- N. Grover, 'Plans to record pregnant women's alcohol consumption in England criticised', *The Guardian*, 16 September 2020 (available [online](#))
- E. Wilkinson, 'NICE: GPs should routinely ask pregnant women about drinking and record details' *Pulse*, 17 March 2022 (available [online](#))

Concluding Remarks

As we have seen in this Section it is clear that pregnant individuals have some moral obligations not to harm the people their fetuses will become. However, what exactly these moral obligations are is less clear. How serious must the harm be before pregnant individuals are morally obliged to avoid it? How much effort and/or personal risk are they obliged to put into preventing the harm?

A further question remains: should we attempt to transfer these moral obligations pregnant individuals have towards their future children into legal obligations? That is, should we attempt to 'encourage' the fulfilment of these obligations through government policy or even legal sanctions? We are left with a very difficult situation. Either:

- we decide that as it is difficult to be clear what specific moral obligations pregnant individuals have towards their future children and because we recognise the importance of respecting

the autonomy of all individuals, including individuals who are pregnant, we decide that developing policy that attempts to 'encourage' or enforce these moral obligations is not ethically justifiable especially where any treatments 'encouraged' are invasive;

or

- we decide that the benefit of preventing harm to future children is so important that we are prepared to sacrifice a pregnant individual's autonomy. If we are to do this, we must decide how serious the harm would have to be and how effective the treatment in order to justify these infringements of autonomy. For instance, we might decide that while it is acceptable to give pregnant individual information about the possible harm caused by smoking and heavy drinking, it is not acceptable to pressure individuals to accept a HIV or genetic test.



Activity 6

What do you think is the answer to this problem of policy relating to maternal-fetal conflict? Explain your answer.

Do you think that the introduction of coercive testing regimes and directive counselling in pregnancy may lead to a slippery slope that ends in routine enforced caesarean deliveries? Why/why not?



Suggested further reading



- R. Bennett, 'The Acceptability of Routine Testing for Blood-borne Communicable Disease' in H. Draper and W. Scott (eds.) *Ethics in Anaesthesia and Intensive Care: Issues in Contemporary Practice* (London: Butterworth, 2003) pp. 205-217 [available as a **digitised reading** via University library]
- P. de Zuleta and M. Boulton, 'Routine antenatal HIV testing: the responses and perceptions of pregnant women and the viability of informed consent. A qualitative study', *Journal of Medical Ethics* (2007) 33 329-336 [available **online** via University library]
- L. M. Purdy, 'Are Pregnant Women Fetal Containers?' in *Bioethics* (1990) 4 [4] 273-291 [available **online** via University library]
- R. Scott, 'Maternal Foetal Conflict' in R.E. Ashcroft, A. Dawson, H. Draper and J.R. McMillan *Principles of Health Care Ethics* 2nd edn. (London: John Wiley & Sons, 2007) pp. 401-407 [**ebook** available via University library]
- R. Bennett, 'Is there a case for criminalising vertical transmission of Human Immunodeficiency Virus (HIV) from mother to child?' *Journal of Medical Law and Ethics*, (2013) 1 (2) p.121-137 [available **online** via University library]
- C. Gavaghan, "'You can't *handle* the truth"; medical paternalism and prenatal alcohol use' *Journal of Medical Ethics* (2009) 35 [3] 300-303 [available **online** via University library]
- S. S. Richardson et al. 'Society: Don't blame the mothers' *Nature* (2014) 512 [7513] 131-132 [available **online** via University library]



Summary

Autonomy and Pregnancy

Compulsory Treatment

- During pregnancy many of the bioethical issues explored in this course unit arise. The key issue is maternal-fetal conflict, i.e. the balancing of the autonomy and interests of the pregnant individual and the fetus they carry.
- English law accepts the principle of respect for individual autonomy, which if taken seriously means that individuals are free to consent to or refuse any tests or treatments, and engage in behaviour others consider harmful.
- However, some suggest that pregnancy changes this situation of individual autonomy at least in some circumstances, because maternal decisions affect the life of a fetus and child-to-be. Special obligations arise, it is argued, whenever a pregnant individual intends to bring the fetus to birth.
- Whether such special obligations exist and how far they extend is controversial, not least because it can lead to a significant restriction of a (pregnant) individual's rights. For instance, contrast forcing a caesarean section in the interests of the child with declining an individual's wish to have a caesarean section in the absence of medical need.

Pregnancy and routine antenatal screening

- It has been argued that routine antenatal screening can also involve an infringement of the pregnant individual's autonomy, albeit a less dramatic one than forced caesarean.
- The ethical issue with genetic testing goes back to the principle of respect for autonomy: making such tests routine or even simply offering them to specific groups means that the nature of the consent given is not the same as the usual 'opt in' when someone decides to have a genetic test.
- Where genetic disorders are non-treatable, the information gained by such antenatal testing is only useful for the potential parents but it cannot prevent harm to the resultant child. Therefore, it is argued, such tests should require the same kind of voluntary consent as other genetic tests directed at adults.
- Given that testing is increasingly becoming cheaper and safer (such as the blood test for Down's syndrome), it might become harder to refuse such tests in pregnancy.



Summary, continued

Maternal-Fetal Conflict

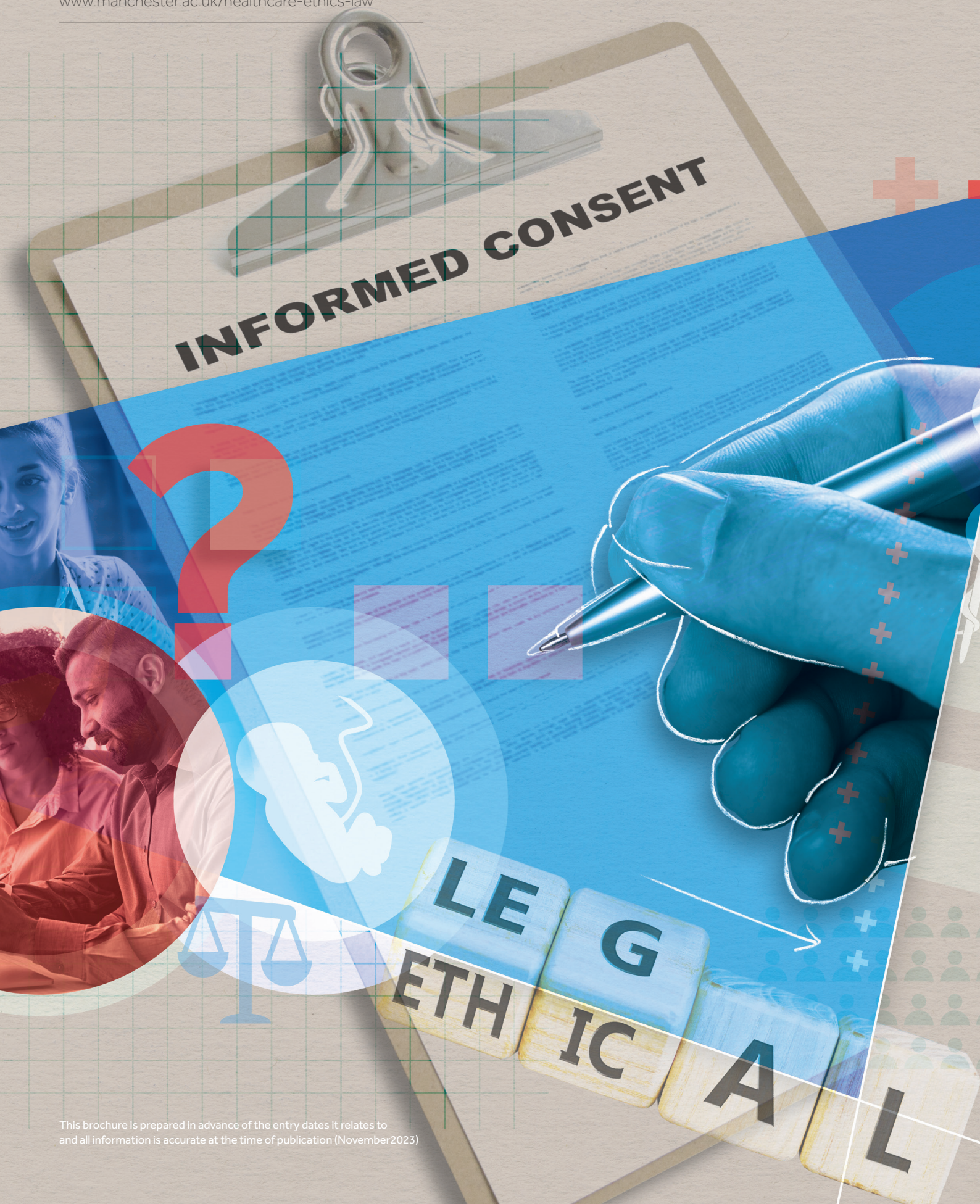
- Many other factors may cause harm to the fetus during pregnancy, not all of which are autonomously chosen. Examples include the taking of legal and illegal drugs, as well as engaging in certain high-risk activities or sports, being overworked, living in a polluted area or eating an unhealthy diet.
- Defining the moral obligations of pregnant individuals towards their yet-to-be-born children is complicated, because any intervention involves an infringement of the individual's autonomy which needs to be justified. If we decide that there are such special moral obligations in pregnancy, the question arises as to whether these should also be turned into legal obligations.

Go to Section 9

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This brochure is prepared in advance of the entry dates it relates to
and all information is accurate at the time of publication (November 2023)