

NUFFIELD COUNCIL^{ON} BIOETHICS

Non-invasive prenatal testing: ethical issues

Review of activities since publication

November 2018



Contents

Highlights	3
Introduction	4
Developments relating to the report's recommendations	4
Supporting and including disabled people	4
The provision of NIPT in the NHS.....	5
The provision of information in the NHS	6
Education, training and resources in the NHS	8
The scope of NIPT.....	9
The regulation of NIPT.....	11
The provision of information in the private sector	12
Good practice guidance.....	13
The development of prenatal screening policy	14
Media coverage of the report	15
Nuffield Council news stories and blogs.....	17
Citations in academic books and articles	17
Presentations	19
Meetings.....	20
Consultation responses.....	20

Highlights

In March 2017, the Nuffield Council on Bioethics published a report on [*Non-invasive prenatal testing: ethical issues*](#). Since its publication, we have been working to strengthen the impact of the report's findings and recommendations. Highlights of developments that have been influenced by or are aligned with the report's recommendations include:

- Public Health England setting up an Information and Education Group responsible for developing patient materials and workforce training in preparation for the roll-out of NIPT across England. The group involved in its work those with first-hand knowledge of people with Down's, Edwards' and Patau's syndrome and their families.
- Public Health Wales revising its patient information materials on NIPT and Down's syndrome in response to our feedback.
- The passing of a motion at the Church of England (CoE) General Synod meeting that the CoE should include and value people with Down's Syndrome and their families, and that unbiased information should be made available for women and couples offered screening for Down's syndrome.
- The UK National Screening Committee appointing new ethics and social science members, and setting up a new ethics task group.
- Contributing to media debates about the 'reflex protocol' for offering NIPT, and the use of NIPT for determining the sex of a fetus. We contributed to a wide range of other broadcast, print and online media coverage throughout the year.

Introduction

In March 2017, the Nuffield Council on Bioethics published a report, [Non-invasive prenatal testing: ethical issues](#). This review sets out how we have been working to strengthen the impact of the report's findings and recommendations and highlights developments relating to or aligned with our recommendations. It also notes where the report has been mentioned or discussed in the media and in academic journals, and where its findings have been presented as part of a conference or other event.

The report made a number of recommendations concerning different areas of the provision of NIPT. Below is a summary of relevant developments as they relate to particular issues: supporting and including disabled people: the provision of NIPT in the NHS; the provision of information in the NHS; education, training and resources in the NHS; the scope of NIPT; the regulation of NIPT; the provision of information in the private sector; good practice guidance and the development of prenatal screening policy.

Developments relating to the report's recommendations

Supporting and including disabled people

Recommendation

The Government should ensure that it is meeting its duties to provide disabled people with high quality specialist health and social care and to tackle discrimination, exclusion and negative societal attitudes experienced by disabled people.

Following the publication of the report, we contacted a number of organisations to make them aware of the report's recommendation on the need to ensure that the Government is meeting its duties to disabled people. These included the Equality and Human Rights Commission, the Department for Education, the BBC, the Academy of Medical Colleges and the Medical Schools Council.

In February 2018, the Church of England General Synod held a [debate](#) on valuing people with Down's syndrome, instigated by a motion proposed by the Bishop of Carlisle to ensure the Church includes and values people with Down's Syndrome and their families, and that unbiased information is made available for women and couples offered screening for Down's syndrome. We wrote to the Bishop of Carlisle and provided a briefing highlighting relevant principles from our report. We also briefed speakers ahead of a fringe event to discuss the motion. The General Synod gave [unanimous backing](#) to the call for people with Down's syndrome to be welcomed, celebrated and treated with dignity and respect.

The provision of NIPT in the NHS

Recommendation

The Working Group supports the introduction of NIPT for Down's, Edwards' and Patau's syndromes in the NHS for women who have been found to have at least a 1 in 150 chance of having a fetus with one of these conditions.

Recommendation

NIPT for significant medical conditions or impairments should only be available within an environment that enables, as far as possible, women and couples to make autonomous, informed choices, and when steps are taken to minimise the potential harms of offering NIPT.

Recommendation

An evaluation of the introduction of NIPT for Down's, Edwards' and Patau's syndromes in the NHS will be important for considering whether and how NIPT will be offered in the future. An evaluation should include: the experiences of people who are offered NIPT, how this offer was made and the pre- and post-test counselling received; any effects on the decisions pregnant women in the UK are making in relation to whether to have screening or not, and whether to continue or terminate a pregnancy following a high chance result or diagnosis; the period in gestation at which women are receiving diagnoses; the rate of failed and inconclusive results, and unanticipated or secondary findings about the woman; and the impact of the introduction of NIPT on linked NHS services, such as genetic counselling, diagnostic testing, termination and laboratory services.

The Government [announced](#) in November 2016 that it intended to offer NIPT for Down's, Edwards' and Patau's syndromes to women with at least a 1 in 150 chance of having a fetus with one of those conditions as part of the NHS fetal anomaly screening programme (FASP) from October/November 2018. At the time of writing, the roll-out of NIPT in England had not begun and no new implementation date had been released.

It was [announced](#) in April 2018 by Welsh Health Secretary, [Vaughan Gething](#), that NIPT would be available to women in the NHS in Wales from the end of April 2018. NIPT is now available in Wales to women with at least a 1 in 150 chance of having a fetus with one of those conditions.

In November 2017, [a study](#) advocating use of the 'reflex protocol' was published in *Genetics in Medicine*. According to the reflex protocol, a blood sample is taken from a women at the time she has the combined test and this sample is automatically used for NIPT for women who are found to have at least a 1 in 800 chance of having a fetus with Down's, Edwards' or Patau's syndromes. Some respondents to the public survey

conducted as part of our evidence gathering activities raised issues about use of the reflex protocol. These relate to concerns that the protocol might not provide women with adequate opportunity for discussion and reflection, and could compromise their ability to give informed consent to NIPT. We published a [news story](#) in response to the publication of the study. Related media coverage appeared in publications including [The Guardian](#), [The Irish Times](#) and online publication [Genomeweb](#). The Nuffield Council's Assistant Director, Catherine Joynson, wrote [an article](#) setting out our concerns for online news sources Bionews. [A response](#) from Jonathan Bestwick, co-author of the reflex study, was published in Bionews. Catherine Joynson was interviewed on ITV London evening news alongside Colette Lloyd, an advocate for people with Down's syndrome. In December 2017, [an article](#) published in *Impact Ethics* by bioethicist Vardit Ravitsky also raised issues with the protocol. Clare Walker, a member of our working group on NIPT, wrote a [letter](#) to the editor of *Genetics in Medicine* which was published online in January 2018 (and in print in March 2018) setting out our concerns with respect to the reflex protocol. A [response to Walker](#) from Wald *et al.* was published in March 2018.

In January 2018, the Government published its [UK strategy for rare diseases: implementation plan for England](#) in which it was noted that the Government would, "...together with UK National Screening Committee, review the evidence to consider reflex testing within Down's screening as a major programme modification in accordance to its published evidence review process."

The National Institute of Health Research (NIHR) announced in May 2018 that it intends to fund [research into the benefits and harms of antenatal and new born screening programmes in the UK](#).

The provision of information in the NHS

Recommendation

Providers of NIPT for significant medical conditions or impairments should ensure, through the provision of high quality information and support, that the following is understood by women and couples as part of the offer of testing: the optional nature of testing; the meaning and implications of a positive or a negative test result; the benefits and limitations of the test (particularly positive predictive values); the choices that testing may lead to; the possibilities of test failure and of unanticipated or secondary findings about the mother; and what they might expect from life with a child or adult with the condition being tested for.

Recommendation

The lack of information on continuation of pregnancy after the diagnosis of a fetal anomaly on the NHS Choices website should be rectified as soon as possible. In addition, Public Health England and the fetal anomaly screening programme should provide detailed briefings for journalists when NIPT is introduced to help ensure that accurate information about NIPT and the conditions being tested for is reported

Recommendation

Public Health England, relevant bodies in other UK countries and the NHS Choices website should develop and publish accurate, balanced and non-directive information for women and couples on NIPT and other prenatal screening tests.

Prior to the publication of our report on NIPT, Louise Bryant, a member of our working group on NIPT, was invited to chair an Information and Education Working Group of the Fetal Anomaly Screening Programme (FASP). The group is responsible for developing patient information materials for women and couples who will be offered NIPT in the NHS in England, and the training of healthcare professionals involved in the offer and delivery of NIPT. Feedback from the FASP group has been that our report has strongly influenced its work. As we recommended, the group actively engaged with organisations such as the Down's Syndrome Association (DSA), Down Syndrome Research Foundation (DSRF) and Support Organisation for Trisomy 13 and Trisomy 18 (SOFT). Focus groups with families with children with Down's syndrome have also contributed to the development of the information. The materials will be published when NIPT becomes available to women in the NHS in England (date tbc).

In April 2018, at the time that NIPT was first made available in the NHS to women in Wales, Public Health Wales published a patient information [leaflet](#) and [video](#) on NIPT. We wrote to Public Health Wales in June 2018 with suggestions for changes to the information provided in an additional leaflet [Information for women offered further tests for suspected chromosomal conditions](#). We thought that the leaflet was overly focused on the medical problems associated with the screened-for conditions, lacking important information about NIPT, and difficult to navigate. In September 2018, Public Health Wales published a revised version of their booklet in which the section on Down's syndrome had been altered substantially in line with our advice. We will continue to engage with Public Health Wales as it reviews and revises its other patient information materials on NIPT and prenatal screening.

We have been in contact with NHS Choices about adding to the NHS Choices website information about NIPT and about pregnancy choices following a diagnosis of fetal anomaly. Current NHS Choices information on [Screening for Down's, Edwards' and Patau's syndromes](#) was updated in February 2018 but currently makes no mention of NIPT. This is unlikely to be changed until NIPT is available to women in England in the NHS. Information about continuing a pregnancy following a diagnosis of fetal anomaly is still lacking, but is unlikely to be added until professional guidelines exist for this area of healthcare ([see below](#)).

Education, training and resources in the NHS

Recommendation

High quality education and training must be compulsory for all health and social care professionals involved in the delivery of NIPT within the NHS prenatal screening pathway.

Recommendation

The NHS should ensure that it has sufficient genetic counselling resources.

The FASP Information and Education Working Group (see above) has been developing training courses and resources for healthcare professionals in preparation for the roll-out of NIPT in the NHS. As we recommended, the group involved in its work those with first-hand knowledge of people with Down's, Edwards' and Patau's syndrome and their families. A series of blogs published between March 2017 and September 2018 document the group's work. In March 2017, it [was reported](#) that a project group supported by four working groups was established to lead the work, involving doctors and midwives, commissioners, educationalists, representatives of parent and support groups and Public Health England (PHE) screening staff. In November 2017, a [blog entry](#) explained the role of NIPT 'cascade training' and the 288 NIPT champions – people responsible for making sure all relevant colleagues in their Trust complete training – in preparing for the introduction of NIPT. Screening Quality Assurance Service (SQAS) and screening and immunisation teams were also responsible for monitoring attendance and ensuring that provider Trusts comply with responsibilities to deliver training. In September 2018, it [was announced](#) that eight training events across England have been held, with 400 people attending. An NIPT e-learning module has also been developed.

In the Chief Medical Officer's 2017 annual report [Generation Genome](#), it was acknowledged that the introduction of NIPT would create an increased demand in the NHS for genetic counselling services: "...Since NIPT is a screening test, further counselling is still required before an invasive procedure. In 2011, about 540,000 of the 723,000 pregnancies in England and Wales choose to have screening but the work, usually by midwives, in counselling the whole group should not be underestimated."

An associated development relating to broader proposals to integrate genetic testing and genomic medicine into the NHS concerns recommendations made in the House of Commons Science and Technology Select Committee report on [Genomics and Genome Editing in the NHS](#). One of the report's conclusions was that: "...with the Genomic Medicine Service (GMS) due to be operational later this year, Health Education England (HEE) should complete detailed workforce planning and modelling as soon as possible. They should also work with the Royal Colleges of Medicine and other stakeholders to embed genomics into relevant curricula and revalidation requirements as a priority. The Government must support them in this work, and

ensure the necessary funding is available.” In its [response](#), the Government said that it: “agrees with the need for detailed workforce planning and the importance of embedding of genomics into relevant curricula and revalidation requirements...”, noting particularly that: “HEE’s strategic approach includes planning for a workforce review that is aligned to the implementation of the GMS across all professions involved in the service, for example, genomic counsellors and specialist nurses through to genomic oncologists and laboratory scientists.”

In addition, Health Education England, has commissioned a review, led by Dr Eric Topol, of how to prepare the NHS workforce to deliver the ‘digital future’, including genomics. An [interim report](#), published in June 2018, suggests healthcare professionals will need to be educated and trained in genomics in order that they are able to: consider the implication of genetic diagnosis for counselling and screening of the extended family; have a sufficient knowledge of genomics to have a sensible dialogue with patients; and know when, how and where to refer patients to for specialist advice.

The scope of NIPT

Recommendation

We recommend that NIPT providers should not offer sex determination of fetuses. We believe that the Government should require test providers to neither generate nor report this information unless there is concern that the fetus may be showing signs of a significant sex chromosome aneuploidy or is at risk of a sex-linked disorder. This should apply to providers and manufacturers whose products are used by women in the UK, wherever the laboratory analysis takes place.

Recommendation

We recommend that the Government considers establishing a moratorium with NIPT manufacturers to agree that prenatal whole genome or exome sequencing will not be offered to pregnant women and couples in the UK for the foreseeable future.

Recommendation

An NIPT test should only be offered if it provides an accurate prediction of whether the fetus has or does not have the significant medical condition or impairment being tested for.

Sex determination

In September 2018, an investigation by the BBC’s [Victoria Derbyshire show](#) claimed that women were using NIPT to inform decisions about sex selective terminations. The Chair of our working group on NIPT, Tom Shakespeare, was interviewed in the

programme. The Labour Shadow Minister for Women and Equalities, Naz Shah MP, appeared on the programme and called for the Government to ban NIPT for sex determination, in line with our recommendation. Media articles in [The Express](#), [The Guardian](#), the [BBC](#), [The Metro](#), [The Daily Mail](#) and others cited our report in its coverage. Assistant Director Catherine Joynson was interviewed by BBC Radio 5 Live on the topic on 17 September 2018 and on 23 September for BBC Radio West Midlands.

In October 2018 the Government published a report, [Sex ratios at birth in Great Britain, 2012-16](#) which concluded that there is “no evidence for sex selective abortions occurring in Great Britain over the period 2012-2106”.

Dr Sylvie Dubuc of the University of Reading has been awarded a grant funded by the ESRC to study [Son preference and sex selection against females in the UK: Evidence, causes, trends and implications](#). The research aims to use mixed methods to “evaluate gender preferences through reproductive decision-making and practice among Asian communities in the UK and gain a contextual understanding of the dynamic factors at play that will inform an ethically founded and gender justice policy framework and interventions aiming to address son preference and potential practices of selective reproduction.” The first, quantitative phase of the project is near completion and the qualitative element of the study is due to begin. The authors previously have [published research](#) in *BMJ Global Health* that considers whether sex ratio at birth is an appropriate measure of prenatal sex-selection. They conclude that sex ratio at birth bias is an inaccurate indicator for changes in sex selection practices within a population.

Relatedly, in March 2017, Professor Wendy Savage of the British Medical Association’s [Medical Ethics committee](#) gave an [interview to the Daily Mail](#) in which she stated that sex-selective terminations should not be banned. The interview attracted coverage in a range of media sources including [The Independent](#) and [The Telegraph](#) and prompted an [Early Day Motion](#) on sex-selective and on-demand abortion sponsored by Labour MP Robert Ffello MP.

Moratorium on whole genome sequencing

In the 2017 annual report of the Chief Medical Officer, [Generation Genome](#), it was noted that: “The Nuffield Council on Bioethics has recently published a comprehensive report on the ethical issues of prenatal testing. As well as raising important points about the impact of contingent non-invasive testing as part of the Down's syndrome screening programme it also touches on the implications of future developments. The potential combination of genomic sequencing methods and non-invasive testing raises the possibility that women without a family history of a severe genetic condition may be offered testing for other genome changes that are associated with congenital abnormalities. I endorse the report’s conclusions about the need for careful evaluation of such developments, especially if these are developed or marketed as commercially available testing services.”

In July 2018, a [motion](#) was passed at the British Medical Association (BMA) on the need for public consultation on the potential for NIPT to be used for whole genome sequencing. The motion stated that: “This meeting recognises that the advent of new

technologies can bring new ethical challenges to light and believes that given the advent of NIPT and the potential for whole genome sequencing the time is right for consultation to determine the views of the public and the profession on the need for limits to the scope of NIPT in practice.” We will engage with the BMA as they begin to implement the motion.

Related developments include proposals to make whole genome sequencing of newborn babies available on the NHS. We have since published a Bioethics briefing note on [whole genome sequencing of babies](#), which reflected several of the concerns raised in the NIPT report. Following on from these pieces of work, Assistant Director Catherine Joynson was invited to sit on Genomics England’s Task and Finish Group on Genomic Analysis in Children. The Group is considering current and potential future uses of whole genome sequencing as a diagnostic tool for unwell children, and as part of newborn screening offered to parents of all newborn babies.

The accuracy of NIPT

Private providers continue to offer NIPT for sex aneuploidy conditions, such as Turner syndrome, and microdeletion syndromes, such as DiGeorge syndrome and 5p deletion syndrome, the accuracy of which continues to be less well-founded.

In November 2017, Cochrane, an independent research organisation, published [a meta-analysis of the evidence on the accuracy of NIPT](#) for detecting abnormal chromosome numbers. The review found that the accuracy of NIPT for Down’s, Edwards’, Patau’s and Turner syndromes was high for women already known to have a high chance of having a fetus with one of these conditions. However, there were few studies on the accuracy of NIPT in unselected populations of pregnant women. Also, the authors were unable to perform meta-analyses of NIPT for several sex aneuploidy conditions (Triple X syndrome, Klinefelter syndrome and 47,XYY syndrome) because there were very few or no studies in one or more risk groups.

The regulation of NIPT

Recommendation

NIPT should be included in the ‘regulated activities’ that are regulated by the Care Quality Commission (CQC), to ensure that the provision of NIPT by hospitals and clinics in England is carried out to high standards of quality and safety, even when NIPT is accessed by pregnant women and couples on a one-off basis.

Following a meeting with Ministers in June 2017, we wrote to the then-Minister for Public Health, Phillip Dunne MP, about extending the CQC’s remit to cover NIPT accessed on a one-off basis in private clinics. Our letter noted concerns about misleading information and lack of support, direct-to-consumer NIPT, and other issues suggesting that the provision of NIPT in private clinics did not always conform to the standards of quality and safety that the report recommended. A response was

received in November acknowledging these issues. After further correspondence, Jackie Doyle-Price MP, Parliamentary Under Secretary of State for Mental Health and Inequalities, wrote to us in September 2018, citing the existing regulatory mechanisms in place pertaining to NIPT and stating that the CQC is not aware of any incidents of patient harm relating to NIPT. The Minister also referred to current challenges of introducing secondary legislation given the Government's current work on EU exit legislation and pressures on the Parliamentary timetable.

In October 2017, we submitted a [response](#) to the [Health and Social Care Select Committee](#) inquiry on the regulation of medicines, medical devices and substances of human origin after Brexit, drawing attention to issues relevant to the regulation of NIPT, an *in vitro* diagnostic device. Our response highlighted changes to EU regulation of in-vitro diagnostic medical devices in light of the new EU In Vitro Diagnostic Device Regulation which was adopted in April 2017. The new regulation will require manufacturers to produce significantly more evidence on clinical performance and would have come into force in the UK after a transition period of five years. Our response noted that if the UK decides to adopt its own regulatory approach, rather than harmonise regulatory requirements in the UK with those of the EU, then the Government should take into account the improvements to the system brought about by the new EU IVD regulation.

The provision of information in the private sector

Recommendation

The Committee of Advertising Practice should more closely monitor the marketing activities of NIPT manufacturers and private hospitals and clinics to ensure that they are not misleading, harmful or offensive. Certification from recognised information quality schemes, such as NHS England's Health Information Standard, should be sought by NIPT providers to help women and couples to know that their information has been quality checked.

Recommendation

We reiterate our earlier recommendation that all NIPT providers, including manufacturers and private hospitals and clinics, should provide accurate, balanced and up-to-date information for pregnant women and couples about the benefits and limitations of NIPT and the conditions being tested for in a variety of formats.

We met with the Committee of Advertising Practice (CAP) in March 2017 and shared some examples of website material from private NIPT clinics that we believed to contain misleading and/or harmful information. No rulings on, or cases of informal resolution of, complaints about advertisements of NIPT have been recorded on the [ASA website](#) since March 2017. However, it is a [strategic priority](#) of the Advertising Standards Authority (ASA) to take a more proactive approach to address problems in

advertising and the organisation has a '[proactive work](#)' programme. We will continue to engage with CAP/ASA with regard to the marketing activities of private NIPT clinics.

In July 2017, we published a [leaflet](#) for private providers of NIPT with guidance on the information they should include on their websites and patient leaflets about NIPT. The leaflet identifies information that it is essential is included on webpages and patient leaflets, such as information on test performance, the possibility of a failed test, follow-up diagnostic testing, and the genetic conditions being tested for, such as Down's syndrome. The guidance leaflet states that information should be provided in an accessible, jargon-free way and providers should be careful not to use offensive language. We wrote to around 45 manufacturers and private providers, enclosing the guidance and encouraging them to join [NHS England's Information Standard scheme](#). Links to the published guidance were also requested from contacts at the Royal College of Obstetricians and Gynaecologists. A year after this information was distributed, a review of patient leaflets and website information provided by private sector providers of NIPT suggested that few had made any changes.

Good practice guidance

Recommendation

We recommend that professional guidance for health and social care professionals on the availability and provision of NIPT in the UK should be developed by relevant Royal Colleges, the Joint Committee on Genomics in Medicine, and other professional bodies.

Recommendation

The Royal College of Obstetricians and Gynaecologists guidance for its members on the termination of pregnancy for fetal anomaly should be renamed immediately to indicate that they cover the continuation of pregnancy after a diagnosis of fetal anomaly, and this part of the guidance should be expanded significantly, or additional guidelines created.

Recommendation

The relevant parts of the professional guidance recommended above (see Paragraph 6.19) should be incorporated into existing NICE guidance, NHS service specifications and other relevant NHS guidance across the UK.

Recommendation

UK-specific guidance for health and social care professionals involved in the provision of NIPT for rare genetic conditions to NHS patients would be helpful, and the scope of the professional guidance recommended above should include this kind of offer and use of NIPT (see Paragraph 6.19).

NICE guidance

In April 2018, NICE began a review of their [guideline on antenatal care for uncomplicated pregnancies](#). As part of this work they launched a public consultation on the [scope](#) for the guideline. Our [response](#) to the consultation underlines the need to provide guidance on continuation of pregnancy after fetal diagnosis in addition or separately to the guidance on uncomplicated pregnancies. To our knowledge, no such guidance has been initiated.

A related development is that NICE are currently undertaking work to produce [revised guidance on termination of pregnancy](#) which is expected to be published in September 2019.

RCOG guidance

In July 2017, we met with senior staff and officers of the Royal College of Obstetricians and Gynaecologists (RCOG). There was agreement that the RCOG guidance on [Termination of Pregnancy for Fetal Abnormality](#) should be updated to incorporate guidance on NIPT and continuation of pregnancy after diagnosis of fetal anomaly. However, to our knowledge, no such guidance has been initiated. Other issues discussed were the need for a systematic review of evidence on the performance of NIPT for different conditions in different populations which would support both the College's work and the report's recommendation that NIPT should only be used if it provides an accurate prediction of the condition tested for. A [meta-analysis of the evidence on the accuracy of NIPT](#) for chromosomal anomalies has since been completed by [Cochrane](#), an independent research organisation.

Other

[Updated FASP guidance](#), published in September 2018, briefly mentions NIPT, noting that: "Planning is underway with a view to implement the offer of NIPT as an additional option in the current screening pathway during 2018 to 2019".

The development of prenatal screening policy

Recommendation

We recommend that the UKNSC takes better consideration of the particular psychological, ethical and social consequences, some of which will be unintended, of any prenatal screening programme where termination of pregnancy is an option.

The UK National Screening Committee (UKNSC) has taken a number of steps to take better consideration of the psychological, ethical and social consequences of prenatal screening where termination of pregnancy is an option.

Catherine Joynson, Assistant Director of the Nuffield Council, presented the findings of the report to the UKNSC at a meeting of the Committee in Belfast in June 2017.

In July 2017, the UKNSC advertised for new Committee members with ethics and social science expertise. Dr Anne-Marie Slowther, Reader in Clinical Ethics, Warwick Medical School, University of Warwick, was appointed. At the UKNSC's stakeholder conference, UKNSC member Professor Roger Brownsword gave a presentation on the UKNSC's approach to ethics in which our was cited, and said that the Committee was increasing its focus on this area of its work.

The UKNSC is exploring how it can improve the way it accesses ethics expertise and engages with stakeholders. It set up an [ethics task group](#) to provide a framework for in-depth consideration of the ethical issues related to screening. Catherine Joynson was invited to participate in one of the initial meetings.

Media coverage of the report

Print

The Sun (1 March 2017) [DNA TEST FEAR: New test for genetic diseases; could be used for selective abortions on the basis of sex](#)

The BBC (1 March 2017) [Women warned about private Down's syndrome tests](#)

BMJ (1 March 2017) [Non-invasive prenatal screening should be banned for sex selection, says ethics report](#)

Daily Mail Online (1 March 2017) ['I fear this new Down's test is a slippery slope to eugenics': Writer IAN BIRRELL, whose daughter was born severely disabled, voices his concerns about Non-Invasive Prenatal Testing](#)

Daily Mail (1 March 2017) [Down's test 'used to choose gender': Warning checks for the condition are driving an 'arms race' to create the perfect baby](#)

BBC News Scotland (1 March 2017) [Fewer Down's syndrome terminations in Scotland](#)

The Sun (1 March 2017) [DNA TEST FEAR New test for genetic diseases 'could be used for selective abortions on the basis of sex'](#)

The Telegraph (1 March 2017) [Ban early pregnancy blood test to curb abortion of baby girls, ethics body demands](#)

Nursing Times (1 March 2017) [Nurses need training on pioneering prenatal screening test](#)

Bionews (6 March 2017) [Use of prenatal tests must be limited](#)

Breitbart (6 March 2017) [Bioethics Council Nixes Sex-Selective Abortion but Oks for Down Syndrome](#)

The Telegraph (22 May 2017) [New NHS test could lead to abortions of 'undesirable' babies, warn experts](#)

The Scottish Sun (22 May 2017) [DESIGNER BABY New NHS test can reveal a baby's sex at just NINE WEEKS – but experts warn it could lead to sex-selective abortions](#)

The Irish Sun (22 May 2017) [DESIGNER BABY New NHS test can reveal a baby's sex at just NINE WEEKS – but experts warn it could lead to sex-selective abortions](#)

Daily Mail (23 May 2017) [NHS blood test that screens babies for genetic traits such as height and hair colour could cause a surge in abortions, expert warns](#)

Daily Mail (11 September 2017) [Fathers can ALTER the sex of their children: Men who produce high-quality sperm are more likely to have sons](#)

BBC (17 September 2018) [Labour calls for ban on early foetus gender test](#)

Metro (17 September 2018) [Parents 'should be banned from using test to determine gender of their baby'](#)

Mail Online (17 September 2018) [Ban parents-to-be from using early gender test, says Labour](#)

ITV (17 September 2018) [Labour calls for ban on parents-to-be using early gender test](#)

The Guardian (17 September 2018) [Labour calls for ban on early foetus sex test](#)

Sky News (17 September 2018) [Labour calls for ban on early baby gender test](#)

The Independent (17 September 2018) [Early gender tests 'leading to selective abortions of girls in UK'](#)

Daily Mail (17 September 2018) [Parents-to-be should be BANNED from finding out their baby's gender in blood tests as early as 9 weeks to avoid girls being aborted for cultural reasons, Labour urges](#)

Metro (17 September 2018) [Calls to ban early gender scans are sexist, patronising and do women a disservice](#)

The Express (September 2018) [Parents should be banned from finding baby's gender to stop abortions for cultural reasons](#)

Broadcast

Tom Shakespeare interviewed by [BBC Radio 5 Live Morning Reports](#) (1 March 2017)

Catherine Joynson interviewed by ITV News London on the Reflex protocol (9 November 2017)

Tom Shakespeare interviewed by [Victoria Derbyshire Show](#) on use of NIPT to determine fetal sex (17 September 2018)

Catherine Joynson interviewed by [BBC Radio 5 Live](#) on use of NIPT to determine fetal sex (17 September 2018)

Catherine Joynson interviewed by [BBC West Midlands](#) on use of NIPT to determine fetal sex (23 September 2018)

Nuffield Council news stories and blogs

News stories

March 2017: [New pregnancy testing technique needs limits says ethics body](#)

July 2017: [Guidance on information that should be provided to patients about NIPT](#)

November 2017: [Nuffield Council on Bioethics raises concerns about the 'reflex' prenatal screening test for Down's syndrome](#)

February 2018: [Nuffield Council on Bioethics welcomes Church of England's call to value people with Down's syndrome](#)

April 2018: [Nuffield Council on Bioethics response to introduction of non-invasive prenatal screening in Wales](#)

September 2018: [Council comment on call for ban on using NIPT for sex determination](#)

Blogs

January 2017: [NIPT – exploring the views of patients, families and advocacy groups](#) by Tara Clancy – visited 284 times

March 2017: [Reflections on reactions to the Council's report on NIPT](#) by Catherine Joynson – visited 121 times

March 2017: A blog post by Catherine Joynson, [The next generation of prenatal testing: let's proceed with caution](#) was published on the NHS Confederation blog.

April 2018: [NHS Wales offers non-invasive prenatal testing one year on from our ethics report](#) – visited 757 times

July 2017: [A new social contract for Generation Genome](#) – visited 518 times

Citations in academic books and articles

2017

Brownsword R and Wale J (2017) [The Right to Know and the Right Not to Know Revisited: Part One](#) *Asian Bioethics Review* **9** (1–2).

Marsden D and Wyatt R (2017) [Get involved with the ethical debate on prenatal testing](#) *Learning Disability Practice* **20** (2).

Northway R *et al.* (2017) [Supporting people across the lifespan: the role of learning disability nurses](#) *Learning Disability Practice* **20** (3).

Brownsword R and Wale J (2017) [Regulating in the Global Village: The Case of Non-Invasive Pre-Natal Tests](#). Paper given at the 1st International Conference on "Medicine, Law and the Internet", 4-6 May 2017, Piraeus Bank Conference Centre, Thessaloniki, Greece.

Bryant LD (2001) [Ethical Issues of Noninvasive Prenatal Testing for Down Syndrome](#) *eLS* 1-6.

Taylor MJ, Dove ES, Laurie G and Townend D (2017) [When Can the Child Speak for Herself? The Limits of Parental Consent in Data Protection Law for Health Research](#) *Medical law review* **26** (3).

Ravitsky V (2017) [The shifting landscape of prenatal testing: between reproductive autonomy and public health](#) *Hastings Center Report* 47 S34-S40.

Harper JC *et al.* (2017) [Recent developments in genetics and medically-assisted reproduction: from research to clinical applications](#) *Human Reproduction Open* **2017** (3).

Montgomery J (2017) [The Virtues of National Ethics Committees, Goals and Practices of Public Bioethics: Reflections on National Bioethics Commissions](#) *Hastings Center Report* 47 S24-S27.

Borry P *et al.* (2018) [Noninvasive prenatal testing: a survey of young \(future\) parents in Flanders](#) *Personalized medicine* **15**(1).

2018

Walker CL (2018) [Response to Wald et al](#) *Genetics in Medicine* **20** (10).

Sheard M (2018) [Valuing people with Down's Syndrome](#) *General Synod of the Church of England*

Zhang S, Han S, Zhang M and Wang Y (2018) [Non-invasive prenatal paternity testing using cell-free fetal DNA from maternal plasma: DNA isolation and genetic marker studies](#) *Legal Medicine* **32**.

Vanstone M, Cernat A, Nisker J and Schwartz L (2018) [Women's perspectives on the ethical implications of non-invasive prenatal testing: a qualitative analysis to inform health policy decisions](#) *BMC medical ethics* **19**(1)

Camporesi S and Cavaliere G (2018) [Eugenics and enhancement in contemporary genomics](#) *Routledge Handbook of Genomics* in *Health and Society* Gibbon S, Prainsack B, Hilgartner and Lamoreaux J eds.

Clarke AJ and Wallgren-Pettersson C (2018) [Ethics in genetic counselling](#) *Journal of Community Genetics* 1-31.

Best M (2018) [The dilemma of prenatal screening](#) *Ethics and Medicine* **34**(2).

Brownsword R and Wale J (2018) [Testing Times Ahead: Non-Invasive Prenatal Testing and the Kind of Community We Want to Be](#) *The Modern Law Review* **81**(4).

Suter S M (2018) [The tyranny of choice: reproductive selection in the future](#) *Journal of Law and the Biosciences* **5** (2).

Wald N J and Old R (2018) [Conflating screening detection rates with the uptake of further testing: A potential source of confusion](#) *Journal of Medical Screening*.

Presentations

2017

15 June 2017: **Hastings Center meeting (US)** on prenatal testing – Working Group chair Tom Shakespeare presented the findings of our report.

23 June 2017: **UK National Screening Committee meeting**, Belfast. Assistant Director Catherine Joynson presented the report's findings to a quarterly meeting of the Committee.

26 June 2017: **PAGE Ethics Workshop II** - organised by Prenatal Assessment of Genomes and Exomes (PAGE) project and the Ethox Centre at the University of Oxford. Working Group member Angus Clarke presented the report's findings.

5 October 2017: **British Society for Genetic Medicine Annual UK Clinical Genomics meeting** in London. Tom Shakespeare gave a plenary presentation on 'The ethics of NIPT: choice, harm and equality'.

8-10 October: **PSGCA (Professional Society of Genetic Counsellors in Asia) workshop** prior to the Asia-Pacific Conference on Human Genetics, Thailand, 17 – Working Group member Tara Clancy gave a presentation including information on the report.

2018

2-4 October 2018: **World Medical Association, Medical Ethics Conference, 2-4 October 2018**, Reykjavik, Iceland. Angus Clarke gave a keynote presentation on prenatal testing at the beginning of a symposium.

8-9 November 2018: **10th Annual NGS & Clinical Diagnostics congress** in London, UK – Tom Shakespeare presented on NIPT and Whole Genome Sequencing.

2019

28-29 March 2019: **British Maternal and Fetal Medicine Society conference** to be held in Edinburgh. Tom Shakespeare is invited to be a plenary speaker on latest advances in prenatal diagnosis.

17–19 June 2019: **RCOG World Congress**, London. Tom Shakespeare is invited to participate in a plenary panel session on the Ethics and Unintended Consequences of NIPT.

Meetings

9 March 2017: **Nicola Blackwood MP** (Parliamentary Under-Secretary of State for Public Health and Innovation) and **Philip Dunne MP** (Minister of State for Health).

20 March 2017: Officers at the **Committee of Advertising Practice (CAP)**.

12 June 2017: Officials at the **UK Department of Health and Social Care**.

28 June: Senior staff and officers of the **British Pregnancy Advisory Service (BPAS)**, **Family Planning Association**, **SOAS South Asia Institute** and **Humanists UK**.

14 July 2017: Senior staff and officers of the **Royal College of Obstetricians and Gynaecologists (RCOG)**.

4 August 2017: Officers of the **Joint Committee on Genomics in Medicine (JCGM)**.

20 October 2017: **Jane Fisher** (Director) **Antenatal Results and Choices (ARC)**.

Consultation responses

April 2018: - [National Institute for Health and Clinical Excellence \(NICE\)](#) consultation on the [draft scope](#) for: Guideline on antenatal care for uncomplicated pregnancies update. Our response is available [here](#).

March 2017: [NIHR 'Health Futures' 20 year forward view consultation](#). NIPT and the report's recommendation on whole genome sequencing of fetuses was highlighted in our submission to the NIHR Futures of Health Project, which focused on health challenges in England in 20-30 years' time, and how they will differ from today. Our response is available [here](#).

October 2017: [Health and Social Care Select Committee](#) inquiry on the regulation of medicines, medical devices and substances of human origin after Brexit. Our response is available [here](#).