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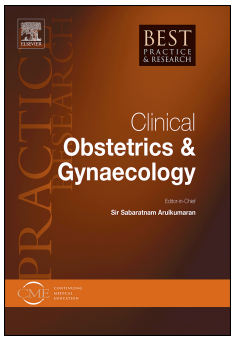


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**Title:**

# Ethical considerations in prenatal genomic testing

**Authors*:**

Ruth Horn*[1,2], Alison Hall[3], Anneke Lucassen[4]

**Affiliations:**

[1] Ethox Centre, University of Oxford, Old Road Campus, OX3 7LF Oxford, UK, ruth.horn@ethox.ox.ac.uk

[2] IEHHS, University of Augsburg, Universitätsstr. 2, 86159 Augsburg, Germany, ruth.horn@med.uni-augsburg.de

[3] PHG Foundation, 2 Worts Causeway, Cambridge, CB1 8RN, UK, alison.hall@phgfoundation.org

[4] Centre for Human Genetics, University of Oxford, Old Road Campus, OX3 7LF, anneke.lucassen@ndm.ox.ac.uk

***** Corresponding author



**Author contributions:**

All authors have contributed equally to this paper.

**Conflicts of interest:**

The authors declare no conflicts of interest.

**Highlights:**

- Prenatal diagnosis raises important ethical issues for professionals.
- Ever broader genome-wide screens, often in the absence of a phenotype, increase complexity and uncertainty.
- Prenatal genomic testing may have implications not only for the fetus, but also for the parents, siblings, and the wider family.
- We highlight three distinctive challenges that may arise: 1. more uncertainty2. time pressures for a binary decision; and 3. the potential impact of fetal results for the pregnant woman and others.

**Abstract:**

This paper discusses ethical issues arising in the context of prenatal genomic testing. While genomic information in the prenatal context might increase reproductive choice, e.g. to better understand a phenotype detected during screening, the availability of ever broader screens, even in the absence of a suspicion of abnormality, will generate increasingly complex and uncertain information. This raises questions of how much and what information should be provided prior to testing and what information should be returned (and to whom) once testing has been performed. As prenatal genomic testing becomes broader and more routine, the information generated will have more often implications not only for the fetus, but also for the parents, siblings and the wider family, raising questions about professionals' responsibilities. Further challenges discussed in this paper include access to genomic testing and justice, as well as ongoing management and post-pregnancy follow-up. The paper highlights the importance of taking into account the particular difficulties that arise in the context of prenatal genomic testing: the uncertainty of the information while choices are binary (to continue with or to terminate pregnancy); the time pressure due to the statutory limits on the availability of termination; and the impact the testing of the fetus has on the woman's body and life.

**Key-words:**

Prenatal genomic testing; ethical aspects; consent; information; reproductive choice

## Introduction

This paper discusses ethical issues that can arise through the offer of genetic testing in prenatal care. It focuses on the offer, and delivery, of testing, as well as the interpretation and communication of results and discusses how these issues may affect the pregnant woman; the potential future child; and wider family members.

Genetic testing has been integrated into prenatal care since the mid-1960s. Initially via amniotic fluid puncture (amniocentesis) and in the 1990s via placental puncture (chorionic villus sampling), to retrieve fetal genetic material and examine chromosomes for numerical and structural changes (e.g. trisomies 21, 18 and 13 also known as karyotyping). As technologies advanced, it became possible to examine fetal genetic material at ever greater resolution, for example, microarrays (for copy number variation) or whole exome or genome sequencing. Less invasive test methods, such as the “non-invasive prenatal test” (NIPT) which extracts cell-free fetal DNA from a pregnant woman's blood sample can be performed at an earlier stage of pregnancy and does not carry the miscarriage risk associated with amniocentesis or chorionic villus sampling (CVS). These advances have enabled more prenatal tests to become routinely available, but the interpretation of test results may not be straightforward, often contrary to expectations.

Greater availability of prenatal testing offers women and couples the opportunity to make better informed decisions about current or future pregnancies and might in some cases inform the development of therapeutic interventions. Although public discussions about genetics tend to assume clear cut results, often the interpretation of genetic variation and its significance in the absence of a particular (suspected) phenotype is complex. It is important to distinguish between the utility of a genetic test in the context of a phenotype (for example, through an anomaly scan, or through positive screening tests on fetal material in maternal serum), and in its absence (for example, prenatal genetic screening) where there is no a priori suspicion of abnormality (1).

Central to prenatal diagnosis in modern democratic societies is the respect and support of reproductive autonomy and the aim therefore to provide non-directive counselling and sufficient information to enable women (and couples) to make informed and voluntary decisions about their pregnancies (2).

Ethical issues arising in the prenatal setting (3) have, at least, three important points for consideration (4):

1. Uncertainty: The results of prenatal genetic tests may not give clear diagnoses or predictions. However, the choices that follow such testing are often binary: to continue with or to terminate the pregnancy.
2. Time pressure: Decisions often need to be made in a matter of days or weeks and may be influenced by statutory limits on the availability of termination. Potential parents often have little time to reflect on information before having to make decisions around how to respond to it.
3. The nature of the relationship between the woman and her fetus: Although decisions to undergo prenatal genetic testing or not will often focus on the impact of the results for the potential future person, it is important to consider that testing necessarily involves interventions on the woman's body or might reveal unexpected information about her health.

**Consent to investigations during pregnancy**

An important ethical challenge in prenatal diagnosis relates to ensuring that pregnant women have a good understanding of the implications of testing before deciding whether or not to proceed. In the prenatal context, genetic testing to assess the risk of a genetic condition in the fetus requires the consent of the pregnant woman to the intervention done on her body (for example, ultrasound, venepuncture to obtain blood samples, amniocentesis or CVS) and the tests or analysis of the biological material collected (blood, placental tissue, cells from amniotic fluid etc.) as both concern the management of her pregnancy. In some cases, trio testing which compares results from the fetus with those of both parents may be necessary to optimise the interpretation of fetal tests. This means that consent from other individuals – both biological parents – may also play an important role in the investigation of the fetus.

The person providing their consent must (a) have been given sufficient, relevant and appropriate information for them to be able to make a decision; (b) have the capacity, or competence to make that decision; (c) be free from coercion or undue influence by others (5). There are several reasons why this might be more difficult during pregnancy than at other times. These include the complexity of the information involved, the difficulty of interpreting results and the fact that others, e.g. the father, may also have an interest in the decision.

One major concern regarding prenatal diagnosis is that it could be seen, by the pregnant woman, as a routine investigation that is expected of her. This might therefore undermine her consent and the woman's reproductive choice (6). The risk of routinisation has been associated with prenatal testing for many decades, and more recently particularly with NIPT which investigates the fetus in a much less invasive or risky way than so-called invasive tests (7).

The concern is that professionals will pay less attention to providing comprehensive pretest information and counselling when offering NIPT than when offering invasive testing (8).

Another challenge to consent for prenatal diagnosis lies in the complexity of the possible results obtained from the test. While genome-wide screening in the absence of phenotype is not recommended in most countries due to its high probability of inconclusive results (9), even more targeted tests can result in uncertainty. One challenge is interpreting genotypic changes in the absence of a phenotype, which may not be expressed until later in pregnancy or childhood. Prenatal testing might generate 'unnecessary' concerns, e.g. where a genetic variant is found which might have no clinical relevance for the future person. It can also lead to 'false reassurance', e.g. where no abnormal results are determined. When taking consent, patients should be informed about both the realistic scope as well as limitations of the respective test.

Furthermore, the perception and definition of what constitutes a serious condition can vary across countries and policy-contexts and is often value-laden. While there are objective criteria to define a serious condition (e.g. available treatments; life expectancy; intensity, frequency and duration of symptoms; quality of life indicators; prognostics) (10) these can be interpreted differently and the assessment and the lived experience of seriousness can be highly subjective depending on people's experiences, values, needs and personal/familial context (11). This is particularly so in the prenatal context where the life of the future child with a particular condition can only be imagined.

However, despite the complex information that might be generated by genetic prenatal tests and the difficulties in their interpretation in a particular context, the pregnant woman, will usually be faced with a binary decision – whether to continue with or to terminate the pregnancy. It is important to make this clear at the outset of testing, especially in the context of societal discourses that hold a genetic code to be a 'blueprint' (12) and an expectation that its analysis will lead to clear-cut information (13).

A particularly important question is how much and what kind of information needs to be provided at the time that a test is offered, and consent is sought, and what levels of understanding are required for such consent (or refusal of consent) to be valid? In clinical genetics, a great deal of emphasis has been placed on the notion of 'consent as a process of communication' (14) in which 'both clinicians and patients are seen as bringing information and values to the discussion' and working together to agree on the information relevant to the

patient (15). Due to the time pressures involved, there is less opportunity for this process to evolve during pregnancy.

Furthermore, valid consent requires that patients are free of undue influence by others. Prenatal testing can be a stressful experience, and it is often invaluable for women to have their partner and other family members present to make decisions together, but this might also pressurise women into making decisions. Women should be supported to make a decision they will be comfortable with, although this may often be intertwined with the partner's or family's views.

**Communication and supporting patient choice in the context of complex and uncertain information**

One practical ethical issue in prenatal diagnosis concerns the question of what information should be communicated and how. In Europe, approximately two out of every 100 pregnancies result in a baby with a congenital anomaly (16). Some, but not all of these will have a genetic explanation and some, but not all of these will be detectable with current genetic or genomic investigations.

As screens become broader, more agnostic and potentially detect more variations within a fetal genome, greater uncertainty will inevitably arise (17). The degree of uncertainty relating to specific variants might be clarified in the future as the result of research, a particular variant classification, may shift from uncertain to clear, but variations in penetrance and expressivity still leave much uncertainty: even where variants have clear evidence of associated pathogenicity with onset in early childhood, there may be a wide range of possible manifestations of disease as well as degrees of severity, and some people with the pathogenic variant will never manifest the associated condition.

Furthermore, some variants found during testing in pregnancy may indicate a high chance of future disease which does not manifest before adulthood and where no interventions are available to alter the onset or course of the disease. Most professional guidelines recommend against searching or returning such findings (18-20), because, amongst other reasons, it might lead the parent(s) to treat the child in ways that are harmful or overly restrictive, labelling the child as being ill or at risk (14). In such cases, such knowledge has the potential to be a burden both for the parents and for the child. Adult-onset conditions also raises ethical questions about a child's right to an open future, i.e. the ability of a child to make these decisions for themselves once they have capacity to do so (21). Information about the risk of developing a disease

concerns not only the future person and his or her rights, but also, those of the pregnant woman (or couple) and her decision to continue the pregnancy or not (22).

Deciding which genetic information constitutes a useful result, and achieving effective communication and counselling when the window for decision-making is inevitably limited during pregnancy is difficult. It is important therefore in prenatal diagnosis to inform women of tight timescales regulating possible decisions to terminate pregnancies, and realistic turnaround times for the tests performed, as well as of realistic expectations and limitations of these tests (4).

**Implications of prenatal genetic testing for others**

A prenatal genetic test can reveal information that is relevant not only to the fetus but also to the parents, siblings, and the wider family. This raises questions about professionals' responsibilities towards others who may have an interest in this information (23). One case where important information relevant to or about others could be revealed is where genetic parentage has been misattributed. This might come to light, for example, through trio testing. While such information is often considered as social information not relevant to the clinical discussion, it might have an important bearing on counselling of recurrence risks and so a real question about disclosure arises (24). As some authors argue, the possibility of such information should be discussed when seeking consent, as not informing the couple would be 'unjustifiably paternalistic' (25).

Another situation where a prenatal genetic test may reveal important information about either parent, or perhaps wider family members, can occur when a genetic variant is identified incidentally. Findings that are incidentally 'stumbled upon' might include adult-onset cancer risks (e.g. *BRCA 1 or 2* deletion) in the fetus found whilst looking for a diagnosis for a scan abnormality. Such a finding might reveal unexpected information about parental health from whom the fetus might have inherited the variant. In such a case, clinical practice should include raising the possibility of unexpected findings as part of consent discussions, and the possibility that this might be disclosed. Because of the range of possible unexpected findings, explicit consent is often impossible.

It may be difficult to distinguish patients' views between generating findings and communicating them, but in practice this is an important distinction (1). There are important arguments in favour of treating genetic information in its broader familial context and making it available for use in the care and treatment of all family members (26). The implementation of any such policy does however, require sensitivity and a careful balance needs to be struck

between treating patient information as personal and confidential, and discussing and disclosing potential familial information appropriately.

Questions about the impact of genetic tests for others are likely to arise as genetic testing becomes more routine, and it is important that such possibilities are raised at the outset so that patients have an understanding of what they can expect.

**Access to genetic testing and justice**

A key principle of publicly funded healthcare systems is that the best possible care should be provided in a consistent manner to those in need. Avoiding inequality (differences in health status or outcomes between individuals or groups) or inequity (where the reasons for these differences are unjust or arise due to injustice) are important principles that inform healthcare provision across all clinical specialties but may be very challenging to address in practice (27).

In the context of prenatal diagnosis, identifying which women are likely to benefit from a particular test, and policy decisions about which tests should be funded, are the subject of ongoing debate (28). Although health professionals may have limited power to influence some aspects of test provision (e.g. commissioning) they can make sure that information about available genetic tests in pregnancy are communicated equally and support those women who are eligible to access a test in their decision-making.

One example where equity of access is sometimes seen as a problem is preimplantation genetic testing for monogenic or single-gene disorders (PGT-M), a technique that allows the diagnosis of a genetic disorder in early embryos created through IVF, before transfer to the uterus (29). PGT-M is an option available in some public healthcare systems across Europe, and elsewhere, for women and their partners. Many legislations stipulate that PGT-M should be available where there is a particular risk that an embryo may not be viable or has an abnormality or diagnosis that indicates a significant probability that the future child will have or develop a serious medical condition. Testing the embryo is performed in vitro before implantation, to determine whether it is at risk of serious genetic disease. Only unaffected embryos are transferred. PGD is an alternative to prenatal diagnosis for couples at risk for transmitting genetic conditions to avoid termination of an affected pregnancy. What constitutes a serious condition however is not always clearly defined and can be highly subjective depending on lived experiences of patients and their families. Some jurisdictions such as England and Wales offer access to PGT-M only if there is no living unaffected child from the current relationship (30). Couples who consider PGT-M for a second child or for a condition that does not count as sufficiently serious are denied what may well be a meaningful option for

them (31), potentially limiting their reproductive autonomy (32). Genome-wide approaches make decisions as to what counts as serious enough to grant access to PGT-M more and more complex. While decisions to grant access are made by professionals according to set criteria, the interpretation of these criteria are subjective and lead to inconsistency of access (32). It is important therefore, that professionals critically reflect upon and analyse their decisions from a range of perspectives, together with colleagues from different disciplines, and in close exchange with the couple.

**Ongoing management and post-pregnancy follow-up**

Prenatal testing can be stressful, and it is important that different healthcare professionals work together to ensure that patients are cared for in a consistent manner (33). For example, procedures should not be undertaken without discussions about the range of findings they might reveal, and the implications for the patient at each stage. It may therefore be helpful for individual departments to identify members of their teams who can coordinate communication between these professionals as well as communication with the patients.

To ensure continuity in care and decision-making support, healthcare professionals should consider the various options available to the pregnant woman and how these might align with the information being communicated. To allow for a person-centred approach that meets the specific needs and preferences of each woman and her partner, professionals should ensure that additional tests, scans or further interventions are offered promptly after results are given (34).

Women and couples also require support after the birth of a child with a genetic condition or after a pregnancy termination (35). They may require follow-up after the pregnancy to arrange for wider family members to be offered genetic testing or to plan further management for children born with a genetic condition, and to access potential sources of support, including patient groups. Sometimes follow-up contact is for ongoing results and outcomes of investigations such as fetal pathology. At other times, emotional and bereavement support may be needed. Couples may also feel the need for further appointments before planning any future pregnancies and should be informed how to re-establish contact with the team or how to arrange appropriate referral at a later point in time. Although the organisation of a continued care approach will require further staff and financial resources there is evidence that ultimately this approach benefits not only the patient but also reduces costs in other care segments (36).

**Conclusion**

This paper has discussed some of the ethical issues that can arise in prenatal diagnosis as the use genetic and genomic technologies becomes part of routine prenatal care. It has highlighted that the particular context of pregnancy should be taken into account to truly support reproductive choices. This includes uncertainty, time pressure and the physical relationship between the fetus and their mother. Prenatal test results, often do not answer the question of how a particular condition might present in the future person. Dealing with uncertainty when choices following testing are binary and time to make a decision is limited, is particularly challenging. Here, it is important to focus not only on the impact prenatal diagnosis has on the fetus or the future person, but also, on the pregnant woman as well as those close to her. These observations have practical implications for pre-test discussions, consent, communication and information provision in the context of prenatal diagnosis, as well as for the provision of access to, and continuity of, care. Inclusive discussions involving researchers, clinicians, patients and scientists are needed to guide best practice for these and other important issues raised by prenatal diagnostic tests.

**PRACTICE POINTS**

- Consent discussions need to pay attention to: the procedure, potential results and possible outcomes of prenatal testing, including available treatments or interventions; the potential for unexpected findings; the timescales for prenatal testing and the interpretation of results; the timeframe for making decisions during pregnancy including any regulatory limitations; and the implications of the testing for others.
- Communication should include the fact that tests do not always provide clear answers about the outcome, and what this means for the life of the persons concerned.
- Relevant information should be given as early and comprehensively as possible in order to support the pregnant woman in her decision-making.
- Provision of information about which genetic tests in pregnancy are available through the health system should be communicated equitably and women who are eligible to access a test should be supported in their decision-making beyond the actual pregnancy.

**RESEARCH AGENDA**

- Further research is needed to clarify the scope and limits of using less targeted tests such as whole genome sequencing in prenatal screening tests, and how this might impact on women’s reproductive choices and on existing screening programmes.

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## CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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