

Expectant parents experience feelings of anticipation, curiosity about foetal development, and a desire for reassurance and certainty during pregnancy

New prenatal genetic tests, often collected via minimally invasive methods, can provide large amounts of data or information about a foetus.

Not all of what is gathered can be translated into meaningful knowledge, or will be useful for parents in making autonomous decisions about their pregnancy.

There is a possibility that too much information can contribute to feelings of anxiety, beget more testing, or lead to invasive procedures in the pursuit of certainty.

In an attempt to alleviate the impact of this ethical concern, current practice in prenatal genomics relies heavily on the practice of acquiring informed consent from parents, implicitly marking it as a fundamental ethical standard.

While informed consent is necessary for any testing procedure, it has epistemic boundaries in the context of prenatal genomics:

- Myopic focus on consent procedures (e.g. information provision) assumes an individualistic conception of reproductive autonomy
- Conflates bodily autonomy and reproductive autonomy
- Denotes decision-making as wholly rational, making implicit claims that access to large amounts of genetic information translates into more robust reproductive autonomy
- Ignores lessons of relational critique of liberal autonomy from feminist bioethics

Enhancing informed consent procedures will not address the root concern that expectant parents will often consent to undergo testing driven by a desire for reassurance, without reflecting on the information they expect to gain, the reasons why they want this information, and what they would do if they received a high-chance result for a genetic condition. This lack of reflection cannot be remedied by access to more information.

We ought not characterise the decision to undergo prenatal genetic testing as merely medical. Expectant parents are, in a sense, consenting to know aspects of foetal development, and this knowledge may change the course of their pregnancy.

The decision to test is medical, but also personal and moral.

There is a temporal aspect specific to pregnancy as people have a short time to decide whether testing suits them, and look forward into an envisaged future with their child.

In order to support a robust and relational reproductive autonomy we ought to:

- Encourage reflection and conversation
- Acknowledge the personal and moral aspects of the decision
- Be honest about the limits of what we can learn from genetic data
- Scrutinise why we test for the conditions we do, and what this assumes about the lives of people living with those conditions

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Challenging the Epistemic Boundaries of Informed Consent in Prenatal Genetic Testing



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