Your choice: Prenatal testing and reproductive autonomy
“This is simply about providing information that allows women to make their own choices” – Ben*, Obstetrician

* Pseudonym. #Images from MCRI information booklet, for use with the Screening Choices web tool.
Overview

The problem:

• Prenatal genomic testing often requires women to make complex decisions about their reproductive options and wellbeing in situations of significant uncertainty, emotional difficulty and personal disorientation.

The question:

• How are women best enabled to make these decisions in ways that promote or achieve reproductive autonomy?
  • Is 'reproductive choice' equivalent to 'reproductive autonomy'? Is it conducive to it?

Structure:

• Background on NIPT
• Prenatal genome testing and disability
• Prenatal genome testing and choice
Prenatal Genomic Testing – what information does NIPT provide?

- Trisomy conditions: highly accurate, lower false positive rate, reduces need for invasive testing
- Fetal sex: x and y chromosomes (ultrasound does genital sex)
- Other rare conditions; sub-chromosomal conditions

Infographic from VCGS: https://www.vcgs.org.au/tests/perceptnipt
The social valuation of disability

• Shifting social norms and decreasing diversity?

• Expressivist critique – sending a discriminatory message to existing people with disabling conditions?

• Obligation to prevent disability (aka harm) or obligation to preserve disability?

http://www.eugenicsarchive.org/
Beyond Trisomy

- Edge cases: differences of sex development, adult onset conditions

- Eg.1: Turner syndrome

- EG. 2: Early onset Alzheimers

- Disorienting: 'major life event that can make it difficult to go on' (Harbin)

- More specifically, *morally disorienting*

Woman with son conceived through IVF. She has Turner syndrome.  https://turnersyndromefoundation.org/2020/05/09/turner-syndrome-and-pregnancy/
Choice and Reproductive Decision-making

- Choice model positions embryos/fetuses as objects of choice, clinicians as morally neutral service providers, and gestator as primary (if not only) moral agent, responsible for choices.

- Gestators, usually women, are *made responsible* for the children that are born.
  - Does this also mean they may be *blamed* for the children that come into existence?

- Women as ‘moral pioneers’ (Rapp)
Autonomy in Reproductive decision-making

Choice is necessary but not sufficient for RA, so how can autonomous decision-making be best enabled?

**Autonomy**: the capacity to make decisions and follow through on courses of action that align with one's deeply held values

- About the authenticity of the desires, emotions, motives that move one to act
- Also about *being able* to act in accordance with those – autonomy is an achievement

How can reproductive autonomy be achieved in conditions of disorientation and epistemic uncertainty?
Alternative models of healthcare decision-making

Shared decision-making in genetic counselling:
- based on information sharing by both parties (doctor/counsellor and patient/client)
- agenda matching and decision agreed upon by both parties

“In SDM, the clinician/counsellor and the client share information on the basis of which a decision is to be made. They then discuss their views and come to an agreed decision for which they share the responsibility” (Elwyn et al)

- Obfuscates relative authority and relations of power
- Relationship to autonomy unclear (Sandman et al)
- Ignores unequal practical and moral consequences of decision-making in reproduction

Image from https://integratedcarefoundation.org/blog/in-shared-decision-making
Moving forward: Reproductive deliberation?

- **Reproductive Deliberation** combines elements of **non-directive 'consumer choice'** and **shared decision-making** models

- **Emphasizes:**
  - Communication (rather than information provision)
  - Connection (internal, and external to other services)
  - Commitment (to values, courses of action consistent with those)

- Focus on deliberation as **process** rather than choice as **outcome** to support and enable the achievement of reproductive autonomy.

*For a decision to be autonomous, it doesn't have to be made on one's own. Instead, it has to be a decision that the maker can ‘own’.*
Ethical, Social and Regulatory Issues in Advanced Prenatal Testing

• Funded by Australian Research Council Linkage Project Scheme, in partnership with Illumina, Victorian Clinical Genetic Services, Murdoch Children's Research Institute.
• 2021-2023: Empirical data collection and ethical/philosophical and regulatory analysis.
• Explores challenges to consumers as well as practitioners presented by expanded prenatal genomic testing to provide direction for future scope of NIPT. Key ethical concerns: information provision (pre and pos-test) and reproductive autonomy, health justice.
• Project team: Prof Catherine Mills (Lead CI, Monash), A/Prof Michelle Taylor-Sands (CI Melb Uni), A/Prof Lisa Hui (CI Melb Uni), Prof Julian Savulescu (Oxford), Prof Martin Delatycki (VCGS), Dr Mark Pertile (MCRI/VCGS), Dr Peter Coleman (Illumina).
References and Further Reading


• Stephenson, N. McLeod, C. Mills, C. 2017. “Simply providing information”: Negotiating the ethical dilemmas of pregnancy termination as they arise in the obstetric ultrasound clinic”. Feminism and Psychology. 27(1): 72-91.