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# Your choice: Prenatal testing and reproductive autonomy

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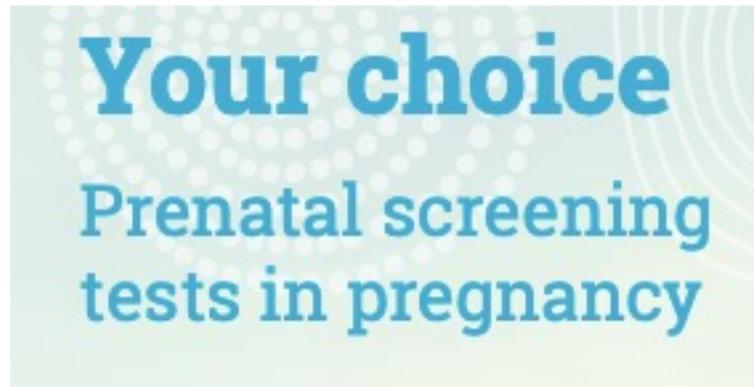
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Then:

*“This is simply about providing information that allows women to make their own choices” – Ben\*, Obstetrician*

Now:



*All prenatal screening is your choice.  
You can decide not to have any  
prenatal screening. #*

\* 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:

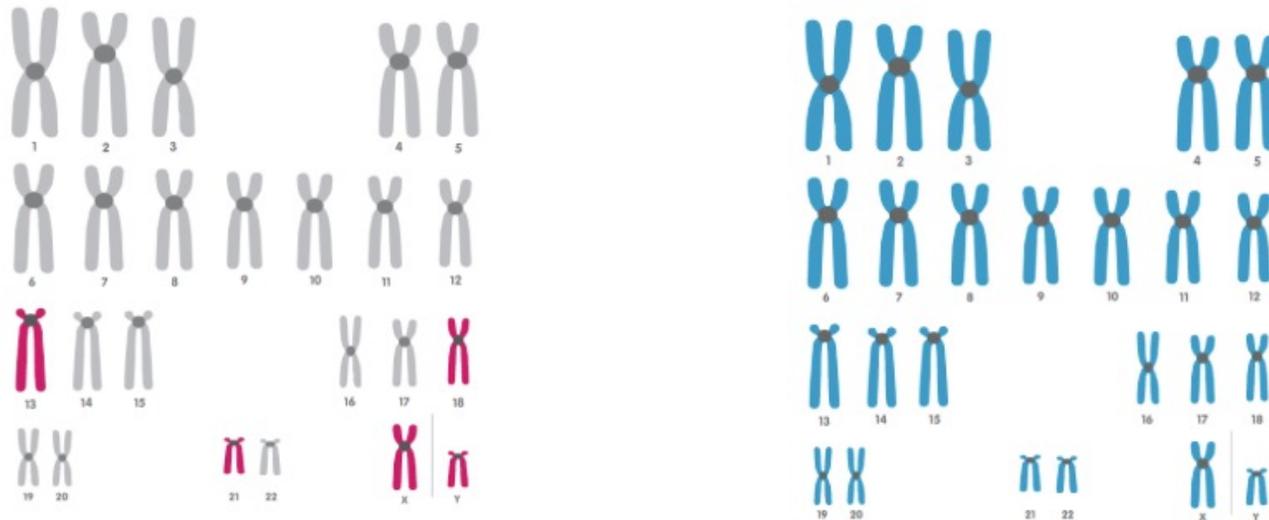
- How are women best enabled to make these decisions in ways that promote or achieve reproductive autonomy?
  - Is 'reproductive choice' equivalent to 'reproductive autonomy'? Is it conducive to it?

## 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>

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# 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?



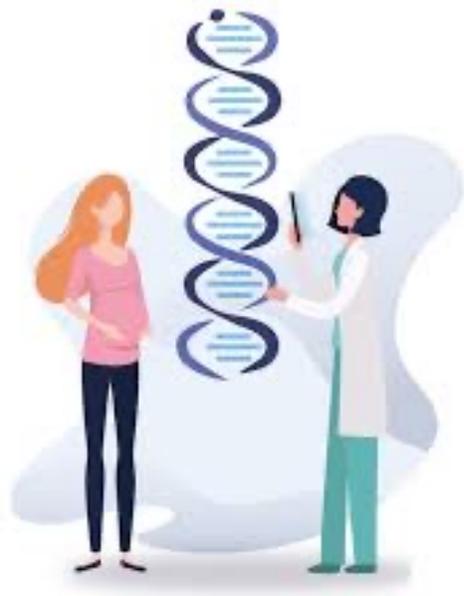
# Beyond Trisomy

- 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



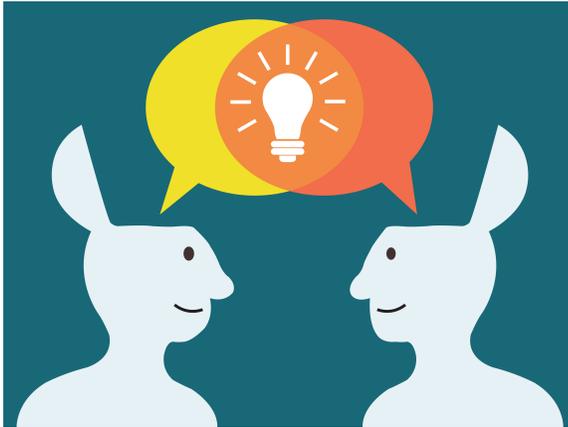
How can reproductive autonomy be achieved in conditions of disorientation and epistemic uncertainty?

# 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)

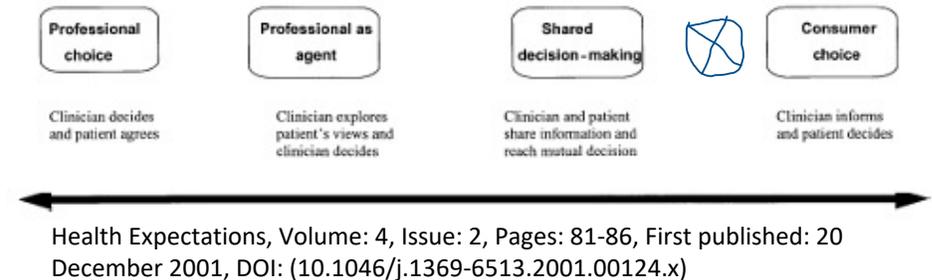


- Obscures relative authority and relations of power
- Relationship to autonomy unclear (Sandman et al)
- Ignores unequal practical and moral consequences of decision-making in reproduction

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 post-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

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