

## Beyond Guidelines: Reclaiming ethical responsibility in primary care

*Isabella Holmes*

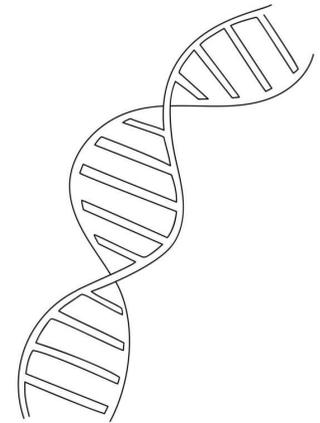
- *The in-progress paper this presentation is based on is co-authored by Gabriel Watts and Janani Mahadeva.*
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- *Special thanks also to Lisa Dive and Ainsley Newson.*

I would like to acknowledge the Gadigal  
people of the Eora Nation, on whose  
ancestral lands I live and work.

I would also like to acknowledge the Kāi  
Tahu iwi, on whose lands we are meeting  
today.

# Our work

- Part of a bioethics research group within the Genomics Health Futures Mission
- Overall goal of the larger project: to design a national approach to embedding genomics in primary care in Australia
- 34 expanded or increased Medicare rebates are now offered for genetic tests to the general population. The provision of these tests is led by GPs, who have varying experience in offering genetic and genomic testing.
- Focused on two tests that have come onto the MBS as paradigm examples of ethical complexity: Reproductive Genetic Carrier Screening (RGCS/ Carrier Screening), and Familial Hypercholesterolemia (FH).



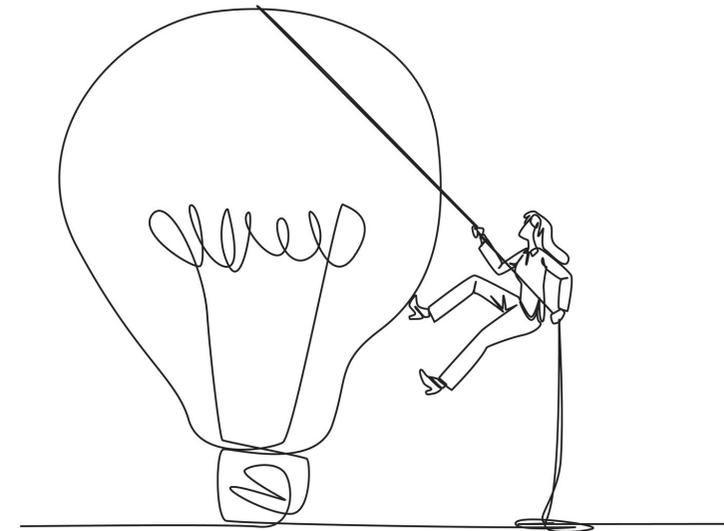
# Australian GPs

- Among GPs there has been persistent calls for reduced workloads, better pay, and streamlined regulation.
- New genetic tests coming to a workforce that may not necessarily feel prepared to handle them
- View of GPs: ethically difficult situations are viewed through a lens legal liability and professional responsibility. Ethics is seen as relevant to early training
- Want quick, easy to understand resources, no time to waste



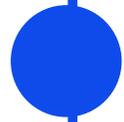
# Australian GPs

- Understandable, and guidelines are good! But more for clinical and legal advice.
- We want to acknowledge GPs schedules, workloads etc.
- However, some concerns for how this 'guideline approach' works for **ethical** advice.



# Guidelines

## Strengths



**Concise** - provide an immediate tool for decision-making



**Consistent** - reduce variation, potentially improve care quality



**Compliance** - professional (and legal) expectations, reducing anxiety about liability, adherence to regulatory standards

## Limitations



**Conflation** – risks replacing moral reasoning with procedural compliance



**Conflict** – potential incompatibility with the core values of general practice



**Constraint** – rather than support in the face ethical challenges raised by novel interventions

# Conflation

- Risks curtailing reflection on what ought to be done, by shifting focus to what is expected
- Potential 'replacement of responsibility'
- Ethical deliberation requires a slower pace than more direct, guideline driven thinking
- GPs not always given the same opportunities as other specialties to reflect with colleagues on moral dimensions of work



# Conflict

- Guidelines aim to reduce variation and improve care quality, could actually undermine the distinctive nature of the GP role itself.
- *"a strong commitment to the patient as a person, to provide continuing and comprehensive care, to embrace broad conceptions of health and disease, and to take an active interest in the prevention of ill-health."* Oakley and Cocking
- *"to prioritise holistic, person-centred healthcare."*
- *Rogers:* GPs would be expected to have some variations in care that are not necessarily ethically wrong. May actually be a feature of good practice



# Constraint

- GP's commitment is to patients as complete individuals, not to isolated clinical encounters
- Ethical guidelines cannot always fully accommodate the moral reasoning and relational virtues that constitute good general practice.
- This can lead to potentially compromised patient care



# Carrier Screening and FH

## Carrier Screening

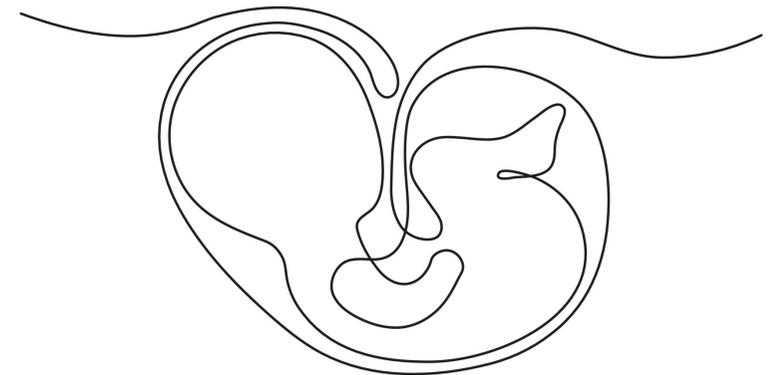
- Tests whether prospective parents carry gene variants for inherited genetic conditions that could be passed to their children.
- Being a 'carrier' typically means you have one copy of a gene variant but don't show symptoms yourself
- MBS: 'Three-Gene-Screen': Cystic Fibrosis, Spinal Muscular Atrophy, and Fragile X.

## FH

- Tests for the gene variant linked to Familial Hypercholesterolemia.
- An inherited genetic condition that causes very high cholesterol levels from birth, which can lead to early heart disease if left untreated.
- Cascade testing: first-degree relatives will also be offered testing and if they test positive then *their* first-degree relatives will be tested etc.

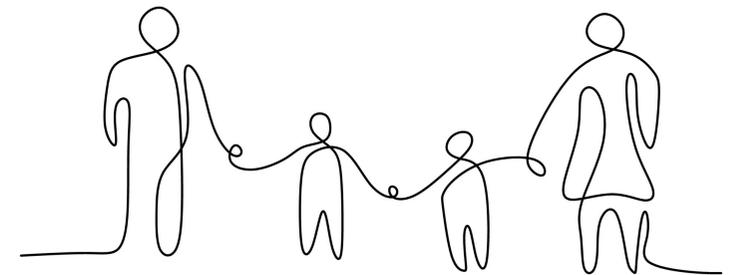
# Carrier Screening - Ethical Issues

- Initial test covered by Medicare, but offered through private companies, parents are then offered expanded testing
- Designed to be offered pre-conception, but often done early in pregnancy, creating complexities for reproductive autonomy and time-sensitive decisions
- Discovering carrier status can affect identity and mental health
- Fragile X carriers in particular there is emerging evidence that being a carrier is connected to personal symptoms



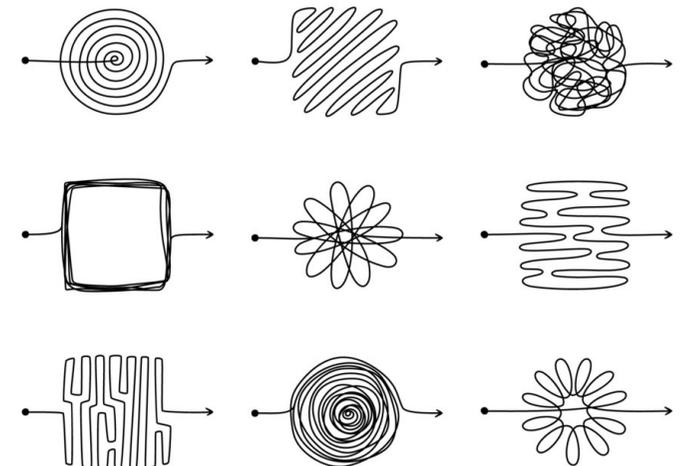
# FH – Ethical Issues

- Cascade testing may create tension between respecting confidentiality and perhaps a moral obligation to notify family members
- Tensions can arise for GPs between public health lens or individual patient lens.
- Follow up care may not be easily accessible.
- A positive FH result may require more time to ensure understanding with limited genetic counselling resources
- Can cause anxiety or guilt, especially if relatives are affected.



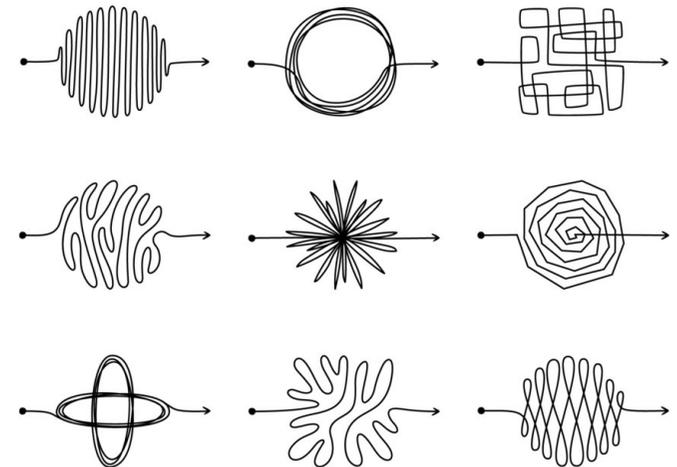
# Beyond Guidelines

- Equity and autonomy risks reduction to compliance with what's offered via Medicare
- Cascade testing guidelines clash with person-centred GP care.
- May be difficult to address unexpected results, mental health, and inequities
- Guidelines can give clarity but limit ethical reflection and flexibility.



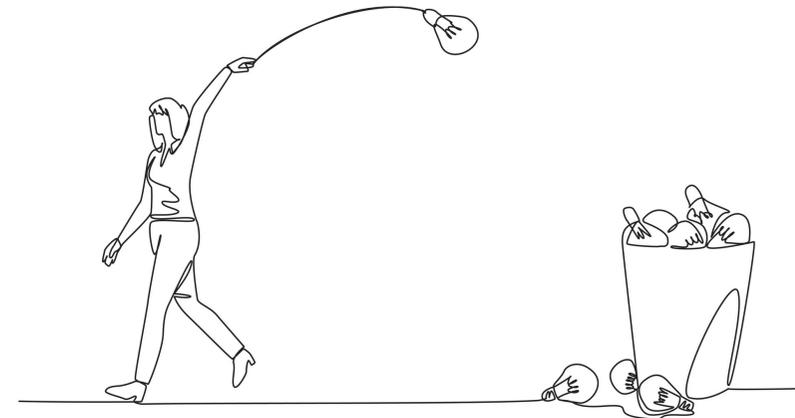
# Other supports

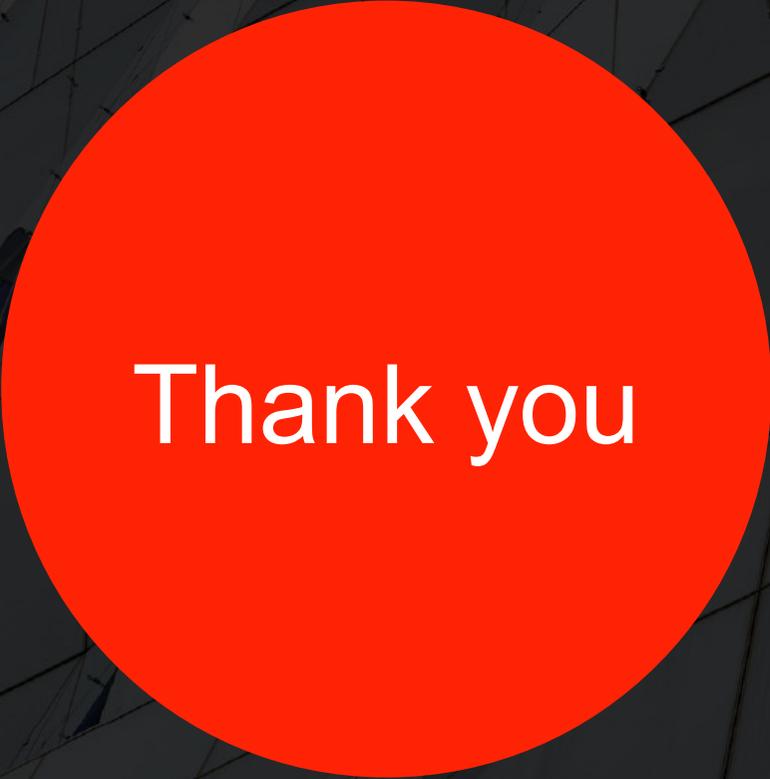
- **Reflection tools:** Case-based prompts and decision aids to help GPs consider “what ought to be done” beyond compliance
- **Support resources:** Accessible genetic counselling and practical CPD modules focused on relational autonomy and patient-centred
- **Decision pathways:** Highlight ethically complex points (e.g., cascade testing, extended panels) with reflective questions
- **Peer reflection:** Structured opportunities for GPs to share challenging cases and strengthen moral agency



# Summary

- **Genomic medicine impact:** Affecting general practice with ethical challenges beyond guideline solutions
- **Limitations of guidelines:** Risk conflating ethics with compliance, conflicting with GP values, and constraining nuanced care.
- **Case examples:** Carrier screening and FH testing show these limitations in real-world settings.
- **Other approaches to ethics supports:** Foster reflection, dialogue, and ethically responsive care alongside systemic changes to avoid further strain on GPs.





Thank you