Aide-Mémoire

Meeting with AGenDA

Date due to MO:	10 November 2025	**Date of Meeting:**	13 November 2025
Security level:	IN CONFIDENCE	**Reference:**	H2025074235
To:	Hon Simeon Brown, Minister of Health		
Consulted:	Health New Zealand: ☐		
Proactive release:	This **title** is proposed by the Ministry of Health for proactive release: ☒		

Contact for telephone discussion

Name	Position	Telephone
James Oughton	Chief Advisor Precision Health, Strategy and Policy	s 9(2)(a)

Author: James Oughton, Chief Advisor Precision Health, Strategy and Policy

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About the Meeting

Purpose of Meeting:	AGenDA are seeking Government support to end genetic discrimination by the insurance industry.	
Details of Meeting:	**Date:** **Time:** **Venue:**	13 November 2025 15:50-16:10 EW 6.6
Attendees	Professor Andrew Shelling Fay Sowerby	
Organisation	Against Genetic Discrimination Aotearoa (AGenDA) - a coalition advocating for protection against genetic discrimination in insurance.	
Ministry representatives	James Oughton - Chief Advisor Precision Health, Ministry of Health	

Comment/ Summary:

- New Zealand currently does not have legal protections against genetic discrimination in health or life insurance, in contrast with most OECD countries.
- The risk of genetic discrimination may result in patients declining genetic testing and participation in genetic research. This may undermine cancer prevention, precision health, and public trust in the health system.
- The Contracts of Insurance Act 2024 includes provision to establish regulations prohibiting or restricting genetic discrimination.
- Work around potential regulatory mechanisms (including public consultation) was paused due to legislative work programme prioritisation. This work could be resumed in the future.

Background and context

1. Against Genetic Discrimination Aotearoa (AGenDA) was established in 2021 by Professor Andrew Shelling. AGenDA is a coalition of clinicians, researchers, patient advocates, lawyers, privacy experts and non-government organisations advocating for protection against genetic discrimination by the insurance industry.

2. Genetic discrimination occurs when health and life insurance companies use genetic test results in underwriting decisions to increase premiums, deny cover, exclude conditions or deny payout.

3. There are currently no legal protections against genetic discrimination in health or life insurance in New Zealand. Insurance companies can request and use genetic test results in underwriting, impacting patients with diseases associated with specific genes (e.g. Huntington's Disease, hereditary cancers).

4. Genetic discrimination may result in patients being denied cover or facing higher premiums. It also creates a potential barrier to the adoption of genomics and precision health, as patients avoid testing or clinical trials due to insurance concerns.

International Context

5. Most OECD countries including Canada, the UK and the US have banned or restricted genetic discrimination in insurance through legislation or voluntary codes.

    a. Canada: Total ban since 2017.

    b. UK: Moratorium/voluntary code since 2001; renewed in 2024.

    c. Australia: Draft legislation for a full ban in life insurance in 2025, health insurance protected since 2007.

Legislative Developments in New Zealand

6. The Contracts of Insurance Act was passed on 15 November 2024 and includes a regulation-making power to prohibit or restrict genetic discrimination. This was added after strong advocacy from AGenDA and others, as well as significant media interest.

7. Ministry officials worked alongside MBIE officials in response to the issues raised at Select Committee as this provided an opportunity to address genetic discrimination as part of the Bill (briefings H2024046097 and H2024044505 refer).

8. MBIE and Ministry officials prepared a discussion paper and planned for a six-week consultation process to determine appropriate regulations to begin in September 2025. However, following Cabinet Economic Policy Committee decisions (Cabinet Minute ECO-25-MIN-0130 refers), consultation was paused. We understand from MBIE this was due to legislative work programme prioritisation.

9. Following the Cabinet meeting, MBIE communicated with a range of stakeholders including AGenDA. Minister Simpson has publicly stated that the consultation pause was not at the request of insurers[1].

[1] https://www.thepost.co.nz/business/360814346/government-cancels-genetic-discrimination-insurance-ban-plan

Public Health and Economic Impact

10. Genetic discrimination can discourage update of genomics. It deters patients from seeking testing and participating in research, undermining cancer prevention and trust in the health system.

11. International evidence shows that protections against discrimination increase uptake of genetic testing, leading to improved health outcomes and cost savings (e.g., reduced cancer and heart disease incidence, lower mortality, and significant treatment cost avoidance).

Likely areas of focus at the meeting with AGenDA

12. AGenDA will likely:

    a. Emphasise New Zealand's position as an outlier to comparable countries.

    b. Present evidence that a ban on genetic discrimination does not increase premiums or destabilise insurance markets.

    c. Highlight the impact of genetic discrimination as a barrier to the adoption of genomics and precision health.

    d. Seek assurance on a timeline for progressing work to determine regulations as part of the Contracts of Insurance Bill.

    e. Advocate for clear consumer protections and oversight.

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[redacted]

James Oughton
Chief Advisor, Precision Health
Strategy and Policy