

Use of genetic testing results in life insurance underwriting – Treasury consultation

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About the Public Interest Advocacy Centre

The Public Interest Advocacy Centre (PIAC) is leading social justice law and policy centre. Established in 1982, we are an independent, non-profit organisation that works with people and communities who are marginalised and facing disadvantage.

PIAC builds a fairer, stronger society by helping to change laws, policies and practices that cause injustice and inequality. Our work combines:

- legal advice and representation, specialising in test cases and strategic casework;
- research, analysis and policy development; and
- advocacy for systems change and public interest outcomes.

Our priorities include:

- Reducing homelessness, through the Homeless Persons' Legal Service
- Access for people with disability to basic services like public transport, financial services, media and digital technologies
- Justice for First Nations people
- Access to sustainable and affordable energy and water (the Energy and Water Consumers' Advocacy Program)
- Fair use of police powers
- Rights of people in detention, including equal access to health care for asylum seekers (the Asylum Seeker Health Rights Project)
- Improving outcomes for people under the National Disability Insurance Scheme
- Truth-telling and government accountability
- Climate change and social justice.

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Recommendation 1 – Legislative ban on use of adverse genetic tests

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Recommendation 2 – Positive duty, oversight and enforcement

A positive duty to eliminate discrimination as far as possible in the provision of services should be introduced into the DDA.

The AHRC should be given additional powers and resources to oversee the positive duty and compliance with the DDA, including to investigate compliance by insurers with the insurance exception and any new genetic test results prohibition.

AFCA should be empowered to deal with complaints about insurer compliance with any new genetic test results prohibition. If AFCA is empowered to deal with complaints about discrimination, further consideration should be given to the relationship between AFCA, the AHRC and other discrimination complaint handling bodies.

ASIC should play a greater role in oversight and enforcement of insurer compliance with their legal obligations not to unlawfully discriminate in the provision of services and legislative or regulatory changes to enable this should be considered.

1. Introduction

Since 2012, PIAC has provided legal advice and representation to people who have experienced discrimination, or otherwise been treated unfairly, by general and life insurance providers because of a mental health condition. In the course of its work, PIAC has identified systemic problems with insurance industry practices that have failed to protect vulnerable consumers from unlawful disability discrimination or other forms of unlawful or unfair behaviour.

PIAC welcomes this opportunity to comment on the issues raised in the Treasury Consultation Paper on the use of genetic testing results in life insurance underwriting. The increased use of genetic testing for diagnosis, prevention and early treatment of disease brings medical and public health benefits but also creates new risks of discrimination in insurance.

In 2021, PIAC published a report outlining the systemic issues identified through its work on mental health and insurance discrimination, and changes to laws and insurance industry practices over the past decade that have attempted to address some of those concerns.¹ This submission draws on PIAC's work on discrimination in life insurance as outlined in our 2021 report, and our experience of the life insurance industry, regulators and dispute resolution processes related to discrimination.

In this submission, we also endorse the submission of Intersex Human Rights Australia (IHRA),² which raises particular issues which genetic testing present for people with innate variations of sex characteristics (also called intersex people), and which adopts similar recommendations to our own. These issues are described in more detail at 5, below.

1.1 Discrimination in life insurance in Australia

As outlined in the Consultation Paper, life insurance is 'risk rated' and usually individually underwritten to determine a person's individual risk of illness, injury or death. Life insurance offerings do, therefore, discriminate between people based on their individual level of risk. Yet discrimination on the basis of disability in the provision of goods and services is prohibited by the *Disability Discrimination Act 1992* (Cth) ('DDA') and similar State and Territory legislation.

This brings insurance into clear conflict with goals of eliminating discrimination against people with disability in line with the DDA and Australia's commitments under the international Convention on the Rights of Persons with Disabilities. Nevertheless, insurance is granted specific exceptions in discrimination legislation which permit life insurers to discriminate. In the DDA, discrimination is permitted if it is:

- based upon actuarial or statistical data on which it is reasonable for the insurer to rely and reasonable having regard to the matter of the data and other relevant factors; or
- in a case where no such actuarial or statistical data is available and cannot reasonably be obtained—the discrimination is reasonable having regard to any other relevant factors.

¹ Public Interest Advocacy Centre, *Mental Health Discrimination in Insurance* (October 2021) https://piac.asn.au/wp-content/uploads/2021/11/21.11.04-PIAC-Report_Mental-Health-Discrimination-Insurance.pdf

² Intersex Human Rights Australia, *Submission on use of genetic testing results in insurance underwriting*, 17 January 2024, available at: <https://ihra.org.au/40726/submission-genetic-testing-results/>

PIAC's 2021 report examined the experience of people faced with insurers relying on these laws to discriminate in respect of mental health conditions. Despite some progress over the previous decade, people were often being denied cover unfairly or having cover subject to broad exclusions for mental health, encountering difficulties when trying to question or challenge decisions, and insurers were not providing clear evidence to justify their discriminatory practices.

2. Impact of discrimination on access to insurance

[Consultation Paper question 2]

PIAC has read and endorsed the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) Final Stakeholder Report of 30 June 30 2023 examining the effectiveness of the FSC moratorium on genetic testing.

In PIAC's view, concerns that people may choose not to undertake genetic testing because of the risk of it impacting on their ability to obtain life insurance are well-founded. PIAC has observed this among clients in respect of mental health discrimination who have expressed hesitation about seeking treatment for mental health concerns out of fear of jeopardising their ability to obtain insurance. We understand the A-GLIMMER report found this to be a real impact in the genetic testing context, where people are reluctant to undergo testing because of concerns about access to affordable life insurance.

In circumstances where life insurance products are individually underwritten, this risk is difficult to mitigate without a prohibition on insurers relying on genetic test results because, without a prohibition, insurers are obliged by their underwriting processes to act on indications of increased risk that genetic testing results may provide.

The safeguards provided by the DDA, requiring insurers to base decisions on actuarial and statistical data, and/or 'other relevant factors', may not provide sufficient protection – they have proved problematic in other contexts like mental health discrimination. The relevant 'actuarial and statistical data' cannot be effectively interrogated – insurers generally will not provide it to consumers – and the ability to rely on 'other relevant factors' gives insurers broad scope to argue they have justification for the discrimination.

Consumers may make a complaint of unlawful discrimination but even then, in PIAC's experience, insurers rarely provide the 'data' relied upon. People are asked to take the insurer's word that their particular medical history presents an increased risk. In the mental health context, insurers also often make assumptions about the impact of a mental health condition or treatment from a mental health professional without asking for further information to allow the insurer to understand the additional risk, if any. PIAC is concerned similar issues could arise in relation to genetic test results, without clearer guidance to insurers about what use can be made of the information.

PIAC remains concerned about life insurer compliance with the requirements of the DDA in respect of mental health, and has long recommended, including in our 2021 Report, that a

regulator (such as ASIC) investigate insurer practices in this regard. So far, such as inquiry has not taken place, but we continue to make that recommendation.

3. Options for genetic discrimination

[Consultation Paper Question 4]

PIAC suggests that if the health benefits of genetic testing in the various forms canvassed in the consultation paper are accepted, there is a strong case for regulating insurer practices in this context. Absent enforceable regulation with strong oversight and enforcement, we think the insurance industry is unlikely to change its practices voluntarily.

The A-GLIMMER report outlines clearly the limitations with the current industry-regulated moratorium and why those should be addressed by legislation, including:

- Public trust in life insurers to do the right thing is low, so people do not trust industry-regulation of the moratorium.
- Lack of oversight by government or enforcement pathways mean that consumers don't have confidence that the use of their data will be in accordance with the rules set.
- Uncertainty about whether the moratorium could be amended or withdrawn at any time.
- Financial limits are significantly less than what most people need to cover their liabilities.
- Low awareness by consumers and industry creates confusion and poor application.

PIAC endorses the recommendations of the A-GLIMMER report regarding the options for addressing concerns about genetic testing and access to life insurance. That is, PIAC suggests the most appropriate option is a total ban, without limits, caps or exceptions. A total ban is preferable to a partial ban because:

- It provides clarity and certainty for both insurers and consumers – insurers will not try to exploit the limits of a partial ban and consumers can be confident that their data does not have to be disclosed in any circumstances.

It provides clarity to health professionals who would not then feel obliged to give people advice on the possible impact of complex financial laws alongside health services.

PIAC also agrees that the prohibition should be framed so as to allow consumers to disclose negative (that is, favourable) genetic results. It is also important to ensure that insurers cannot use this exception to refuse to offer insurance coverage to individuals on the basis that they have not chosen to have a genetic test. Otherwise, insurers could seek to get around any legislative prohibitions by simply refusing to offer cover, for example, to anyone who had chosen not to take a genetic test where there was a family history of a certain disease.

Recommendation 1 – Legislative ban on use of adverse genetic tests

A total prohibition on the use of adverse genetic test results by life insurers should be legislated. The ban should not prohibit the disclosure by consumers of negative results.

4. Oversight and enforcement

[Consultation paper question 9/10]

PIAC outlined in our 2021 Report some of the difficulties people face in challenging insurer decision-making and enforcing their rights under the DDA, including the split dispute resolution between the AHRC and AFCA, and the burden enforcement places on individuals to lodge and prosecute complaints against well-resourced opponents.

PIAC raised concerns about the division of complaint handling in respect of discrimination in insurance between AFCA and the AHRC and State/Territory-based anti-discrimination bodies. This is a significant issue for consumers, particularly given that insurers almost always refer consumers to AFCA for complaints but do not indicate that complaints may also be made to other bodies, like the AHRC. This can become a problem when consumers make a complaint to AFCA and then discover that AFCA is unable to make a determination because of the limitations in AFCA's Rules, for example, in respect of decisions to refuse insurance cover (Rule C.1.4(d)) and decisions to offer life insurance on non-standard terms (Rule C.1.4(b)).

In PIAC's view, it is in consumer interests to ensure complaint processes are accessible and clear. Given AFCA is the most obvious forum for consumers for complaints about insurance, we suggest it would be appropriate for AFCA to be able to deal with complaints about unlawful discrimination by insurers. However, if AFCA is accepting discrimination complaints, it is important that AFCA's jurisdiction to do so is clear, and its relationship with other anti-discrimination bodies like the AHRC is made explicit.

The A-GLIMMER Report's recommendation included a suggestion that the DDA or financial services legislation be amended to provide a positive duty on insurers not to discriminate. Anti-discrimination legislation in Victoria already includes a positive duty to eliminate discrimination, applicable to insurers, which enabled VEOHRC in its 2018 investigation into travel insurance to interrogate insurers and make strong recommendations. PIAC would welcome a positive duty on financial service providers to eliminate discrimination in the DDA alongside greater inquiry and enforcement powers for the AHRC, or mandating a clear a role for ASIC in enforcement.

PIAC considers that ASIC should play a greater role in oversight and enforcement of insurer compliance with their legal obligations not to unlawfully discriminate in the provision of services. To the extent ASIC does not already have powers to investigate and impose penalties on insurers for breach of these laws, we suggest amendments to ASIC's oversight powers should be considered – in relation to any new prohibition on using genetic test results but also more broadly in respect of breach of anti-discrimination laws.

Recommendation 2 – Positive duty, oversight and enforcement

A positive duty to eliminate discrimination as far as possible in the provision of services should be introduced into the DDA.

The AHRC should be given additional powers and resources to oversee the positive duty and compliance with the DDA, including to investigate compliance by insurers with the insurance exception and any new genetic test results prohibition.

AFCA should be empowered to deal with complaints about insurer compliance with any new genetic test results prohibition. If AFCA is empowered to deal with complaints about discrimination, further consideration should be given to the relationship between AFCA, the AHRC and other discrimination complaint handling bodies.

ASIC should play a greater role in oversight and enforcement of insurer compliance with their legal obligations not to unlawfully discriminate in the provision of services and legislative or regulatory changes to enable this should be considered.

5. Impact of genetic testing discrimination on intersex people

As noted in the introduction, genetic testing in insurance presents particular issues for people with innate variations of sex characteristics (also called intersex people), including the very real risk of discrimination against them. These issues are outlined in detail in the submission to this inquiry by Intersex Human Rights Australia (IHRA). For example, they submit that:³

People with innate variations of sex characteristics applying for life insurance mostly do so knowing that they will be subject to adverse individual risk rating. This is because nearly all cases will not be possible to fulfil the insured's duty to honest disclosure without revealing the applicant's diagnostic status. Certainly, by the time the intersex applicant has completed a life insurance application form, they will be aware that they are providing information which can, and probably will be used by the insurer to justify an adverse risk assessment. Research on a variety of intersex variations... may provide the life insurance provider with evidence of increased risk that can be used to justify a higher premium charge. This alone may be sufficient to deter the applicant from proceeding with the application.

And further note that:⁴

intersex applicants for life insurance products are discriminated against by insurers. Intersex individuals are subject to higher life insurance costs whenever they are identified by the insurer as having intersex status, including where such identification is not based on genetic test results known to the insurer.

IHRA also observes that the questions mandated by life insurance providers, asking intrusive questions in relation to sex characteristics, may themselves be discriminatory:⁵

IHRA notes the care taken by life insurance companies offering products in Australia to avoid including in their application forms any questions relating to race or sexuality. It is submitted that the intimate nature of questions in life insurance application forms regarding the 'health' of the applicant's

³ Intersex Human Rights Australia, *Submission on use of genetic testing results in insurance underwriting*, 17 January 2024, p8 available at: <https://ihra.org.au/40726/submission-genetic-testing-results/>

⁴ Ibid, p9

⁵ Ibid, p10.

reproductive organs represents de-facto inclusion of a question requiring applicants with innate variations of sex characteristics to disclose their intersex status. Whether or not this represents a breach of section 27 of the *Sex Discrimination Act* remains for the courts to decide. Regardless, IHRA submits that such questions are experienced as intrusive and discriminatory by people with innate variations of sex characteristics, and in many cases may result in sufficient distress to deter the intersex applicant from proceeding with the application. In other cases, increased premium charges will be the deterrent. In either case, discrimination has been experienced.

On the basis of these various forms of discrimination, it is unsurprising that IHRA's position is to support moves towards community risk-related insurance (rather than individual risk), or for genetic discrimination to be made unlawful:⁶

This submission has argued that allowing (or even mandating) the provision of life insurance on a community risk-related basis enables insurers to avoid genetic discrimination against individual applicants. If such a solution is regarded as a 'step too far' for the life insurance sector, however, we call, as an alternative, for genetic discrimination to be made unlawful, including in the provision of insurance. Importantly, adopting this alternative legislative strategy would address the significant community concerns about genetic discrimination in life insurance in a number of recent studies.

The submission by IHRA and experiences of intersex people therefore reinforce the need, identified above in relation to PIAC's work in relation to mental health and insurance discrimination, for strong legislative action in this area.

⁶ Intersex Human Rights Australia, *Submission on use of genetic testing results in insurance underwriting*, 17 January 2024, p10 available at: <https://ihra.org.au/40726/submission-genetic-testing-results/>