



Australian  
Human Rights  
Commission

# Use of genetic testing results in life insurance underwriting

Australian Human Rights Commission

Submission to the Australian Treasury

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# 1 Introduction

The Australian Human Rights Commission (Commission) welcomes the opportunity to provide a written submission in response to the Australian Government Treasury (Treasury) Consultation Paper on the use of genetic testing results in life insurance underwriting.<sup>1</sup> This is an area that has potentially significant human rights implications and must be considered and addressed in the context of international human rights law and obligations.

The Commission is Australia's National Human Rights Institution, established under the *Australian Human Rights Commission Act 1986* (Cth) (AHRC Act),<sup>2</sup> with recognised independent status and roles in United Nations human rights fora. The Commission's operations are determined independently of the government through the President and Commissioners.

The Commission provides independent and impartial services to promote and protect human rights and fundamental freedoms in Australia. The Commission undertakes a range of policy development and research tasks that aim to promote compliance with Australia's human rights obligations, while also investigating and conciliating complaints of unlawful discrimination and breaches of human rights. The Commission also has a role in promoting an understanding and acceptance of human rights in Australia.<sup>3</sup>

The *Disability Discrimination Act 1992* (Cth) prohibits discrimination on the basis of genetic predispositions to disability.<sup>4</sup> The use of genetic testing in life insurance underwriting raises significant concerns regarding life insurance policies and practices which may unfairly discriminate on the basis of a disability (or disabilities) that may exist, presently or in the future (due to a genetic predisposition), referred to as 'genetic discrimination'.

It is vital that the regulatory environment evolves with ongoing advances in medical/health technology and genetic research by protecting human rights and preventing discrimination and unethical practices. Laws and regulations must continue to meet community expectations and maintain public trust in relation to the use of information. The issue is likely to impact a large proportion of the population into the future, as genetic technology develops and becomes more readily available as both a diagnostic and preventative health tool. Genetic discrimination needs to be given appropriate consideration as a discrete area of discrimination on the basis of disability.

The Commission acknowledges that the issue of genetic discrimination raises intersecting regulatory and policy considerations across discrimination law, financial services law and health policy. The Australian Government should

consider all three of these areas in determining an appropriate and rights-based approach, giving significant weight to the broader public interest in relation to genetic testing, genetic privacy and genetic discrimination.

The relationships and complexities across the regulatory environment need to be adequately considered to ensure any policy or legislative decision is enforceable in both a discrimination and financial services context, with meaningful and appropriate recourse available.

In response to concerns raised by the Parliamentary Joint Committee on Corporations and Financial Services (PJCCFS) in its 2018 Inquiry into the life insurance industry,<sup>5</sup> the Commission acknowledges the attempt to address genetic discrimination and levels of participation in genetic testing via the Financial Services Council Moratorium on Genetic Tests in Life Insurance (Moratorium).<sup>6</sup> However, the Commission shares the concerns raised in the *Final Stakeholder Report* of the Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response (A-GLIMMER) project (A-GLIMMER Report),<sup>7</sup> regarding the appropriateness of the Moratorium and self-regulatory model. The PJCCFS was clear on the need to monitor the evolving landscape of genetics and genetic testing to determine whether other forms of regulation or legislation are required.<sup>8</sup>

The Commission supports the need to implement a more robust regulatory framework to prevent genetic discrimination in the life insurance industry in all circumstances.

This submission sets out the Commission's position in relation to the findings and recommendations made in the A-GLIMMER Report, alongside the human rights and discrimination perspectives. The Commission makes recommendations in relation to both the regulatory framework and a rights-based approach, highlighting broader human rights implications of risk-rated insurance models requiring further consideration.

## 2 Recommendations

The Commission recommends:

**Recommendation 1: The Australian Government should review section 46 of the *Disability Discrimination Act 1992 (Cth)*, taking into consideration:**

- **Australia's international human rights obligations, giving specific regard to United Nations *Convention on the Rights of Persons with Disabilities***

- **the implications of risk-rated insurance on disability discrimination protections.**

**Recommendation 2: The Australian Government should prioritise reforms to the *Privacy Act 1988* (Cth) to provide certainty for insurance organisations who collect and handle sensitive information.**

**Recommendation 3: The Australian Government should legislate a prohibition on the use of adverse genetic testing results by life insurers, and other types of risk-rated insurance.**

**Recommendation 4: Alongside a prohibition on genetic discrimination in the *Disability Discrimination Act 1992* (Cth), the Australian Government should introduce an equivalent prohibition and/or positive duty in the appropriate financial services legislation, subject to enforcement actions by the relevant financial services regulator.**

**Recommendation 5: The Australian Government should ensure the Australian Human Rights Commission has adequate resourcing to promote, educate and support relevant stakeholders to understand and meet any new legal obligations introduced under the *Disability Discrimination Act 1992* (Cth) if legislative change is made.**

### **3 International Human Rights Framework**

Australia has ratified a range of international human rights instruments that set out clear rights and obligations relating to people with disability, most notably the *Convention on the Rights of Persons with Disabilities* (CRPD). Obligations contained in international treaties are binding as a matter of international law, but not as a matter of domestic law until their provisions are incorporated into domestic legislation.<sup>9</sup>

The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) is the principal binding international human rights instrument that explicitly addresses disability. Australia ratified the CRPD in 2008, accepting the obligation to protect and promote the rights of people with disability in domestic laws and policies.

The purpose of the CRPD is to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disability and to promote respect for their inherent dignity’.<sup>10</sup> This includes rights to non-discrimination and equality before the law, and health.<sup>11</sup> The realisation of these rights inherently includes individuals with existing disability and those who may acquire disability in the future.

Australia is bound by international human rights law, and as a State Party to the CRPD, to ensure that the fundamental human rights and freedoms of all people with disability are upheld and protected,<sup>12</sup> by taking ‘all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities ... [and] to eliminate discrimination on the basis of disability by any person, organisation or private enterprise’.<sup>13</sup>

Article 3 of the CRPD sets out the general principles, all of which apply to the formulation and implementation of legislation, policies, and services. The following are particularly relevant regarding the issue of genetic testing and life insurance:

- non-discrimination (b)
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (d)
- equality of opportunity (e)<sup>14</sup>

The human rights model of disability espoused in the CRPD and the principles in article 3 are particularly important in the context of this consultation and should guide the Government’s response and decision-making, as explained in section 5 below.

### **3.1 Non-discrimination**

Article 5 of the CRPD expands on the protections and enforceability of the right to equality and non-discrimination established under international law to explicitly address the experience and rights of people with disability, redefined in the context the human rights model of disability which affirms that impairments must not be taken as legitimate grounds for the denial or restriction of human rights.<sup>15</sup> This right is grounded in the concept of transformative equality and is both a right and central principle of the CRPD. Specifically, article 5 obliges State Parties to ‘prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds’.<sup>16</sup>

### **3.2 Right to privacy**

Article 17 of the International Covenant on Civil and Political Rights (ICCPR) protects against arbitrary or unlawful interferences with privacy.<sup>17</sup> The right to privacy relates to the collection, storage, security, use, disclosure or publication of personal information.

State Parties must set up legal systems to authorise such interferences, in line with human rights principles and obligations.<sup>18</sup> Importantly, 'public authorities should only be able to call for such information relating to an individual's private life the knowledge of which is essential in the interests of society'.<sup>19</sup>

The right to privacy is further elaborated in CRPD Article 22.

### **3.3 Right to health**

The right to the highest attainable standard of physical and mental health is a universal human right protected under the International Covenant on Economic, Social and Cultural Rights (ICESCR), and in other thematic treaties. This right is interdependent with other human rights, and with the social determinants of health which contribute to its realisation.

The right to health contains both freedoms (e.g. to be free from non-consensual treatments) and entitlements (e.g. to have access to health care and protection). Importantly, the right to health includes an obligation on State Parties to prohibit discrimination on all grounds in relation to access to health care and other determinants of health. Non-discrimination in the context of the right to health also imposes an obligation on State Parties to recognise and respond to the specific health needs of different groups.

Article 25 of the CRPD outlines that people with disability 'have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability'.<sup>20</sup> Notably, article 25 obliges State Parties to:

Prohibit discrimination against persons with disabilities in the provision of health insurance, and **life insurance** where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner.<sup>21</sup>

Article 25 of the CRPD provides a framework to critically analyse insurance practices in Australia, alongside the broader conceptual underpinnings of the CRPD.

The CRPD is informed by the structure and content of the right to health in international law<sup>22</sup> and includes the need to consider the interdependent nature of this right with other key rights. The CRPD has a 'clear emphasis on social inclusion and equal access to the social, environmental and material determinants of health'.<sup>23</sup> Commentators have highlighted that, in most cases, the most significant barrier to the achievement of health is access to appropriate health care, rather than the presence of an impairment or access to impairment-related care.<sup>24</sup>



The obligation to prohibit discrimination on the basis of disability contained in article 25(e) explicitly targets insurance practices that treat people with disability unfavourably.<sup>25</sup> The call for provision of insurance to people with HIV/AIDS is an example of a human rights campaign that challenged discrimination in the use of actuarial data.<sup>26</sup>

Insurance policies that deny people with disability life insurance or discriminate against them in the provision of life insurance, including any federal law that allows this, are contrary to the obligations and rights under the CRPD.

Additionally, policies or laws which disincentivise people to seek health services, such as genetic testing, conflict with article 25 of the CRPD and article 12 of the ICESCR, by impeding the right to the highest attainable standard of health for fear of discrimination.

### **3.4 Non-binding instruments**

The UNESCO *Universal Declaration on the Human Genome and Human Rights* is a non-binding international legal instrument, that is indicative of the international perspective on both the prospects for progress brought about by scientific advances. The Declaration emphasises the need to respect human dignity and prohibit all forms of discrimination based on genetic characteristics.<sup>27</sup>

The United Nations *Guiding Principles on Business and Human Rights* are a global standard and internationally accepted framework to guide the practices of businesses to align with human rights obligations.

## **4 Australian legislative framework**

### **4.1 Disability Discrimination Act 1992 (Cth)**

The Disability Discrimination Act provides protection for everyone in Australia against discrimination on the basis of disability. It aims to eliminate discrimination against people with disability, promote community acceptance of the principle that people with disability have the same fundamental rights as all members of the community, and ensure that people with disability have the same rights to equality before the law as other people in the community.<sup>28</sup>

The definition of disability under the Disability Discrimination Act is broadly interpreted to include temporary or permanent disability, and physical, intellectual, sensory, neurological, learning and psychosocial disabilities, diseases or illnesses, physical disfigurement, medical conditions and work-related injuries. The Disability Discrimination Act protects against discrimination on the basis of a

disability (or disabilities) that presently exist, previously existed, may exist in the future (including because of a genetic predisposition to that disability) or a disability that is imputed to a person.<sup>29</sup> This definition could be interpreted to protect people against genetic discrimination.

The Disability Discrimination Act makes it unlawful to discriminate against a person in defined areas of public life, including employment, education, accessing public places, and access to goods and services.

The Disability Discrimination Act defines discrimination on the grounds of disability as:

- ‘direct discrimination’ in which a person with disability is treated less favourably than a person without disability in circumstances which are ‘not materially different’<sup>30</sup>
- ‘indirect discrimination’ in which a condition or requirement that is the same for everyone disadvantages a person with disability, and is not reasonable in the circumstances.<sup>31</sup>

The Disability Discrimination Act has provisions that allow for exemptions from the Act across a range of areas, including superannuation and insurance.

The Commission has published guidelines to assist providers of insurance to comply with the Disability Discrimination Act in making decisions in individual cases and in developing broader policies and procedures. The Guidelines are not legally binding but aim to provide guidance as to when discrimination by insurance providers may be lawful or unlawful.<sup>32</sup>

(a) Exemption – superannuation and insurance

The Disability Discrimination Act generally makes it unlawful to discriminate against a person because of disability when providing life insurance. There is, however, a partial exemption relating to insurance and superannuation at section 46 which provides that discrimination in relation to the provision of insurance or superannuation by either refusing to offer a product, or in respect of the terms or conditions on which the product is offered or may be obtained, is not unlawful discrimination if the discrimination:

- is based upon actuarial or statistical data on which it is reasonable to rely, and the discrimination is reasonable having regard to the matter of the data and other relevant factors<sup>33</sup> (the ‘data limb’); 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<sup>34</sup> (the ‘no data limb’).

These limbs are sequential. The data limb must be considered before the no data limb.<sup>35</sup> An insurer or superannuation provider cannot argue that the no data limb of the exemption applies if data is available, or can be reasonably obtainable, that meets the requirements of the data limb.<sup>36</sup> If such data is available, an insurer or superannuation provider cannot ignore it.<sup>37</sup>

Section 46 provides that so long as a life insurance provider can satisfy these requirements, any decision to refuse to provide a life insurance policy to a person with disability, or to charge higher premiums based on their disability, is exempt from the core anti-discrimination provisions of the Disability Discrimination Act.

In its *Free & Equal Position Paper: Reform agenda for federal discrimination law*, the Commission highlights stakeholder concerns regarding the inappropriate use of the exemption under section 46 of the Disability Discrimination Act by insurance providers, including a lack of transparency in the use of actuarial and statistical data and disclosure of the information used to inform decisions.<sup>38</sup> The Commission identified insurance policies and section 46 of the Disability Discrimination Act as an exemption warranting particular scrutiny in any review process.

**Recommendation 1: The Australian Government should review section 46 of the *Disability Discrimination Act 1992 (Cth)*, taking into consideration:**

- **Australia’s international human rights obligations, giving specific regard to United Nations *Convention on the Rights of Persons with Disabilities***
- **the implications of risk-rated insurance on disability discrimination protections.**

(b) Moratorium on Genetic Tests in Life Insurance

In 2019, following the 2018 PJCCFS Inquiry, a partial Moratorium was introduced requiring applicants to disclose genetic test results only for policies above certain limits. The current Moratorium prohibits the use of genetic information for life insurance policy decisions up to the following thresholds:

- \$500,000 of lump sum death cover
- \$500,000 of total permanent disability cover

- \$200,000 of trauma and/or critical illness cover
- \$4,000 a month of any combination of income protection, salary continuance or business expenses cover.

In these cases, it would be a breach of the Moratorium to use genetic information to refuse a policy or charge higher premiums, regardless of actuarial or statistical data, or any other relevant factors, up to the specified policy thresholds. The Moratorium does not provide legal protection against unlawful genetic discrimination and is industry self-regulated.

The A-GLIMMER report noted that the Moratorium's financial limits were too low and not reflective of the average Australian salary or mortgage.<sup>39</sup> Treasury's Consultation Paper also demonstrates that these limits are considerably below the average sum insured of individual policies.<sup>40</sup> This raises concerns about the adequacy of existing limits to protect against genetic discrimination.

(c) Complaints made under the Disability Discrimination Act

The complaints mechanism available under the AHRC Act remains the only legal avenue to monitor compliance with the Disability Discrimination Act. It is reliant on a person alleging disability discrimination lodging a complaint with the Commission.

The Disability Discrimination Act receives the highest number of complaints compared to other federal (or Commonwealth) Discrimination Acts; in the 2022–2023 reporting year, 46% of all complaints received by the Commission were lodged under the Disability Discrimination Act. This statistic highlights the extent and prevalence of disability discrimination in Australia, reflective of ongoing stigmatisation, barriers and poor community understanding of the rights of people with disability.

The exemption under section 46 of the Disability Discrimination Act adds a layer of complexity, requiring an understanding of how the exemption applies in practice and what may constitute discrimination in the context of risk-rated insurance. This, along with the Moratorium, may deter people from making a complaint to the Commission and influence the lack of complaints data relating to genetic discrimination in insurance. Additionally, the Moratorium provides an alternative dispute/complaints pathway via the Financial Services Sector for people who allege insurers are requesting genetic information in a way that is contrary to the standards in the Moratorium. The main form of disability discrimination in insurance raised through the Commission complaints pathway is in relation to blanket exceptions applied to certain mental health conditions.

It should be specified that the Commission's complaints data is not a comprehensive representation of the issues because it does not account for complaints lodged directly with life insurance providers, or with other regulatory bodies (such as the Australian Financial Complaints Authority, the Australian Securities and Investments Commission, and state-and territory-based Human Rights Commissions). The Commission does not have visibility of complaints made to other agencies, and therefore is unaware of alternative avenues being pursued by aggrieved persons.

The complaints-handling model in federal discrimination law is a hybrid Alternative Dispute Resolution (ADR) model, based on conciliation of individual complaints. Aggrieved persons who allege discrimination on the basis of disability in insurance can lodge a complaint with the Commission and if accepted, the matter will proceed to conciliation. If a settlement cannot be reached through conciliation, the aggrieved person can institute civil proceedings in the Federal Circuit and Family Court or the Federal Court and seek a range of enforceable remedies, including damages.

The Commission notes that the complaint process can be lengthy and requires individuals to invest a significant amount of effort and resources. Individuals must also first be aware of the requirements and protections that exist under the Disability Discrimination Act to know that they can lodge a complaint. Due to these reasons, people may not lodge or pursue complaints with the Commission.

The A-GLIMMER Report demonstrates that there is a general lack of awareness of the Moratorium as well as lack of adherence to its terms by insurance providers, highlighting consumers' ongoing difficulties in obtaining life insurance products and broader stakeholder concern about genetic discrimination.<sup>41</sup>

In its Free & Equal Position Paper – *A reform agenda for federal discrimination laws* – the Commission proposes a responsive regulatory framework to promote and enforce compliance with federal discrimination law, and to enhance complaints processes, including through the introduction of a positive duty (which differs from the one proposed in Treasury's Consultation Paper, as explained in section 6.2).<sup>42</sup>

## **4.2 Privacy Act**

The *Privacy Act 1988* (Cth) is the principal piece of legislation protecting the human right to privacy in Australia. Under the Privacy Act, genetic information is included in the definition of 'sensitive information' which attracts additional privacy protections.<sup>43</sup>

Genetic information is stored within an individual's DNA, a widely accepted form of biometric information that can be used to both identify an individual and gain insights about them. Biometric information is especially sensitive information because it is unchangeable and unique to the individual. Where an individual's biometric information revealed, it can breach their human right to privacy.<sup>44</sup>

The Privacy Act is currently being modernised,<sup>45</sup> with several proposed changes having been 'agreed to' or 'agreed in-principle' by the Australian Government in September 2023. Changes will have implications for how sensitive information is defined and dealt with under the Act.<sup>46</sup>

The Commission welcomes the progress that is being made towards comprehensive reform in this area, however notes that the Government itself recognises there is still significant work to be done.<sup>47</sup> Until these reforms have been finalised, the Act remains outdated. This creates difficulties for many industries, including insurance organisations, as there will continue to be uncertainty about their obligations when collecting and handling sensitive information (such as genetic information).

**Recommendation 2: The Australian Government should prioritise reforms to the *Privacy Act 1988* (Cth) to provide certainty for insurance organisations who collect and handle sensitive information.**

### **4.3 A Human Rights Act for Australia**

Currently, Australia does not adequately protect human rights and is without a comprehensive Human Rights Framework or federal Human Rights Act. A consequence of this is the lack of accountability of governments to ensure that inherent and fundamental human rights of all people are explicitly considered and embedded in law and policy. This creates gaps in the way Australia respects, protects, and fulfils its human rights obligations.

The Commission proposes a model for a Human Rights Act and Framework in Australia, in its final *Free and Equal* report on *Revitalising Australia's Commitment to Human Rights*,<sup>48</sup> informed by extensive consultation and research.

A national Human Rights Act and Framework would introduce, among other measures, a more robust assessment of the compatibility of legislation and policies, such as those within the Financial Services Sector, to be scrutinised in the context of domestic and international human rights protections and would ensure that there are consequences for not adequately considering human rights.

## 5 A human rights approach

### 5.1 Human rights model of disability

The CRPD represents a fundamental shift in how disability should be viewed and understood, applying universal human rights principles to State obligations to respect, protect and fulfil the specific rights of people with disability. The CRPD builds on the social model of disability,<sup>49</sup> by establishing a human rights model that recognises people with disability as rights-holders who can and should determine the course of their lives to the same extent as any member of society, rather than being seen or treated as ‘objects’ of charity, medical treatment and social protection.<sup>50</sup> The human rights model embraces disability as a natural part of human diversity, defining limitations imposed by social and physical environments as infringements on people's rights.<sup>51</sup>

Article 1 of the CRPD describes disability as including ‘those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.<sup>52</sup> Without diminishing the impact of impairment, the human rights model of disability recognises that the removal of these ‘disabling’ barriers enables people with disability to participate in their communities and live fully and effectively.

The social and human rights models of disability are complementary in nature and inform a rights-based and person-centred approach to policy development and implementation for people with disability. Legal frameworks and policies aimed at eliminating disability discrimination (inclusive of genetic discrimination) should reflect the human rights model to work towards the progressive realisation of Australia’s obligations as a State Party to the CRPD.

While the CRPD does not provide commentary or specific reference to genetic discrimination, it prohibits all discrimination on the *basis* of disability which has been interpreted to include genetic factors that may predispose a person to disability and perceived disability.<sup>53</sup> The Disability Discrimination Act provides explicit protection against genetic discrimination, and discrimination on the basis of imputed disability, in its definition of disability.<sup>54</sup>

Approximately 4.4 million people in Australia (or 18% of the population) have some form of disability.<sup>55</sup> However, this figure is based on a narrow definition of disability and does not account for all people with chronic medical conditions, an estimated 50% of the general population,<sup>56</sup> nor Australians with psychosocial disability.<sup>57</sup> Anyone can acquire disability or a health condition throughout their lives or face a fatal situation or condition leading to impairment. People are more

likely to acquire disability as they age. Therefore, it is reasonable to claim that disability affects, or will affect, the lives of far more than 4.4 million people in Australia.

Preventing people with disability, or those with a known genetic predisposition to disability or illness, from accessing life insurance on an equal basis as others perpetuates the medicalised view that disability is 'abnormal' and that the lives of people with disability are less valuable. Providing lesser financial protection for people with disability and their families further reinforces social and economic inequities between people with, and without, disability. Instead, the human rights model underpinning the CRPD 'embraces the assumption that the lives of people with disabilities have equal value and dignity and on that basis are entitled to the equal allocation of resources'.<sup>58</sup>

The human rights principles of 'legitimate', 'objective' and 'reasonable' – as they apply to differential treatment in the context of discrimination and to limitations on rights – are well established under international human rights law.<sup>59</sup> The concept of 'reasonableness' is intrinsically linked to the values and perceptions of the society in which it is being applied. This includes consideration as to whether the policies or procedures serve or compete with public interest.

With regard to insurance, the removal of barriers, investment decisions, and access to preventative healthcare, coupled with addressing the social determinants of health,<sup>60</sup> can result in better health and life outcomes for people with disability or those with genetic predispositions.

The Commission encourages insurers to move away from a deficit view of disability based on cost or risk assumptions, and instead to view disability through the lens of a human rights model and as a measure of diversity. Basing policies on a preconception of costs related to 'normal' or 'healthy' disadvantages anyone who strays from this artificial norm.

## **5.2 Community-rated versus risk-rated insurance**

Insurance is predicated on the distribution or 'pooling' of risk across a broad range of people within the community through the purchase of insurance products (by way of premiums), to mitigate potential risk. This allows for risk to be transferred from an individual to the insurer, indemnifying them against future events that may cause loss.<sup>61</sup> There are three insurance categories in Australia: health, life, and general insurance.

Health insurance, inclusive of both public and private health insurance schemes, is based on community-rated models of insurance. This means that risk is shared across the pool of members, and all individuals pay the same premiums for the



same product or coverage, without discrimination. Under the *Private Health Insurance Act 2007* (Cth), when setting premiums or paying benefits, private health insurers cannot discriminate on the basis of an individual's health status, use of health services, race, gender, sexuality, or claiming history.<sup>62</sup> Importantly, this guarantees the ability to seek or renew a policy without fear of exclusion or denial of coverage.

Community rating ensures that people who may have a higher level of claims history, or those who may be more likely to make a claim due to existing or predicted health conditions or disability, are not disadvantaged or required to pay higher premiums. The principles of community rating prevent health insurers from using health or genetic information to ascertain individual risk. However, generalised health information may be used to determine the overall premiums charged to sustain the pool.<sup>63</sup>

In contrast, life insurance is based on a risk-rated model, which takes into account the individual characteristics of applicants when assessing the risk (i.e. the likelihood of making a claim) that they bring to the insurance pool. The assessment of risk, referred to as the underwriting process, requires that insurers have access to all relevant information about the individual in question in order to assess the risk. This may include health information, genetic or genomic test results, lifestyle factors, and family history (including protective factors in the context of genetic information).<sup>64</sup> Under the *Insurance Contracts Act 1984* (Cth), applicants have a duty to disclose relevant information to aid in the risk assessment.<sup>65</sup> Based on individual risk assessment, life insurers can choose to charge higher premiums, set certain terms and conditions in the policy, or deny access to certain products. The nature of risk-rated insurance allows for the differential and unequal treatment of people with disability accessing life insurance and their ability to protect and support themselves and/or their families in this context.

The experience of disability is diverse. Blanket exclusions or risk-rating based on genetic information or disability status, ultimately considers worst case scenario, losing the nuance of individual experiences and diminishing the importance of preventative health care. While actuarial data and statistics may provide a generalised measure of risk, it is not always an accurate representation of individual risk as there are many other variables which positively or negatively influence a person's health and life outcomes, some beyond individual control or awareness. The legitimacy and proportionality of blanket exclusions, or increased premiums, on the basis of disability or genetic information is also questionable, particularly where there is little evidence available, or provided, to justify this.

The A-GLIMMER Report highlights that the use of genetic or genomic testing information in life insurance underwriting acts as a barrier to people undertaking genetic testing or participating in research, due to concerns about the impact it may have on their access to life insurance.<sup>66</sup> There can be a significant impact on the health of individuals, such as missing out on preventative and protective health care. Risk-rating in insurance can also disincentivise individuals with family history, known genetic predispositions and/or existing disability from seeking out life insurance cover in the first place or to update their policies, denying them equal opportunity to financial protection in the event of loss of income or life.

Additionally, it may not be possible to accurately assess, or price risk based on genetic information alone, due to variability in outcomes. Dr Simon Longstaff notes that the use of genetic testing to determine insurance risk must be weighted more heavily in the balance of public interest rather than the commercial interest of insurers.<sup>67</sup> In this context, Dr Longstaff highlights that there is a strong public interest to ensure people have access to medical diagnoses and to preventative medicine, from both the individual and public health perspectives, to avoid more adverse health consequences in the future.

Some insurers fear 'adverse selection', an imbalance caused by the purchase of insurance by individuals with higher risk ratings, leading to higher pay outs by insurers and unsustainability of the insurance sector. Commentary exists regarding the risk of adverse selection occurring as a result of restricting the use of genetic and potentially other types of information under a risk-rated model. The Commission notes that both the A-GLIMMER Report and the Treasury Consultation Paper point to a lack of convincing evidence supporting these claims.<sup>68</sup> Additionally, purchasing life insurance is influenced by someone's financial circumstances, and it is unlikely that someone would select a policy that greatly surpasses their financial means based solely on their health status.

From a human rights perspective, the risk-rated model raises broader human rights concerns for people with disability, particularly the rights to non-discrimination, privacy and the right to health, and is likely in conflict with the human rights model of disability. Charging different premiums based on a person's genetic predisposition to illness or disease and/or disadvantaging people who have sought genetic testing, without necessarily having access to the same information from others for equal comparison, means that those individuals carry the balance of risk for others who may have higher, but unknown, genetic risk factors or likelihood of illness.

While beyond the scope of this consultation, the Commission recognises that this topic raises far-reaching questions regarding the acceptance of other forms of

discrimination in risk-rated insurance. Prohibiting the use of genetic information may still allow diagnostic information to be used by insurers, as there would then be an 'existing condition', subject to different provisions and disclosure requirements. It is not consistent to discriminate on the basis of disability in some instances but not others, particularly when the existence of impairment is being justified as a legitimate ground for the denial or restriction of human rights and equal opportunity.

The Commission encourages further consideration of the appropriateness of risk-rated insurance models compared to community-rated models in the context of Australia's international human rights obligations, particularly the obligation to prevent and eliminate discrimination on the basis of disability.

## **6 Regulation of genetic discrimination in life insurance underwriting**

### **6.1 Commentary on the A-GLIMMER Report**

The A-GLIMMER Report is the outcome of a project of the same name, led by experts in the fields of genetics and funded by the Australian Government, to independently investigate the effectiveness of the Moratorium. The Project sought a wide variety of stakeholder views to assist in evaluating the impact of the Moratorium across four different stakeholder groups: patients and consumers; health professionals; the financial industry; and the genetic research community.

The project found that the Moratorium is inadequate to address and prevent genetic discrimination in life insurance, and that self-regulation of the financial service industry is an ineffective regulatory model to address genetic discrimination. Instead, the A-GLIMMER report recommends that a legislated model of prohibition should replace the Moratorium.

The Commission acknowledges the expertise of the project team, the independence of the project, and the compelling evidence base including stakeholder experiences and views. The Commission broadly agrees with the recommendations in the A-GLIMMER report, including the role of the Commission to promote, educate, and support individuals and all relevant stakeholders to understand and meet any new legal obligations under the Disability Discrimination Act.

The A-GLIMMER report included two recommendations:

1. The Australian Government amend the *Disability Discrimination Act 1992* (Cth) ('the Act') to prohibit insurers from using genetic or genomic test results to discriminate between applicants for risk-rated insurance, and consider amendments to the regulation of financial services to ensure insurers are subject to a positive duty to not discriminate.
2. The Australian Government allocate responsibility and appropriate resources to the Australian Human Rights Commission ('AHRC') to enforce, promote, educate and support individuals and all relevant stakeholders to understand and meet the new legal obligations under the Act. The AHRC should consult with a range of genetics and genomics experts and stakeholders to achieve this goal.

There are two concepts embedded within the first recommendation: a prohibition on genetic discrimination, and the introduction of a positive duty.

The second recommendation deals with the kinds of functions that should be allocated to the Commission. Most of the proposed functions are consistent with the Commission's existing statutory functions, with the exception of the proposal that the Commission have an 'enforcement' function. This would represent a significant change to the operations of the Commission in relation to discrimination occurring in the insurance industry.

Each of these issues are considered separately.

## **6.2 Prohibition on genetic discrimination**

The Commission strongly endorses a legislated ban on the use of adverse genetic testing results by life insurers and in risk-rated insurance more broadly.

The Commission supports the A-GLIMMER recommendation that the Disability Discrimination Act prohibit insurers from using genetic or genomic test results to discriminate between applicants for risk-rated insurance. As shown in the A-GLIMMER Report, industry self-regulation is inadequate to address the problem of genetic discrimination.<sup>69</sup>

Further, research annexed to the A-GLIMMER Report found, based on an analysis of similar regimes in comparable jurisdictions, that there was no strong evidence that a legislative prohibition would have significant impact on 'adverse selection' or result in the market becoming unsustainable.<sup>70</sup>

The Commission strongly endorses a total legislated ban on the use of adverse genetic testing results by life insurers. A partial ban would still allow for discrimination in some cases on the basis of disability type and was found to be insufficient by A-GLIMMER, and therefore, is not supported by the Commission.

The prohibition could be achieved either through an amendment to the existing insurance exemption in section 46 of the Disability Discrimination Act or through the introduction of a new prohibition in the Disability Discrimination Act. The most appropriate mechanism should be considered as part of a more thorough review of section 46 (and of all existing exemptions under the Disability Discrimination Act, as previously recommended by the Commission).<sup>71</sup>

**Recommendation 3: The Australian Government should legislate a prohibition on the use of adverse genetic testing results by life insurers, and other types of risk-rated insurance.**

### 6.3 Positive duty

The second aspect of recommendation 1 in the A-GLIMMER Report is that the Australian Government ‘consider amendments to the regulation of financial services to ensure insurers are subject to a positive duty to not discriminate’. However, it is not clear what is meant by a ‘positive duty’ in this context.

As noted in the previous section, the Commission supports a direct prohibition on genetic discrimination. This would amount to a duty on insurers not to engage in discrimination on this basis. Individuals would also be able to bring a complaint alleging disability discrimination to the Commission under its existing complaints mechanisms.

The language of ‘positive duty’ has been used recently in relation to the new section 47C of the *Sex Discrimination Act 1984* (Cth) (Sex Discrimination Act). Section 47C imposes a ‘positive duty’ on an employer or a person conducting a business or undertaking (PCBU), to ‘take reasonable and proportionate measures to eliminate, as far as possible’ five kinds of discriminatory or otherwise prohibited conduct.<sup>72</sup> The ‘duty holder’ is the employer or PCBU, and the positive duty is imposed on them to take measures to eliminate certain prohibited conduct, including conduct engaged in by their employees, workers or agents, or conduct directed to their employees or workers by others. In a policy sense, it is reasonable for employers and PCBUs to have this positive duty to create workplaces that are free of this kind of prohibited conduct because of their ability to control the conduct of their employees and agents, and their ability to exercise a degree of control over the workplace more generally.

In December 2023, the Commission acquired new enforcement powers under the AHRC Act to ‘ensure compliance’ with the positive duty in section 47C of the Sex Discrimination Act, including by conducting inquiries, issuing compliance notices, seeking enforcement of compliance notices in court, or accepting

enforceable undertakings. There are no financial penalties for breach of the positive duty in s 47C of the Sex Discrimination Act.

The Commission supports the introduction of a broader 'positive duty' into the Disability Discrimination Act and other federal discrimination laws. In its 2021 report, *Free & Equal: A Reform Agenda for Federal Discrimination Law*, the Commission recommended the introduction of a positive duty on duty holders to take reasonable and proportionate measures to eliminate discrimination.<sup>73</sup> This aligns with the expectations of the United Nations *Guiding Principles on Business and Human Rights*,<sup>74</sup> and the final report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.<sup>75</sup> Importantly, a positive duty would bring a shift in culture from being complaints driven towards a more proactive and preventative model in businesses. The implementation of a positive duty would necessarily require procedures to be put in place, such as policies, training, compliance plans and auditing.

The positive duty proposed in the A-GLIMMER Report appears different in scope to the positive duty introduced in the Sex Discrimination Act, and that proposed by the Commission to be introduced in federal discrimination law. The A-GLIMMER Report does not clearly identify how the proposed positive duty in relation to the provision of insurance would operate, and how it would be different from the proposed prohibition directed to insurers, requiring them not to discriminate. It appears from the context of the report that the difference may only be in relation to how the prohibition is enforced. For example, the report says that:

While the [Disability Discrimination] Act provides a legal pathway for redress for discrimination by individuals, it does not ensure that insurers are subject to a positive duty not to discriminate which carries a penalty for breach.<sup>76</sup>

It appears that what is envisaged is a process pursuant to which a regulator can bring an action seeking to enforce the prohibition on discrimination (including by way of a financial penalty), regardless of whether or not there has been a complaint by an individual. The A-GLIMMER Report suggests that this function 'may be best placed within national financial services legislation or the regulation of financial services'.

The Commission considers that, in addition to a prohibition on genetic discrimination in the Disability Discrimination Act that can be the subject of a complaint by an individual to the Commission, there is merit in an equivalent prohibition being included in appropriate financial services legislation, which could be subject to enforcement action by an appropriate financial services regulator. This is likely to be more effective than seeking to give the Commission

a new enforcement role in what is a highly specific and technical area that extends beyond the Commission's usual realm of expertise.

This approach would introduce additional incentive and cause for the financial services sector to implement practices and policies to prevent life insurers requesting and using genetic information, and for the appropriate regulator to proactively monitor compliance, beyond complaints. For example, private health insurers are subject to the provisions under the Disability Discrimination Act to not discriminate on the basis of disability in the provision of health insurance products, as well as having industry specific obligations under the *Private Health Insurance Act 2007* (Cth).<sup>77</sup>

**Recommendation 4: Alongside a prohibition on genetic discrimination in the *Disability Discrimination Act 1992* (Cth), the Australian Government should introduce an equivalent prohibition and/or positive duty in the appropriate financial services legislation, subject to enforcement actions by the relevant financial services regulator.**

## 6.4 Functions to be allocated to the Commission

The Commission agrees with the A-GLIMMER Report that the Australian Government should allocate responsibility and appropriate resources to the Commission to promote, educate and support individuals and all relevant stakeholders to understand and meet the new legal obligations under the Disability Discrimination Act.

The proposed public awareness and education functions sit squarely within the Commission's existing functions under the Disability Discrimination Act. For example, the Commission currently has functions to:

- promote an understanding and acceptance of, and compliance with, the Disability Discrimination Act
- undertake research and educational programs, and other programs, on behalf of the Commonwealth for the purpose of promoting the objects of the Disability Discrimination Act
- prepare and publish guidelines for the avoidance of discrimination on the grounds of disability.<sup>78</sup>

The Commission is the appropriate body to carry out these functions in relation to the prohibition on genetic discrimination identified in section 6.2 above.

The Commission agrees that specific funding should be allocated to these public awareness, education and guidelines functions when the relevant legislative change is made.

**Recommendation 5: The Australian Government should ensure the Australian Human Rights Commission has adequate resourcing to promote, educate and support relevant stakeholders to understand and meet any new legal obligations introduced under the *Disability Discrimination Act 1992* (Cth) if legislative change is made.**

For the reasons identified above, the Commission considers that any separate enforcement role be given to an appropriate financial services regulator.

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<sup>1</sup> See Treasury (Cth), *Use of Genetic Testing Results in Life Insurance Underwriting* (Consultation Paper, November 2023) <[Use of genetic testing results in life insurance underwriting | Treasury.gov.au](https://www.treasury.gov.au)> ('*Treasury Consultation Paper*').

<sup>2</sup> *Australian Human Rights Commission Act 1986* (Cth) s 7.

<sup>3</sup> *Ibid* s 11(1)(g).

<sup>4</sup> *Disability Discrimination Act 1992* (Cth) s 4 (definition of 'disability' para (j)).

<sup>5</sup> See Parliamentary Joint Committee on Corporations and Financial Services, Parliament of Australia, *Inquiry into the life insurance industry* (Final Report, 27 March 2018) ('*Life insurance industry final report*') <[https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/Corporations\\_and\\_Financial\\_Services/LifeInsurance/Report](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report)>.

<sup>6</sup> See Financial Services Council, *FSC Standard No. 11: Moratorium on Genetic Tests in Life Insurance* (21 June 2019).

<sup>7</sup> Jane Tiller et al, *The A-GLIMMER (Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness and Response) Project: Final Stakeholder Report* (Monash University, 2023) <https://doi.org/10.26180/23564538> ('*A-GLIMMER Report*').

<sup>8</sup> *Life insurance industry final report* (n 5) 156.

<sup>9</sup> *Bradley v Commonwealth* (1973) 128 CLR 557 at 582 (Barwick CJ and Gibbs J); *Dietrich v The Queen* (1992) 177 CLR 292 at 305 (Mason CJ and McHugh J); *Minister for Immigration and Ethnic Affairs v Teoh* (1995) 183 CLR 273 at 286–287 (Mason CJ and Deane J) and 315 (McHugh J).

<sup>10</sup> *United Nations Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) art 1 ('*CRPD*').

<sup>11</sup> See *Ibid* arts 5, 25.

<sup>12</sup> See *ibid* art 4.

<sup>13</sup> *Ibid* art 4(1)(b) and (e).

<sup>14</sup> *Ibid* art 3.

<sup>15</sup> See *United Nations International Covenant on Civil and Political Rights*, GA 2200A (XXI) (23 March 1976, adopted 16 December 1966) arts, 2, 16, 26; *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, GA RES 2200A (XXI) (entered into force 3 January 1976) art 2(2); *United Nations Universal Declaration of Human Rights*, GA Res 217/A(III) (adopted 10 December 1948) arts 1, 2, 6, 7; UN Human Rights Committee, *CCPR Comment No. 18: Non-discrimination*, 37<sup>th</sup> sess, UN DOC HRI/GEN/1/Rev.9 (Vol. I) (10 November 1989).

<sup>16</sup> *CRPD* (n 10) art 5(2).



- <sup>17</sup> *United Nations International Covenant on Civil and Political Rights*, GA 2200A (XXI) (23 March 1976, adopted 16 December 1966) art 17 ('ICCPR').
- <sup>18</sup> UN Human Rights Committee, *General Comment No. 16: Article 17 (Right to Privacy) The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation*, 32<sup>nd</sup> sess (8 April 1988) [6].
- <sup>19</sup> *Ibid* [7].
- <sup>20</sup> *CRPD* (n 10) art 25.
- <sup>21</sup> *Ibid* art 25(e).
- <sup>22</sup> Penelope Weller, 'Article 25: Health', in Ilias Bantekas, Michael Ashley Stein, Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 707.
- <sup>23</sup> *Ibid*.
- <sup>24</sup> *Ibid* 708-709 referencing Jennifer Randall et al, 'Stigma and Discrimination: Critical Human Rights Issues for Mental Health' in Michael Dudley, Derrick M Silove, and Fran Gale (eds), *Mental Health and Human Rights: Vision, Praxis, and Courage* (OUP 2012) 113.
- <sup>25</sup> Penelope Weller, 'Article 25: Health', in Ilias Bantekas, Michael Ashley Stein, Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 731.
- <sup>26</sup> *Ibid* 731 referencing Marcia Neave, 'Anti- Discrimination Laws and Insurance: The Problem of AIDS' 1 (1988) *Insurance Law Journal* 10.
- <sup>27</sup> See *Universal Declaration on the Human Genome and Human Rights*, GA Res 53/152 (9 December 1998, adopted 11 November 1997).
- <sup>28</sup> *Disability Discrimination Act 1992* (Cth) s 3.
- <sup>29</sup> *Ibid* s 4 (definition of 'disability' para (h)-(k)).
- <sup>30</sup> *Ibid* s 5.
- <sup>31</sup> *Ibid* s 6.
- <sup>32</sup> See Australian Human Rights Commission, *Guidelines for providers of insurance and superannuation under the Disability Discrimination Act* (November 2016) <<https://humanrights.gov.au/our-work/disability-rights/guidelines-providers-insurance-and-superannuation-under-disability>>.
- <sup>33</sup> *Disability Discrimination Act 1992* (Cth) sub-ss 46(1)(f) and (2)(f)
- <sup>34</sup> *Ibid* sub-ss 46(1)(g) and (2)(g).
- <sup>35</sup> *QBE Travel Insurance v Bassanelli* (2004) 137 FCR 88, [28]
- <sup>36</sup> *QBE Travel Insurance v Bassanelli* (2004) 137 FCR 88, [28]
- <sup>37</sup> *Ibid*.
- <sup>38</sup> See Australian Human Rights Commission, *Free and Equal: A reform agenda for federal discrimination laws* (Position Paper, December 2021) 276 <[Free and Equal: A reform agenda for federal discrimination laws \(2021\) | Australian Human Rights Commission](#)> ('*Free and Equal: Reform agenda for federal discrimination law*').
- <sup>39</sup> *A-GLIMMER Report* (n 7) 24.
- <sup>40</sup> *Treasury Consultation Paper* (n 1) 8 referencing APRA December 2022 LRS 750 Data.
- <sup>41</sup> See *A-GLIMMER Report* (n 7) 5.
- <sup>42</sup> See '*Free and Equal: Reform agenda for federal discrimination law* (n 38) 91-186.
- <sup>43</sup> *Privacy Act 1988* (Cth) s 6.
- <sup>44</sup> See for example *ICCPR* (n 17) art 17; *United Nations Universal Declaration of Human Rights*, GA Res 217/A(III) (adopted 10 December 1948) art 12; *CRPD* (n 10) art 22.

- <sup>45</sup> Attorney-General's Department, 'Government Response: Privacy Act Review Report' (28 September 2023) <<https://www.ag.gov.au/rights-and-protections/publications/government-response-privacy-act-review-report>>.
- <sup>46</sup> See Attorney-General's Department, 'Government Response: Privacy Act Review Report' (28 September 2023) 22, 24, 28, 31, 33, 35 <<https://www.ag.gov.au/rights-and-protections/publications/government-response-privacy-act-review-report>>.
- <sup>47</sup> Ibid.
- <sup>48</sup> See 'Free and Equal: Revitalising Australia's commitment to human rights', *Australian Human Rights Commission* (Webpage, 7 December 2023) <<https://humanrights.gov.au/Revitalising-Australia%E2%80%99s-commitment-to-human-rights>>.
- <sup>49</sup> The social model of disability recognises that 'disability' is a result of the physical, attitudinal, communication and social barriers that have been built into society. It acknowledges disability as form of socially created oppression and focuses on removing these barriers to ensure people with disability can participate as equal members of society, without minimising or denying the reality of impairment or its impacts.
- <sup>50</sup> 'Convention on the Rights of Persons with Disabilities', *United Nations Department of Economic and Social Affairs: Social Inclusion* (Web page, 2023) <<https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>>.
- <sup>51</sup> Anna Lawson and Angharad E. Beckett, 'The social and human rights models of disability: towards a complementarity thesis' (2021) 25(2) *International Journal of Human Rights* 351 quoting Rehabilitation International, 'UN Convention on the Human Rights of People with Disabilities: Ad Hoc Committee Seventh Session – Daily Summaries' (on file with the authors) (24 January 2006).
- <sup>52</sup> CRPD (n 10) art 1.
- <sup>53</sup> Committee on the Rights of Persons with Disabilities, *General Comment No. 6 (2018) on equality and non-discrimination*, UN Doc CPRD/C/GC/6 (26 April 2018) [20]-[21].
- <sup>54</sup> *Disability Discrimination Act 1992* (Cth) (definition of 'disability' para (j)-(k)).
- <sup>55</sup> Australian Institute of Health and Welfare, 'People with Disability in Australia' (Catalogue No DIS 72, July 2022) 19 <<https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability>>.
- <sup>56</sup> Australian Bureau of Statistics, *Health Conditions Prevalence* (15 December 2023) <<https://www.abs.gov.au/statistics/health/health-conditions-and-risks/health-conditions-prevalence/latest-release#cite-window1>>.
- <sup>57</sup> Mental illnesses are the second leading cause of non-fatal burden of disease in Australia, and are the most common chronic condition. It is estimated that 43% of Australians aged 16-85 have experienced a mental illness at some point in their life: See Australian Institute of Health and Welfare, *Australian Burden of Disease Study 2022* (Report, 13 December 2022) 4 <<https://www.aihw.gov.au/reports/burden-of-disease/australian-burden-of-disease-study-2022/contents/about>>; Australian Bureau of Statistics, *Health Conditions Prevalence* (15 December 2023) <<https://www.abs.gov.au/statistics/health/health-conditions-and-risks/health-conditions-prevalence/latest-release#cite-window1>>; Australian Institute of Health and Welfare, 'Prevalence and impact of mental illness' (Web Article, 14 February 2024) <<https://www.aihw.gov.au/reports/mental-health/prevalence-and-impact-of-mental-illness>>.
- <sup>58</sup> Penelope Weller, 'Article 25: Health', in Ilias Bantekas, Michael Ashley Stein, Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 709.

- <sup>59</sup> See United Nations Committee on Human Rights Committee, *General Comment No. 18: Non-discrimination*, 37th session, UN Doc HRI/GEN/1/Rev.7 (10 November 1989) [13].
- <sup>60</sup> The social determinants of health are non-medical factors that influence health outcomes and include things such as income, education, social inclusion and housing. The social determinants of health relate directly and indirectly to other universal human rights and are central to the realisation of the right to health under the Article 12 of the *International Covenant on Economic, Social and Cultural Rights*.
- <sup>61</sup> Australian Law Reform Commission, *Access All Ages – Older Workers and Commonwealth Laws* (Final Report No 120, March 2013) 134 < <https://www.alrc.gov.au/publication/access-all-ages-older-workers-and-commonwealth-laws-alrc-report-120/>>.
- <sup>62</sup> *Private Health Insurance Act 2007* (Cth) s 55-5 (1)-(2).
- <sup>63</sup> Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia* (Report No 96, May 2003) 654.
- <sup>64</sup> Financial Services Council, *FSC Standard No. 11: Moratorium on Genetic Tests in Life Insurance* (21 June 2019) [3.5]; *A-GLIMMER Report* (n 7) 9.
- <sup>65</sup> *Insurance Contracts Act 1984* (Cth) ss 20B, 21.
- <sup>66</sup> *A-GLIMMER Report* (n 7) 19, 23.
- <sup>67</sup> See Jennifer Cowley, 'The price of life: Genetic testing results and the cost of insurance', *LSJ Online* (online, 13 December 2023) < <https://lsj.com.au/articles/the-price-of-life-genetic-test-results-and-the-cost-of-insurance/>>.
- <sup>68</sup> *A-GLIMMER Report* (n 7) Appendix VII – Second Health Professionals Study: Dowling et al, 'Health professionals' views and experiences of the Australian moratorium on genetic testing and life insurance: A qualitative study' (2022) 30(11) *European Journal of Human Genetics*, 6. <<https://doi.org/10.1002/ajmg.a.63565>>; *Treasury Consultation Paper* (n 1) 12.
- <sup>69</sup> *A-GLIMMER Report* (n 7) 31.
- <sup>70</sup> *A-GLIMMER Report* (n 7) Appendix VII – Second Health Professionals Study: Dowling et al, 'Health professionals' views and experiences of the Australian moratorium on genetic testing and life insurance: A qualitative study' (2022) 30(11) *European Journal of Human Genetics*, 6. <<https://doi.org/10.1002/ajmg.a.63565>>;
- <sup>71</sup> See *Free and Equal: Reform agenda for federal discrimination law* (n 38) 272-8.
- <sup>72</sup> See Australian Human Rights Commission, *Guidelines for Complying with the Positive Duty under the Sex Discrimination Act 1984 (Cth)* (August 2023) 6.
- <sup>73</sup> See *Free and Equal: Reform agenda for federal discrimination law* (n 38) 58-80.
- <sup>74</sup> See *Ibid* 75; United Nations Office of the High Commissioner for Human Rights, *Guiding principles on business and human rights: Implementing the United Nations "Protect, Respect and Remedy" Framework*, UN Doc HR/ Pub/11/04 (16 June 2011) <[https://www.ohchr.org/documents/publications/guidingprinciplesbusinesshr\\_en.pdf](https://www.ohchr.org/documents/publications/guidingprinciplesbusinesshr_en.pdf)>.
- <sup>75</sup> See *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (Final Report, September 2023) vol 4, 310-315 (recommendations 4.27 and 4.28).
- <sup>76</sup> *A-GLIMMER Report* (n 7) 32.
- <sup>77</sup> *Private Health Insurance Act 2007* (Cth) Div 55-5.
- <sup>78</sup> *Disability Discrimination Act 1992* (Cth) s 67(g), (h), (k).