Australian Genomics and the Australian Alliance for Indigenous Genomics Joint Consultation Response

On the use of genetic testing results in life insurance underwriting

January 2024

The position of Australian Genomics and ALIGN on the use of genetic testing results in life insurance underwriting

- **Legislation must be introduced** to protect consumers, remove the fear of genetic discrimination, and ensure government oversight of insurers' compliance.
- The legislation **should not contain any limits, caps, or exclusions**, to ensure that consumers can be confident that their genetic results are fully protected. Partial consumer protection is inadequate.
- Compliance with the legislation must be monitored, and there needs to be a **strong pathway for enforcement and consumer complaints**, so that consumers know where they can go to get help if an insurer is not complying with the legislation.
- Particular attention should be given to the **significant impact genetic discrimination has on Aboriginal and Torres Strait Islander People** and the critical importance of these protections to avoid compounding inequity of access to genetic and genomic healthcare services and research.

Australian Genomics

Australian Genomics[1] is an Australian Government initiative supporting genomic research and its translation into clinical practice. Through broad engagement and a national collaborative approach, Australian Genomics achieves two key objectives: to improve efficiency, reach and timeliness of genomic research projects, and to support Commonwealth, State and Territory health departments in the implementation of genomics research outcomes by refining and communicating evidence to inform policy development.

Australian Genomics engages with current and emerging government policy and priorities to identify gaps and opportunities, to support policy and action for integrating genomic technologies into the health system. By interfacing with consumers, government, industry and global genomics initiatives, Australian Genomics drives change and growth in the sector.

Australian Alliance for Indigenous Genomics (ALIGN)

The Australian Alliance for Indigenous Genomics (ALIGN)[2] is a national consortium, led by the Indigenous Genomics Group at Telethon Kids Institute (TKI) and the Australian National University (ANU), in partnership with Aboriginal and Torres Strait Islander stakeholders, peak bodies and Communities, as well as research, clinical, industry and institutional partners from across Australia. ALIGN seeks to build and extend Indigenous leadership and involvement in genomic science,

research, precision health care, data sciences, ethics, and Indigenous knowledge systems to reduce health inequality among Australia's First Peoples.
Aboriginal and Torres Strait Islander governance both underpins and leads ALIGN's work, and is instrumental in bringing forward the voices, values, and priorities of Aboriginal and Torres Strait Islander peoples, locally and nationally.

The significance of the issue to Australian Genomics and ALIGN

Australian Genomics has been advocating for enhanced consumer protections regarding the use of genetic information by insurers since the formation of our collaborative. Australian Genomics engaged with the Parliamentary Joint Committee on Corporations and Financial Services' Inquiry into the Life Insurance Industry in 2016/2017, developed material to inform our professional and community partners about the Financial Services Council (FSC) Moratorium, and partnered with the Australian Genetics & Life Insurance Moratorium: Monitoring the Effectiveness & Response (A-GLIMMER) project.

Research clearly demonstrates that when insurers are legally permitted to use genetic information in insurance underwriting, it deters Australians from undertaking potentially life-saving genetic testing, and limits advances in health genomics as Australians reject opportunities to participate in genomic research.

There is extensive evidence that the Australian public are not engaging in clinical genomic healthcare because of concerns about the use of test results by insurers, and that the industry-managed Moratorium is inadequate[3].

Australian health policy is increasingly embracing the transformative potential of genomics to improve health system efficiency and the health and wellbeing of the Australian people. A $500M investment in genomic research through the Genomics Health Futures Mission is catalysing genomic innovation; there are genomic health policies driving change through Commonwealth and State Governments; and cross-jurisdictional consultation is underway on the establishment of a sustained national health genomics entity 'Genomics Australia'[4]. The system-wide impact of genomics will be attained with the adoption of genomics at population scale, in screening for reproductive carrier status or risk of adult-onset conditions like cancer and heart disease. Such population screening programs have already undergone extensive pilot testing, have demonstrated cost-effectiveness and are ready for clinical implementation in the health system. By transitioning health care from reactive management of disease to proactive genomic intervention health funders (Governments and insurers alike) will save billions of dollars.

The current reluctance of Australians to undertake genetic/genomic testing due to the risk of use of the information by insurers will compromise this potential, and undermine genomic implementation efforts currently underway. There is also the high risk of increasing inequities for Aboriginal and Torres Strait Islander peoples, who experience a disproportionate burden of disease but who in many cases feel unable to safely engage in genetic and genomic testing, owing to a history of exploitative research practices and continuing lack of basic protections.

Responses to the Consultation Paper questions

1. Are there particular fields of health care and medical research that are impacted by participant reluctance to take genetic tests due to impacts on life insurance access?

The impact of the legal use by insurers of genetic information in underwriting risk-rated insurance products is already impacting clinical genetic health care as well as research involving genetics and genomics. As genomics is being mainstreamed into the standard practice of more clinical disciplines (with publicly funded testing now offered for genetic testing in areas including nephrology, cardiology, neurology, precision oncology and reproductive carrier testing), this impact will be exacerbated unless adequate protections are introduced. Critically, as Australia moves to implement genetic/genomic testing for genetic predisposition for disease at population scale in the next decade, all adult Australians will have the opportunity to learn their risk of developing a genetically linked health condition. It is predicted that the majority of Australians will choose to access a publicly funded genetic screening program when it is available, and at least 1-2% will receive a result identifying an increased chance of a future condition. Consequently, hundreds of thousands of Australians will be exposed to genetic discrimination if adequate protections are not in place. This impact will not be limited to particular, narrow fields of health care and medical research, as the impact and potential of genomics will transcend traditional boundaries and eventually affect and underpin all areas of health care.

2. Which aspects of the current Moratorium provide inadequate protections for consumers: consumer and industry awareness, financial thresholds, compliance by life insurance industry, or other?

The A-GLIMMER project outlines evidence that **the current Moratorium provides inadequate consumer protections across all these domains**:

- Financial thresholds: most patients, the public, healthcare professionals and researchers felt the Moratorium's financial limits to be too low (see also discussion about Option 3 - Legislating a financial limit, below). Importantly, the financial thresholds are accumulative across policies, making it difficult for consumers to easily understand when they have exceeded them. They are also set at a level which, should consumers insure themselves to stay below them, will not meet the requirements for adequate insurance for many consumer scenarios[5].
- Compliance by the life insurance industry: A-GLIMMER's research documents instances of non-compliance with the Moratorium (as has the FSC Life Code Compliance Committee) and most stakeholders were concerned that compliance with the Moratorium is self-regulated by the insurance industry[3].
- Consumer and industry awareness: only 53% of non-genetic healthcare professionals were found to be aware of the Moratorium, and 84% patients had never heard of it.

The key issues with the current Moratorium, however, are the self-regulation by the industry, without oversight or monitoring by Government, and the partial protection it affords. The public does not trust the insurance industry to act in consumers' best interests, and the uncertainty of a Moratorium erodes consumer confidence further.

3. As a consumer, has your willingness to undertake genetic testing been impacted by the existing Moratorium?

In 2020, the Commonwealth Government commissioned a review of the policy landscape relating to genomics in Australia. The resultant *Essentially Ours* report identified genetic discrimination through insurance as one of the issues raised most frequently by stakeholders (p 179). Specifically, the consultation process identified the confusion arising from the Moratorium as an **urgent issue contributing to patients choosing not to undergo genetic testing or to participate in genomic research** (p 180)[6].

The significant impact of having no legislated environment to manage life insurance risk rating for the general population has far more acute consequence for Indigenous Australians. For many Aboriginal and Torres Strait Islander people, accessing genetic and genomic health services is already difficult. Barriers include the lack of culturally safe pathways and specialist services (including experiences of racism and discrimination), geographical location, cultural and community priorities and obligations, and a lack of culturally appropriate resources and information about these services. Aboriginal and Torres Strait Islander people can expect to live on average 9 years less than their non-Indigenous counterparts and experience much higher rates of chronic diseases such as diabetes, cancer, and cardiovascular disease. For those that wish to seek life insurance, heritable disease risk rating will most likely impact their insurance premiums. Including the results of genetic tests could further push policy premiums outside of an affordable range. Generational impacts of perceived genetic disorders or conditions will further disadvantage this already highly vulnerable population, and further discourage Indigenous Australians from having the preventive care for which so many barriers already exist.

Allowing insurers to use genomic information exacerbates existing barriers to genomic testing for Aboriginal and Torres Strait Islander people, which in turn prevents the dearth of genomic research with Aboriginal and Torres Strait Islander people from being effectively addressed. Additionally, the ability to accurately define disease risk in Indigenous Australians is severely hampered by a lack of genetic information and the lack of an Indigenous reference genome. Recent studies have also shown that the scale of genetic diversity contained within Indigenous genomes is extremely high, with Silcocks *et al.* 2023 describing it as "the highest proportion of undescribed genetic variation outside of Africa"[7]. Due to historical exploitation and inadequate community engagement, the level of genetic information from Aboriginal and Torres Strait Islander individuals contained in clinical reference databases is almost non-existent. Current approaches to interpreting genetic information from Indigenous patients fall back on information from the broader non-Indigenous Australian public, increasing the potential for the estimation of disease risk to be inaccurate. Without broader engagement and large clinical studies that link known disease phenotypes to unique genetic variation, further genomic inequality is likely to occur. Without adequate protections against genetic discrimination, this broader engagement in genomic research will continue to be blocked.

4. **Of the options outlined above, which do you think is most appropriate to manage concerns about genetic testing and access to life insurance, including those concerns identified in the A-GLIMMER report (see pages 10-11)? Would you change any aspects of that option?**

Australian Genomics and ALIGN strongly advocate for a complete legislative ban on the use of genetic testing results in life insurance underwriting (option 2). Legislation must be introduced to protect consumers, remove the fear of genetic discrimination, and ensure government oversight of insurers' compliance. **Legislation should be introduced as a permanent solution that does not**

contain any limits, caps, or exclusions, to ensure that consumers can be confident that their genetic results are fully protected and to prevent further confusion among health providers and consumers. **A partial ban would provide inadequate consumer protection.**

A complete ban, consistent with the A-GLIMMER recommendations, will resolve the risk of insurance discrimination, without delaying definitive action with an alternative approach that will require future evaluation, monitoring, and intervention. Only a complete ban will future-proof the resolution of consumer risks of genetic discrimination in risk-rated insurance underwriting.

This approach will provide clarity for consumers, without the complexities of thresholds and exceptions, or the threat of expiration. This is particularly important when insurance literacy of consumers in Australia is low and exacerbated by low product knowledge, and low trust of providers[8]. With any policy intervention less than a complete legislative ban, healthcare practitioners and researchers will still need to inform patients of the risk when they're being counselled about a genetic intervention, and the risks will still need to be presented on every clinical and research consent form - a known deterrent to uptake of genetic and genomic tests[9].

Critically, the ban must still allow consumers to voluntarily share favourable genetic test results – such as a negative result that indicates they do not have a familial variant that has affected family members. This will ameliorate the risk of applicants being wrongly discriminated against for a family history of a genetic condition, when genetic testing has demonstrated they have not inherited the pathogenic variant.

The Attorney-General's Department Privacy Act review (2023) introduced a number of reforms aimed at strengthening the protection of personal information, and the control individuals have over that information. One proposal was to amend the definition of sensitive information to include genetic and *genomic* information. Only a complete ban would address risks of genetic data security breaches when this sensitive information is held by insurers, and the frequency of data breaches has increased in recent years. Further, as artificial intelligence gains prominence in industry, underwriting practices may become more granular, compounding risks to consumer privacy and security[10].

Many nations globally have introduced legislative protections against the use of genetic information by insurance companies. In fact, legislative prohibition on the use of genetic results by insurers has been enacted in Austria (2005), Belgium (1992), Canada (2017), Denmark (1997), France (2004/2011), Ireland (2005), Poland (2015), and Portugal (2005)[11].
Many similarities are shared by Canada and Australia: population size, economy, health system and system of government (federations, constitutional monarchies, and parliamentary democracies). The Indigenous peoples of both Canada and Australia are survivors of colonialism, with similar experiences in disadvantage and trauma.
Given these similarities, Canada is the best exemplar to consider in introducing policy changes to the use of genetic information by insurance companies. Canada's Genetic Non-Discrimination Act (GDNA, 2017[12]) provides excellent protections for its public, which Australian Genomics and ALIGN recommend be reflected in the Australian policy response:

- The GNDA introduced a complete ban on the use of genetic information by insurers;

- It includes criminal sanctions, citing the need for public rights to be defended by the state, and not by individuals given the financial 'war chest' at the disposal of insurance companies in a civil case;
- It does not preclude applicants from providing genetic test results to show they don't have a familial pathogenic/disease-causing variant;
- GDNA contains additional prohibitions (at section 3) that:
    - Prohibit any entity from requiring a person to undergo a genetic test as a condition to providing goods/services or entering into a contract;
    - Prohibit any entity from refusing to provide goods/services or entering into a contract on the grounds that the individual has not undergone a genetic test; and
    - Prohibit third parties collecting, using or disclosing genetic information without an individual's written consent[12].

Australians feel strongly that legislation is needed to regulate the use of genetic information in insurance underwriting: at least 93% of health professionals, 88% of patients with experience of genetic testing, 78% of the general public, and 86% of researchers[3]. If the Australian Government does not move to introduce a complete ban on the use of genetic information in insurance underwriting after undertaking a public consultation, there is a risk of considerable loss of trust that consumer protections are of paramount concern to Government.

5. What are the key concerns with each option?

Option 1: No Government intervention

The current ability for the life insurance industry to legally use genetic information in risk-rated insurance underwriting, and the industry self-regulated Moratorium without Government oversight, is deterring Australians from having potentially life-saving genetic testing. The evidence for this is comprehensively presented in the A-GLIMMER report as well as the Commonwealth-commissioned *Essentially Ours* report, and is a growing concern amongst healthcare practitioners, patients and the public, and Parliamentarians – with Private Members' Motions put forward and supported by Labor, Liberal and Independent Members calling on Government to intervene.

The inadequacy of industry self-regulation to manage the use of applicants' genetic information is demonstrated in the instances of non-compliance with the FSC Moratorium by insurance companies[3]. Any continued ability of insurers to ask for and/or use genetic test results in underwriting exposes consumers to the risk of misuse of this information.

Insurers may suggest that any policy change prohibiting the use of genetic information in underwriting will undermine the viability of the insurance industry, with potential downstream impacts on Australian healthcare affordability. However, similar concerns voiced by insurers in Canada were contradicted by the findings of experts commissioned by the Canadian Privacy Commission prior to introduction of the GNDA legislation[13]. There is no evidence that the Canadian insurance industry has suffered as a result of the complete ban introduced there in 2017.

While genomics has great promise to revolutionise healthcare, current genetic knowledge is incomplete – genetic professionals (clinicians and scientists) are often unable to categorically determine the association of a genetic variant / result to an individual's future disease risk, especially

in populations that lack sufficient genetic information (such as Aboriginal and Torres Strait Islander people). The penetrance of a particular pathogenic variant (i.e., the proportion of individuals with that genotype that exhibit the physical trait, or phenotype) requires specialist interpretation, and complete penetrance is rare. Insurers would not be capable of adequately or reliably determining the implications of genetic test data on an individual's future disease risk. Single-gene disorders are also relatively rare, and multifactorial considerations with both genetic and environmental risks come into play. Further, genetic variants are continually being re-classified based on new evidence, and insurance companies wouldn't have the expertise to keep up with this. Irrespective of the actuarial algorithms applied, it would be impossible for insurers to interpret the results of a genetic test accurately, consistently, and appropriately, and be able to use that information to understand the future risk of disease of an individual, or their family. Even if the above were not true, and insurers were one day able to perfect their algorithms for perfect estimates, the ethical, moral, public health and consumer protection arguments would remain. The ongoing use of genetic information by insurers is discriminatory, and Government intervention is critical.

Option 3 - Legislating a financial limit

If insurers are legally permitted to ask consumers for genetic information under any circumstances, it exposes Australians to the risk of misuse of that information, and genetic discrimination. Further, even a legislated financial limit will be exceedingly challenging to set, to evaluate, and to monitor compliance.

In 2019, the 22 million active life insurance policies were held by 12.5 million working-aged Australians: 63% of which were held through superannuation. However, 39% of Australians have more than one superannuation account, and 14% have three or more superannuation accounts[14]. Despite the number of life insurance policies in Australia, there is concerning evidence of widespread underinsurance in our nation. While 15 million people are paying $17.3 billion in life/individual insurance, there are significant gaps in the level of cover: an estimated 1 million Australians are underinsured for death/TPD, and 3.4 million underinsured for income protection[5]. The implication of this underinsurance is that if Australian families had to exercise their life insurance policy, only 28% would be able to maintain their family's standard of living, and the median level of income protection would meet only 21% of that family's needs[14]. This epidemic of underinsurance is estimated to cost the Government well over $600 million per annum in social security payments of death and TPD underinsurance[15]. In this context, **it is in the interest of Government and economic policy to introduce policy that encourages the uptake of adequate levels of insurance**. If insurers are legally permitted to require disclosure of genetic information at a specific limit, it will perpetuate the incentivisation underinsurance into the future.

There is no question that the current FSC/CALI Moratorium financial limits for disclosure of genetic test results are patently too low at 70% of the average death cover; 59% of the average Total and Permanent Disability (TPD) cover; and 52% of the average disability insurance cover. Further, the determination of a fair and reasonable financial limit – and monitoring and updating this limit into the future, will compound the complexity of ensuring industry compliance, and ensuring consumer understanding of when disclosure of genetic information is required, as well as contributing to further uncertainty for consumers and a continued deterrence from participating in testing and research.

The operationalisation and enforcement of a legislated limit would be exceedingly burdensome on Government to monitor into the future.

With a legislated financial limit, how would Australians know if this has been reached across multiple life insurance policies, associated with different superannuation accounts? How would insurers navigate the process of applications above or below the limit, and when it is legal for genetic information to be requested? Given the instances of industry non-compliance with the Moratorium, the onus will be on Government to ensure insurance companies comply with the legislated limits on disclosure, and adequately enforce penalties in case of breach – dependent upon industry self-reporting, which is fraught with information asymmetry, and conflict of interest.

A financial limit also perpetuates the risk of inadvertent disclosure of genetic test results by applicants who might be naïve to, or confused by, the requirements of the limit.

For consumer confidence to be preserved with a legislated financial limit on disclosure of genetic test results to consumers, the public would need adequate transparency on the relative weighting by insurers of genetic test results versus family history, and other risk factors. Should a legislative limit be implemented by Government, it would also require that the actuarial algorithms to be standardised for the use of genetic information and available in the public domain, for consumer confidence. Health professionals who must communicate risks of genetic testing to their patients and research participants would also need to remain up to date with the changing financial limits in order to properly provide what is essentially financial advice in a context of fluctuating and uncertain consumer protections.

The complexity of implementing a financial limit on the disclosure of genetic information, and burden to taxpayers for downstream Government monitoring, enforcement, review, and amendment to the financial limit to evolve with Australians' financial ecosystem, make this an inappropriate and inadequate response to the need for policy change. **A complete legislative ban on the access to and use of genetic and genomic information by insurers is the only viable and sustainable option to be considered**.

6. Is there any evidence to suggest that Government intervention may give rise to adverse selection?

Australian Genomics and ALIGN acknowledge the need for a stable insurance industry, and recognise that there is asymmetric information between insurer and applicant, that the application process attempts to minimise with the various requirements for disclosure. However, there is scarce and inconsistent evidence as to the impact of adverse selection by high-genetic risk patients, and many publications present counter arguments to the notion of adverse selection in risk-rated insurance after a genetic diagnosis[10,16,17]. Further, **adverse selection has not been recorded as a substantive outcome of complete bans in other countries that have provided legislative protection for their public**. Many of these countries have had bans in place for decades.

In an evaluation of genetic factors in life insurance, Macdonald (2009) concludes that "little, if any strong empirical evidence has been found for the presence of adverse selection"[16]. Before the introduction of a complete ban on the use of genetic information for insurance in Canada, economists Hoy and Durnin (2012) assessed the potential economic impact, and concluded: "a ban on such information would likely have no significant negative implications for insurers or for the efficient operation of markets such as life insurance", and further posit that "the institution of such a

ban would seem not only unproblematic for the insurance market but even economically and socially desirable"[17].

A complete legislative ban on the use of genetic information in insurance underwriting would remove the spectre of genetic discrimination for the Australian public, and would remove a significant barrier to uptake of genetic and genomic testing. Empowered with the knowledge of their predictive or diagnostic results, Australians will be supported by healthcare professionals to implement preventative measures or additional screening, that can reduce their likelihood of developing a condition. This may not only be life saving for the individual, but save the health system costly interventions and insurers payouts on avoidable death or disability: the "economically and socially desirable" outcome specifically called out by the modelling experts[17].

Government should also monitor the implications of a ban on the use of genetic test results in risk-rated insurance underwriting to ensure the industry does not opportunistically and unreasonably inflate premiums of all policies, without evidence of adverse selection.

7. Should there be any difference in the treatment of diagnostic and predictive genetic tests?

The **policy intervention in the form of a complete ban must include all genetic and genomic results**, be they predictive or diagnostic, polygenic scores, pharmacogenomic, epigenetic information, or other genetic results – and whether this information was the result of a clinical or research test. This was the scope included in the FSC/CALI Moratorium, so should be an approach familiar to the insurance industry.

In the 2022 report of the UK code triennial review, it was reported that "Although predictive genetic results may provide an additional source of useful information for insurers, insurers currently believe the information they already have available to them allows a robust assessment of an individual's risks"[18].

8. Is there an option not listed that you believe should be considered?

No: Australian Genomics and ALIGN strongly recommend that a complete legislative ban, without any limits, caps or exclusions must be introduced, to prohibit the use of genetic testing results in life insurance underwriting. This is the only viable option to adequately protect consumers, and mitigate the risk of stifling uptake of genomic health interventions for fear of genetic discrimination. This option also provides the most cost effective and sustainable solution for the taxpayer and Government, by eliminating complexities which would need to be constantly monitored.

9. Of the options outlined above, which do you think is the most appropriate enforcement body given capacities and enforcement powers?

We agree with the consultation paper statement that **effective enforcement will be critical to ensure consumer confidence in the protections enacted**. Enforcement would ideally involve both Australian Human Rights Commission (AHRC), as recommended by A-GLIMMER report, and the Australian Securities and Investment Commission (ASIC).

There will also need to be a clear pathway for consumer concerns to be raised and investigated, so that consumers know where they can go to get help if an insurer is not complying with the legislation.

10. Is there an enforcement option not listed that you believe should be considered?

Strong penalties, including criminal sanctions as included in Canada's GNDA legislation, must be in place to penalise insurers found to be in breach of the legislation. This ensures individuals are protected by the state, rather than only having an option to pursue remedies in a civil setting, which is critical given the depth of the pockets of the insurance companies. Most individuals would not, or could not, take on an insurer who had discriminated against them unlawfully.

Like GNDA, the ban must also prevent insurers from seeking, receiving and using genetic, genomic and other health data from third parties without explicit consent of the applicant, given the increasing personal data trading globally.

We also strongly advocate for periodic review of legislation after implementation, to ensure the terms are providing sufficient protections to the Australian public and the outcomes are consistent with the intention of the legislation. However, it should be very clear from the outset that this periodic review is not an opportunity for the protections to be adjusted or minimised, or for the insurance industry to lobby for the introduction of exceptions, caps or limits. Such a review process, that provided the industry with this opportunity, would erode consumer confidence and contribute to further uncertainty and deterrence.

Summary of the position of Australian Genomics and ALIGN on the use of genetic testing results in life insurance underwriting:

- **Legislation must be introduced** to protect consumers, remove the fear of genetic discrimination, and ensure government oversight of insurers' compliance.
- The legislation **should not contain any limits, caps, or exclusions**, to ensure that consumers can be confident that their genetic results are fully protected. Partial consumer protection is inadequate.
- Consumers **must be able to share negative test results** to protect against discrimination on the basis of family history.
- **The ban must include all genetic and genomic results**, be they predictive or diagnostic, polygenic scores, pharmacogenomic, epigenetic information, or other genetic results – and whether this information was the result of a clinical or research test.
- Compliance with the legislation must be monitored, and there needs to be a **clear pathway for enforcement and consumer complaints**, so that consumers know where they can go to get help if an insurer is not complying with the legislation.
- The Australian Government must consider the **significant impact genetic discrimination has on Aboriginal and Torres Strait Islander People** as legislation is drafted, to avoid compounding current inequities in genomic health care and research.

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