

We are concerned that the current FSC-proposed solution will not achieve the intended benefits of a moratorium on the use of genetic test results in life insurance.

The goals of such a moratorium should be;

- a) To remove a current barrier compromising the success of genomic medicine in Australia,***
- b) To reduce consumer fears related to insurance, which deter the uptake of clinical genetic testing and research participation***
- c) To minimize or eliminate genetic discrimination in the Australian life insurance industry***
- d) To achieve a transparent agreement, in good faith, between industry and government.***

We outline 8 major concerns below.

1. Government involvement and oversight is required

- The FSC has proposed an industry self-regulated moratorium, which is unlike the UK moratorium (now the Code on Genetic Testing and Insurance), which is an agreement between industry and government.
- The PJC made specific and repeated criticisms of problems related to industry self-regulation around the use of genetic test results in Australian life insurance. Issues related to the conflicted nature of industry self-regulation were also made apparent by the Banking Royal Commission.
- The Human Genetics Society of Australasia, Australian Genomics and the AGNDWG Group are aligned in their public position statements regarding the need for government involvement (see attachments).
- We have ongoing concerns regarding industry self-regulation, particularly regarding the operation of the Life Code Compliance Committee (see endnote 1).
- Regulatory oversight must include meaningful penalties for insurers, to ensure compliance

2. There should be no limits – or limits, if applied, should be consistent with the UK limits

- The inclusion of limits is not necessarily consistent with bans that have been implemented internationally (see 2017 [Geneva Association document](#) and endnote 2).
- The majority of countries where bans or moratoria have been implemented have included no financial limits at all – FSC has chosen to model limits on 2 of the countries which (in the minority) have financial limits. A moratorium with limits as proposed by FSC is unlikely to achieve the aim of removing the deterrent effect generally, although the moratorium is an important first step.
- If any limits are to be applied, the UK model should be followed, as recommended by the PJC.
- Not only does the UK model have much higher limits (close to twice the ceiling amounts) than those proposed by FSC, **those limits apply to only one genetic condition** - Huntington's Disease. HD is one of the very few known adult-onset genetic conditions which have 100% penetrance.

3. Results generated from research studies should be excluded from all disclosure as per the UK policy

- If disclosure is required above a certain level, only results generated by clinically accredited laboratories should be considered.

4. Planning or considering having a genetic test needs to be removed from clause 9

- Despite acknowledging almost a year ago (1 December 2017) that the recommended question in FSC's genetic testing policy about whether an applicant was "considering" a genetic test was "horrible", and explicitly undertaking to a Parliamentary Committee to removing that question, the draft moratorium expressly incorporates that language again at clause 9, allowing insurers to ask for and use the results of previously taken, **planned or considered** genetic tests. The

“planned or considered” needs to be removed, and insurers advised to change their standard questionnaires, to cease asking about “planned or considered” tests.

5. Any moratorium should apply to genetic tests taken under its current terms

- Consistently with the PJC’s recommendations, the terms of the moratorium should apply indefinitely to genetic tests taken before the moratorium is lifted, to ensure certainty for consumers who are making decisions about testing under the current terms.
- See draft Moratorium on Genomic Tests and Personal Insurance Products in Australia for a proposed clause in this regard.

6. There should be regular compliance reporting, a specific complaints handling process and a Nominated Genetics Underwriter (NGU) role

- Reporting to the government should be a requirement of the moratorium
- There should be a specific process for addressing complaints and appeals regarding the use of genetic test results.
- Requiring member insurers to have a Nominated Genetics Underwriter (NGU) (as in the UK) would provide an immediate group of contact points for reporting, reviews etc
- See draft Moratorium on Genomic Tests and Personal Insurance Products in Australia for proposed clauses addressing each of these aspects.

7. Non-FSC members should be able to opt in to the Moratorium

- The moratorium should formally allow non FSC-member Insurers to voluntarily opt in to the obligations (or allow government to require non-FSC insurers offering risk-rated insurance to abide by the moratorium) including having their data included in the government reporting.
- See draft Moratorium on Genomic Tests and Personal Insurance Products in Australia for proposed clauses in this regard.

8. All risk-rated policies should be covered by the moratorium

- The scope doesn’t adequately explain what policy types are covered – for clarity, it should be made clear that all types of risk-rated policies sold by FSC insurers are covered (rather than only “life insurance”).

End notes

1 Concerns regarding LCCC

Source: LCCC charter

- The LCCC is established by and funded through the FSC
- The LCCC is comprised of only 3 members
 - One industry representative, appointed by the FSC, and considered independent if he/she has not been employed by FSC or an FSC insurer within the last 12 months
 - One consumer representative, appointed by the FOS
 - One chairperson, appointed jointly by the FSC and FOS
- The members can be terminated on 7 days’ notice by the appointor
- There is no requirement on the LCCC to investigate any allegation made
- There is no requirement on the LCCC to impose any sanction, regardless of the results of an investigation
- The sanctions to be imposed have little or no punitive value – the worst being the ability to publicly name the insurer as non-compliant with the Code (removing an insurer from membership of FSC is not an available sanction)

- Complaints concerning the LCCC will be determined by a party jointly appointed by the FSC and the FOS – not independently appointed by the FOS to investigate
- There is no mechanism if FSC and FOS cannot agree on the appointment of the independent party

Source: 2017 LCCC Annual report:

- The LCCC states that it should be able to determine whether breaches are significant (currently an insurer who self-reports decides whether the breach is significant or not) as well as other changes that should be made to the Code, yet these changes have not been made in the current draft
- The inaugural chair resigned, and the LCCC was unable to convene from Nov 2017 to Feb 2018, demonstrating the inherent issues in of the appointing parties to prevent the LCCC from carrying out its proposed functions by delaying appointment of representatives
- The LCCC states that it lacked resources to investigate all of the breaches notified to it
- Only 56 investigation files were opened from 747 referrals received.
- Only 2 investigations were completed within the financial year. One identified a breach, and the LCCC is “working with” the insurer
- No sanctions were imposed in the financial year

2 **2017 [Geneva Association document](#): “Genetics and Life Insurance – A View Into the Microscope of Regulation”**

- Of 21 countries listed in that document,
 - 13 do not require disclosure of genetic results to insurers in any circumstances, (no limits)
 - 10 have an imposed restriction without limits (Austria, Belgium, Canada, Denmark, France, Ireland, Poland, Portugal, Singapore, Spain) – some even ban the collection of family history information.
 - A further 3 do not have an imposed or formal agreed ban, but the insurance industry voluntarily does not ask for any genetic test results when underwriting.
 - 4 have financial limits of any kind (UK, Germany, Switzerland, Netherlands – see below for further detail)
 - We know there are other countries (such as Sweden and others) which also have legislation regulating this issue, that didn’t make it into the summary document
- Remaining countries are Australia, India/China (no regulation), and the US (focussed on health insurance, now looking at life insurance)
- Of those that have limits:
 - The UK, which is the model the Parliamentary Inquiry recommended, has limits of £500,000 for life policies, ONLY for specific genetic tests (the only test being for Huntington Disease).
 - **Further, research results are excluded from disclosure altogether.**
 - Germany and Switzerland – both subject of legislation, with specific penalties applicable for breach. In Switzerland, genetic test results are not provided to the insurer but to a designated doctor, only if the results of the test are reliable both technically and in medical practice, and for which the scientific value of the test for the calculation of premiums has been demonstrated. The doctor can only provide to the insurer the risk group the insured should be in – no other details.
- Netherlands has lower limits but it also limits the asking of **all** hereditary questions below those limits to certain circumstances.
- By number, international standards actually favour banning insurers from asking for genetic test results, without any limitation. It is not correct to say that the approaches in Switzerland and Germany are representative of international standards.
- Further, those limits are applied in the context of legislative frameworks with criminal penalties for breach, which are not similar in any way to the FSC’s proposed moratorium.