***Table S1: Findings of the Parliamentary Committee regarding genetic testing and life insurance***

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| **Section** | **Finding** |
| 9.84 | The evidence indicates that genetic data is not presently sufficiently accurate or reliable for a duty to disclose to be appropriate |
| 9.85 | Individuals’ genetic information can be used by insurers to charge a higher premium, exclude insurance cover for certain conditions or deny insurance, which has occurred even in instances where individuals have taken proactive steps to reduce their likelihood of having a certain condition |
| 9.86 | The continual developments in the area of genetics, as well as costs reductions, mean that the reliability, availability, and number of genetic tests is increasing. Thus, the problem of genetic discrimination is likely to become even more significant in the near future |
| 9.87 | Fears that adverse selection as a consequence of consumers not having to disclose predictive genetic testing results would make the life insurance market unsustainable may be overstated |
| 9.88 | Despite the existence of adverse selection as a phenomenon in insurance, on balance, there is presently greater benefit to consumers in preventing a duty of disclosure from arising in respect of predictive genetic tests |
| 9.89 | The use or perceived use of genetic information by life insurers has impacted on participation in public health research projects and other forms of research, and reduced participation by the public in research projects may compromise Australia's competitiveness in international research |
| 9.90 | The committee is highly concerned about evidence received that individuals are not undertaking potentially life-saving genetic testing due to fears of unfair treatment by life insurers |
| 9.92 | The committee is not persuaded that legislation should be the first response |
| 9.93 | The FSC1, in discussion with the AGND Working Group2, should prohibit any life insurers from using the outcomes of predictive genetic tests at least in the medium term. This should be done as a matter of some urgency and take a form similar to the United Kingdom's Moratorium. However, similar to the United Kingdom's Moratorium, this prohibition should not prevent a consumer from being able to provide genetic information to a life insurer in order to demonstrate that they are not at risk of developing an inherited condition. The moratorium should be reviewed five years after being imposed, with the review to take into account consumer impacts (for consumers generally, and for consumers who have adverse genetic test results). Any moratorium arrangements should apply indefinitely to predictive genetic test results obtained before the lifting of the moratorium, if it is lifted, to avoid sharp jumps in premiums for existing insureds. |
| 9.94 | The committee acknowledges the significant concerns raised during this inquiry about the conflicts of interest inherent in the FSC's self-regulatory regime. As set out in chapter 4, the committee supports the co-regulatory approach outlined in the ASIC3 Enforcement Review Taskforce Position Paper, particularly the requirements for industry codes to be registered. |
| 9.95 | In terms of the recommendations made in this chapter ... the committee is of the view that these safeguards would be significantly strengthened by them becoming part of a registered co-regulatory approach between ASIC and the FSC. The committee considers that a co-regulatory approach would strike an appropriate balance between safeguarding against the improper use of genetic information by the life insurance industry while still allowing it to operate efficiently. |
| 9.96 | The committee further considers that the government should monitor the FSC's adoption of the changes to the Code and Standard 11 and 16 as well as whether life insurers are abiding by such changes. If life insurers fail to implement and abide by the revised Code and standards, then the committee suggests that the government implement legislation to ban the use of genetic information by life insurers, except where the consumer provides genetic information to a life insurer to demonstrate that they are not at risk of developing a disease. In this instance, the government should closely consider the approach taken by Canada. |
| 9.97 | The committee also suggests that the government should maintain a watching brief on developments in the field of genetics and predictive genetic testing in order to be in a position to consider whether legislation or another form of regulation banning or limiting the use of genetic information is required in light of future developments. |

1. FSC = Financial Services Council; 2. AGND Working Group = Australian Genetic Non-Discrimination Working Group; 3. ASIC = Australian Securities and Investments Commission

**Source:** Commonwealth of Australia, Parliamentary Joint Committee on Corporations and Financial services – Life Insurance Industry report, 2018 (16)