

## Chapter 9

### Genetic information

9.1 Genetic testing and genetic information can be predictive or diagnostic in nature. Predictive genetic testing refers to the testing of a person who does not present any signs or symptoms of a disease but whose family history places them at a higher risk.<sup>1</sup> Diagnostic genetic testing is used to confirm a person's diagnosis when a disease is suspected based on the presentation of certain signs and symptoms.<sup>2</sup>

9.2 While genetic information may indicate a possibility of an individual or their family member contracting an inherited condition, such information is not of itself a guarantee of this as other factors, such as lifestyle, may play a role.<sup>3</sup>

9.3 It is also not possible to predict from genetic test results the exact time when a condition will be diagnosable, the rate in which a condition will progress, how severe it will be or when a person will die.<sup>4</sup> However, genetic information has the ability to potentially improve health outcomes by allowing for early medical intervention and lifestyle changes.<sup>5</sup> This potential has seen an investment by the Victorian, New South Wales and Queensland Governments of approximately \$25 million each into implementing genomics into clinical healthcare.<sup>6</sup>

9.4 Currently, predictive genetic testing is available for inherited conditions such as some forms of cancer and heart disease as well as some neurological conditions,

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1 Human Genetics Society of Australasia, *Position Statement: Genetic Testing in Life Insurance in Australia*, March 2016, p. 1, <https://www.hgsa.org.au/documents/item/20> (accessed 20 September 2017).

2 Human Genetics Society of Australasia, *Position Statement: Genetic Testing in Life Insurance in Australia*, March 2016, p. 1, <https://www.hgsa.org.au/documents/item/20> (accessed 20 September 2017); Professor Margaret Otlowski, Law Dean, University of Tasmania; and Chair, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 62.

3 Human Genetics Society of Australasia, *Position Statement: Genetic Testing in Life Insurance in Australia*, March 2016, pp. 1, 2, <https://www.hgsa.org.au/documents/item/20> (accessed 20 September 2017).

4 Human Genetics Society of Australasia, *Position Statement: Genetic Testing in Life Insurance in Australia*, March 2016, p. 1, <https://www.hgsa.org.au/documents/item/20> (accessed 20 September 2017).

5 Human Genetics Society of Australasia, *Position Statement: Genetic Testing in Life Insurance in Australia*, March 2016, p. 2, <https://www.hgsa.org.au/documents/item/20> (accessed 20 September 2017); See also, Dr Kate Stockhausen, Manager, Ethics, Australian Medical Association, *Committee Hansard*, 8 September 2017, p. 29.

6 Professor Margaret Otlowski, Law Dean, University of Tasmania; and Chair, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 66.

such as Huntington's disease.<sup>7</sup> Continual developments and technological advances mean that the number of inherited conditions that predictive genetic testing is available for, as well as the methods for such testing, is increasing. For example, the identification of predisposition to inherited conditions is now available through direct-to-consumer testing and whole genome sequencing.<sup>8</sup>

9.5 As the use of genetic testing and the role of genomics in health care increases, concerns have been raised around privacy and genetic discrimination.<sup>9</sup> Genetic discrimination has been defined as 'the differential treatment of asymptomatic individuals or their relatives on the basis of their actual or presumed genetic characteristics'.<sup>10</sup> At its core, genetic discrimination reflects the belief that, as a person has no control over their genetic makeup, it would be unfair to discriminate against them.<sup>11</sup>

9.6 Genetic discrimination raises important questions about how predictive genetic test results affect an individual and their family's ability to obtain life insurance, as well as associated questions regarding research participation and public health outcomes.

9.7 This chapter will focus on the use of predictive genetic information (genetic information) by the life insurance industry and begins by looking at developments in the use of genetic information by insurance companies in several international jurisdictions. The use of genetic information by insurance companies in Australia is then considered, followed by a discussion of reform, including arguments for a ban on life insurers using genetic information on one side, and continued self-regulation by the life insurance industry on the other. The chapter concludes with the committee's views and recommendations.

## **Genetic information and the life insurance industry in international jurisdictions**

9.8 In response to the rapid developments in the area of genetic testing and research and concerns over genetic discrimination, several countries have enacted

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7 Human Genetics Society of Australasia, *Position Statement: Genetic Testing in Life Insurance in Australia*, March 2016, p. 1, <https://www.hgsa.org.au/documents/item/20> (accessed 20 September 2017).

8 Human Genetics Society of Australasia, *Position Statement: Genetic Testing in Life Insurance in Australia*, March 2016, p. 2, <https://www.hgsa.org.au/documents/item/20> (accessed 20 September 2017); Dr Kate Stockhausen, Manager, Ethics, Australian Medical Association, *Committee Hansard*, 8 September 2017, p. 31.

9 Professor Margaret Otlowski, Law Dean, University of Tasmania; and Chair, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 59.

10 M. Otlowski, S. Taylor and Y. Bombard, 'Genetic Discrimination: International Perspectives', *Annual Review of Genomics and Human Genetics*, vol. 13, 2012, p. 434.

11 M. Otlowski, S. Taylor and Y. Bombard, 'Genetic Discrimination: International Perspectives', *Annual Review of Genomics and Human Genetics*, vol. 13, 2012, p. 434.

legislation or voluntary agreements to restrict or fully ban the use of genetic information by insurance companies.

### ***United Nations Educational, Scientific and Cultural Organization***

9.9 The Universal Declaration on Human Genome and Human Rights was passed by the United Nations Educational, Scientific and Cultural Organisation in 1997. This declaration aims to protect against the use of genetic information in a way that is contrary to human rights and dignity.<sup>12</sup>

### ***European Union***

9.10 Genetic discrimination is prohibited in countries in the European Union through the Council of Europe's *Convention on Human Rights and Biomedicine*.<sup>13</sup> Legislation has also been enacted in European countries such as Belgium, Denmark, Holland and Sweden that prohibits insurers using genetic information when setting premium levels.<sup>14</sup>

### ***United Kingdom***

9.11 An agreement in the form of a voluntary concordat (a concordat is an agreement between parties relating to matters of mutual interests) and a moratorium regarding the use of a customer's genetic information by life insurers is in place in the United Kingdom.<sup>15</sup>

9.12 The Concordat and Moratorium are agreed to by both the United Kingdom Government and the Association of British Insurers. The Concordat is an agreement to uphold the principle that insurance companies should, unless otherwise stated, have access to relevant information in order to fairly price risk for the benefit of all consumers.<sup>16</sup> The Moratorium is a separate document that sits alongside the Concordat and allows consumers to obtain significant levels of life insurance without having to disclose the results of genetic testing.<sup>17</sup>

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12 Library of Parliament, *Legislative Summary – Bill S-201: An Act to prohibit and prevent genetic discrimination*, 6 December 2016, p. 3.

13 Australian Genetic Non-Discrimination Working Group, *Submission 60*, p. 4.

14 Australian Genetic Non-Discrimination Working Group, *Submission 60*, p. 4.

15 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014.

16 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014, clause 1.

17 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014, clause 21(c); Genetic Alliance UK, *Insurance, Privacy and the Concordat and Moratorium*, 12 May 2016, pp. 1–2, <http://www.geneticalliance.org.uk/information/living-with-a-genetic-condition/insurance-privacy-and-the-concordat-and-moratorium/> (accessed 24 August 2017).

9.13 The exception to this, as stated in the Moratorium, is a predictive genetic test for Huntington's disease where life insurance is sought for over £500 000.<sup>18</sup> Such an exception is only in place due to the United Kingdom Government seeking advice from experts regarding an application from the Association of British Insurers to use the genetic test results of Huntington's disease. Under the Moratorium any such applications to use genetic information from the Association of British Insurers must go through this process.<sup>19</sup>

9.14 The Moratorium also prohibits the use of results from direct-to-consumer tests as well predictive or diagnostic test results acquired as a part of clinical research, such as through the 100 000 Genomes Project.<sup>20</sup>

9.15 The 100 000 Genomes Project will sequence 100 000 genomes from around 70 000 people with the aim of creating a new genomic medicine service for the National Health Service that will offer a diagnosis for patients, potentially identify new and effective treatments, and enable new medical research.<sup>21</sup>

9.16 Under the Moratorium, consumers and policyholders are allowed to use genetic test results to demonstrate that they are not at risk of an inherited disease.<sup>22</sup>

9.17 While the agreement is in operation until November 2019, the UK Government does not see a reason to introduce legislation regarding the use of genetic information or family history.<sup>23</sup> A review of the agreement was scheduled to take place in 2016.<sup>24</sup> At the time of this report, the status of this review is unclear.

9.18 Table 6.1 below illustrates the positions taken in response to the use of genetic information by insurers in European Union countries and the United Kingdom. The table outlines whether a country has a regime of self-regulation or not as well as:

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18 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014, clause 21(d); Genetic Alliance UK, *Insurance, Privacy and the Concordat and Moratorium*, 12 May 2016, pp. 1–2, <http://www.geneticalliance.org.uk/information/living-with-a-genetic-condition/insurance-privacy-and-the-concordat-and-moratorium/> (accessed 24 August 2017).

19 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014, clause 35.

20 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014, clauses 21(c), 36.

21 Genomic England, *The 100,000 Genomes Project*, 2017, <https://www.genomicsengland.co.uk/the-100000-genomes-project/> (accessed 20 September 2017).

22 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014, clause 22.

23 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014, clauses 3, 38.

24 HM Government and Association of British Insurers, *Concordat and Moratorium on genetics and Insurance*, 2014, clause 38.

- the stage at which insurers are limited or banned from using genetic information;
- whether the limitation or ban is restricted to certain products and/or to a financial limit of insurance coverage;
- whether a consumer can disclose their test results if they choose to and whether an insurer can ask a consumer to undertake a genetic test; and
- whether the regulation of the use of genetic information by insurers includes how an insurer can use a consumer's family history.

**Table 6.1: European approaches to the use of genetic information by life insurance companies**

Country	Type of regulation/ self-regulation	Policy stage	Are restrictions product specific?	Are there financial limits to regulations?	Can the consumer disclose a test by choice?	Can insurers ask consumers to take a test?	Is Family History included?
UK	Voluntary agreement	Applications	Yes	Yes	Yes	No	No
Germany Switzerland	Law	All	Yes	EUR 300,000 CHF 400,000	No	No	No
Holland Sweden	Law	All	No	EUR 250,000 SEK 1,284,000	No	No	No
Belgium	Law	All	Yes	No	No	No	Yes
Portugal	Law	All	No	No	No	No	Yes
Ireland	Law	Applications	No	No	No	No	No
Austria Denmark France	Law	All	No	No	No	No	No

Source: Financial Services Council, *Submission 26.2*, p. 8.<sup>25</sup>

25 See also M. Otlowski, S. Taylor and Y. Bombard, 'Genetic Discrimination: International Perspectives', *Annual Review of Genomics and Human Genetics*, 13, 2012, p. 443; The information provided by this source was accurate at its time of publication in 2012.

## *United States*

9.19 The *Genetic Information Non-Discrimination Act* is an American federal law providing protection for individuals from genetic discrimination in relation to health insurance and employment. The Act prevents health insurers from using genetic information in relation to decisions about eligibility, coverage, underwriting or premium setting. This protection includes persons who have tested positive for a predisposition to Huntington's disease prior to presenting any symptoms.<sup>26</sup> As a federal law, the Act sets the minimum level of protection that states in the United States must provide.<sup>27</sup> The Act is not retroactive, meaning it does not apply to genetic discrimination prior to the Act's enactment.<sup>28</sup>

## *Canada*

9.20 On 4 May 2017, the *Genetic Non-Discrimination Act* was passed into federal Canadian law. Under the Act insurers are prohibited from requesting that a person undergo a genetic test or from requiring the disclosure of previous or future genetic test results. The Act aims to protect predictive and diagnostic genetic tests and information obtained in clinical and research settings.<sup>29</sup>

9.21 However, the Act does not prohibit an insurer's access to family medical history. This means that a person will have to report their medical condition if a family member applies for insurance but not their genetic test results.<sup>30</sup> The Act also does not indicate whether someone would have to inform an insurer that they have had a genetic test. Under the Act, genetic discrimination may be a criminal offence.<sup>31</sup>

9.22 Prior to the enactment of the Act, the Canadian Institute of Actuaries released a research paper to support its position in opposing the Act. The paper noted that the Act will have a substantial impact on insurance companies with premiums increasing from between 30 to 50 per cent.<sup>32</sup>

9.23 The Canadian Life and Health Insurance Association believes that legislative regulation is unnecessary and announced that it would include in its Industry Code a commitment that insurers would not request or use genetic test information for life

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26 Genetic Information Nondiscrimination Act, *Genetic Information Nondiscrimination Act*, June 2010, p. 3, <http://www.ginahelp.org/GINAhelp.pdf> (accessed 24 August 2017).

27 Genetic Information Nondiscrimination Act, *Genetic Information Nondiscrimination Act*, June 2010, p. 7, <http://www.ginahelp.org/GINAhelp.pdf> (accessed 24 August 2017).

28 Genetic Information Nondiscrimination Act, *Genetic Information Nondiscrimination Act*, June 2010, p. 7, <http://www.ginahelp.org/GINAhelp.pdf> (accessed 24 August 2017).

29 *Genetic Non-Discrimination Act*, s. 3.

30 Canadian Association of Genetic Counsellors, *Genetic Non-Discrimination Act (GNA)*, 17 May 2017, p. 2, <https://www.cagc-accg.ca/doc/S201%20fact%20sheet%20-%20final%20copy%20-%20May%202017%202017.pdf> (accessed 20 September 2017).

31 *Genetic Non-Discrimination Act*, s. 7.

32 Canadian Institute of Actuaries, *Canadian Institute of Actuaries' Proposed Amendment to Bill S-201, An Act to prohibit and prevent genetic discrimination*, 21 November 2016, p. 2.

insurance application up to \$250 000.<sup>33</sup> This would mean that about 85 per cent of applications would not require disclosure of genetic information.<sup>34</sup>

9.24 Unlike Australia where the *Life Insurance Code of Practice* is mandatory for all members of the Financial Services Council (see the next section for further details), the Canadian Industry Code and proposed commitments is voluntary for members of the Canadian Life and Health Insurance Association.

9.25 The Office of the Privacy Commissioner in Canada published two reports that considered the effect that the Act would have on the Canadian insurance industry.<sup>35</sup> Both reports found that there would be no significant impact on the industry or insurance markets by banning the use of genetic information.<sup>36</sup>

9.26 A primary reason for this finding was that severe single gene disorders certain to cause premature death and requiring a high level of expensive coverage, such as Huntington's disease, occur so rarely as to have minimal effect on the insurance markets and the notion of pooled risk.<sup>37</sup>

9.27 However, both the Canadian Office of the Privacy Commissioner and the Library of the Canadian Parliament found that such a position may change as technology continues to advance and the reliability and predictability of genetic test results, as well as the number of conditions that can be identified, increases.<sup>38</sup>

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33 Canadian Life and Health Insurance Association, *Canada's Life and Health Insurers Announce Commitment on Use of Genetic Testing Information*, 11 January 2017, [https://www.clhia.ca/domino/html/clhia/clhia\\_lp4w\\_lnd\\_webstation.nsf/page/07AC1F9D1616B528852580A4006D544E](https://www.clhia.ca/domino/html/clhia/clhia_lp4w_lnd_webstation.nsf/page/07AC1F9D1616B528852580A4006D544E) (accessed 20 September 2017).

34 Canadian Life and Health Insurance Association, *Canada's Life and Health Insurers Announce Commitment on Use of Genetic Testing Information*, 11 January 2017, [https://www.clhia.ca/domino/html/clhia/clhia\\_lp4w\\_lnd\\_webstation.nsf/page/07AC1F9D1616B528852580A4006D544E](https://www.clhia.ca/domino/html/clhia/clhia_lp4w_lnd_webstation.nsf/page/07AC1F9D1616B528852580A4006D544E) (accessed 20 September 2017); Simmie Palter, 'The Genetic Non-Discrimination Act: Bill S-201', *DDO Health Law*, <http://ddohealthlaw.com/the-genetic-non-discrimination-act-bill-s-201/> (accessed 20 September 2017).

35 Office of the Privacy Commissioner of Canada, *The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context*, July 2011; Office of the Privacy Commissioner of Canada, *The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance*, March 2012.

36 Office of the Privacy Commissioner of Canada, *The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context*, July 2011, p. 2; Office of the Privacy Commissioner of Canada, *The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance*, March 2012, p. 2.

37 Office of the Privacy Commissioner of Canada, *The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context*, July 2011, p. 2.

38 Office of the Privacy Commissioner of Canada, *Statement on the use of genetic test results by life and health insurance companies*, 10 July 2014, p. 4, [https://www.priv.gc.ca/en/opc-news/news-and-announcements/2014/s-d\\_140710/](https://www.priv.gc.ca/en/opc-news/news-and-announcements/2014/s-d_140710/) (accessed on 20 September 2017); Office of the Privacy Commissioner of Canada, *The Potential Economic Impact of a Ban on the Use of Genetic Information for Life and Health Insurance*, March 2012, pp. 2–3; Library of Parliament, *Legislative Summary – Bill S-201: An Act to prohibit and prevent genetic discrimination*, 6 December 2016, p. 2.

9.28 The Library of the Canadian Parliament also found that it was difficult to determine the prevalence of genetic discrimination in Canada and internationally with different parties claiming 'discrimination is already a problem' or 'that there is no evidence that [discrimination] is widespread' or that 'there is not enough reliable information on which to base conclusive statements'.<sup>39</sup>

9.29 Currently, the constitutionality of the Act is being challenged, with the argument made that the Act seeks to legislate matters that are in the jurisdiction of Canadian provinces.<sup>40</sup>

## **Genetic information and the life insurance industry in Australia**

### ***Background***

9.30 As explained in chapter 8 of this report on access to medical information by insurers, a consumer has a duty to disclose all relevant information. Additionally, the *Privacy Act 1988* and the *Disability Discrimination Act 1992* allow insurers in Australia to use a consumer's genetic information where such information has been obtained with consent and its use is both justifiable and reasonable.

9.31 Life insurers explained to the committee that the reason they require a customer's genetic information is due to the principle of pooled risk. This principle was examined in chapter 8 of this report on access to medical information by insurers.

9.32 The 2003 report *Essentially Yours: The Protection of Human Genetic Information in Australia* by the Australian Law Reform Commission and the Australian Health Ethics Committee of the National Medical and Research Council (ALRC report) considered, in response to the rapidly developing area of human genetic information, how best to protect privacy, prevent unfair discrimination, and ensure high standards are in place for research.<sup>41</sup>

9.33 The ALRC report made note of how the area of genetics has produced two conflicting yet equally powerful reactions. The first being public support for advancements in medicine for better treatments and diagnosis. The second being concerns over privacy and genetic discrimination and how the use of genetic information will be regulated.<sup>42</sup>

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39 Library of Parliament, *Legislative Summary – Bill S-201: An Act to prohibit and prevent genetic discrimination*, 6 December 2016, p. 2.

40 Library of Parliament, *Legislative Summary – Bill S-201: An Act to prohibit and prevent genetic discrimination*, 6 December 2016, p. 7.

41 Australian Law Reform Commission and the National Medical and Research Council, *Protection of human genetic information*, 6 May 2003, <https://www.alrc.gov.au/inquiries/protection-human-genetic-information> (accessed 18 October 2017).

42 Australian Law Reform Commission and the National Medical and Research Council, *Protection of human genetic information*, 6 May 2003, <https://www.alrc.gov.au/inquiries/protection-human-genetic-information> (accessed 18 October 2017).

9.34 A key recommendation of the ALRC report was that a standing committee, known as the Human Genetics Commission of Australia, be established to provide high-level technical and strategic advice on emerging issues in genetics to the Australian Government, industry and community.<sup>43</sup>

9.35 The ALRC report also recommended that this advisory body be consulted in the development of guidelines and policy for genetics.<sup>44</sup> Other recommendations included, but were not limited to; the Human Genetics Commission of Australia determining what types of genetic tests should be used by insurers.<sup>45</sup>

9.36 The government established the Human Genetics Commission of Australia for a three year period from 2012–2015. In terms of recommendations relevant to life insurance, the government noted that the majority of the recommendations were directed at greater self-regulation of the life insurance industry.<sup>46</sup>

### ***Self-regulation and use of genetic information by the life insurance industry***

9.37 The Financial Services Council (FSC) is responsible for a self-regulatory regime that consists of commitments presented in the Life Insurance Code of Practice (Code) and a series of standards. The Code and standards are mandatory for FSC members, including a number of life insurers, to adhere to.<sup>47</sup>

9.38 Standard 11 relates to the use of genetic test results in life insurance underwriting and Standard 16 relates to the use of family history information. Standard 11 was first adopted by members of the IFA (the former name of the FSC) in 1998 and was updated on 7 December 2016. Standard 16 was first approved by the FSC Board on 1 December 2005 and was updated 7 December 2016. The updates to both standards were done in consultation with Associate Professor Kristin Barlow-Stewart, Director of the Master of Genetic Counselling at The University of Sydney.<sup>48</sup>

9.39 The FSC submitted that they have been working with the geneticist community, including geneticists both within and outside of the insurance industry,

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43 Australian Law Reform Commission and the National Medical and Research Council, *Essentially Yours: The Protection of Human Genetic Information in Australia- Executive Summary*, March 2003.

44 Australian Law Reform Commission and the National Medical and Research Council, *Essentially Yours: The Protection of Human Genetic Information in Australia- Executive Summary*, March 2003.

45 Australian Law Reform Commission and the National Medical and Research Council, *Essentially Yours: The Protection of Human Genetic Information in Australia- List of Recommendations*, March 2003.

46 Australian Government, *Full Australian Government Response to ALRC Report 96*, 9 December 2005, <http://www.alrc.gov.au/inquiries/health-and-genetics/full-australian-government-response-alrc-report-96> (accessed 28 September 2017); Australian Genetic Non-Discrimination Working Group, *Submission 60*, p. 4.

47 Financial Services Council, *Submission 26.2*, pp. 2–4.

48 Financial Services Council, *Submission 26.2*, p. 4.

since the early 1990s to develop standards that balanced the interest of the individual consumer with a risk management focus required by insurers.<sup>49</sup> The FSC believe that the standards promote best practice and allow customers to be proactive in their health care management without fear of insurance implications.<sup>50</sup>

9.40 The FSC informed the committee that Standard 11 specifies that insurers must not ask a consumer to undergo a genetic test.<sup>51</sup> However, where an applicant has already undertaken a genetic test prior to the application process, insurance companies do have access to the results of such tests.<sup>52</sup> Standard 11 also ensures that genetic test results are only used in assessing the applicant's risk and not risk associated with their family members.<sup>53</sup>

9.41 The FSC asserted that Standard 11 does not dissuade consumers from participation in medical and scientific research.<sup>54</sup> However, the disclosure of genetic information obtained through such studies is required where the consumer is aware of such results, that is, where participation in the research is not anonymous.<sup>55</sup>

9.42 In addition, the FSC drew the committee's attention to the FSC's updated Standard 11 of 7 December 2016 made in response to the rapid advancement in the field of genetics.<sup>56</sup> The update included new suggested wording to be used by life insurers when asking insurance applicants about genetic testing. These words are:

10.11 Members should give consideration to the following uniform wording when developing wording in personal statements with regard to genetic tests

10.11.1 Have you ever had or are you considering having a genetic test where you have received (or are currently awaiting) an individual result?<sup>57</sup>

9.43 Standard 11 explains that such words will provide insurance applicants with clarity where they have participated in a medical research project but have not received individual results.<sup>58</sup>

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49 Financial Services Council, *Submission 26.2*, p. 2.

50 Financial Services Council, *Submission 26.2*, p. 2.

51 Financial Services Council, *Submission 26.2*, p. 3.

52 Financial Services Council, *FSC Standard No. 11 Genetic Testing Policy*, 7 December 2016, clause 10.2.

53 Financial Services Council, *Submission 26.2*, p. 3.

54 Financial Services Council, *Submission 26.2*, p. 3.

55 Financial Services Council, *FSC Standard No. 11 Genetic Testing Policy*, 7 December 2016, clauses 10.3–10.3.2.

56 Financial Services Council, *Submission 26.2*, p. 3.

57 Financial Services Council, *FSC Standard No. 11 Genetic Testing Policy*, 7 December 2016, clauses 10.11–10.11.1.

58 Financial Services Council, *FSC Standard No. 11 Genetic Testing Policy*, 7 December 2016, clause 10.11.2.

9.44 However, at the public hearing on 1 December 2017, Mr Nick Kirwan, Policy Manager at the FSC, acknowledged that the question contained in clause 10.11.1 was 'horrible'. To this end, he explained to the committee that the FSC is prepared to commit to changing the question.<sup>59</sup>

9.45 The FSC has a Genetic Testing Underwriting Database which commenced in 2000.<sup>60</sup> This database records any underwriting decision made by a member of the FSC involving genetic test results.<sup>61</sup>

9.46 Under Standard 11, FSC members must provide the FSC with de-identified data on applications involving genetic testing.<sup>62</sup> FSC members must also agree to the data regarding genetic testing and insurance applications being made publicly-available as a means to support research.<sup>63</sup>

9.47 The committee was interested in understanding how many applications for life insurance involve genetic information. Noting the requirements under Standard 11 for FSC members to provide the FSC with de-identified data on applications involving genetic testing, the committee asked the FSC for the total number of applications for life insurance that involved genetic information since the approval of Standard 11. Importantly, the committee was only interested in a numerical total, not the raw data itself.

9.48 Nevertheless, the FSC were unable to provide the committee with the number of applications involving genetic testing. Instead, the FSC informed the committee that academics at the University of Sydney intended to publish their findings based on the independent review of the database, and that the data is highly sensitive and would require skilled analysis in order to be of any use.<sup>64</sup>

9.49 The FSC also stated that to its knowledge, the number of Australians who have had predictive genetic testing is low, although this number is likely to increase significantly in response to continuing developments in the field of genetics and the reduced costs of accessing genetic testing.<sup>65</sup>

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59 Mr Nick Kirwan, Policy Manager, Financial Services Council, *Committee Hansard*, 1 December 2017, p. 31.

60 Financial Services Council, *FSC Standard No. 11 Genetic Testing Policy*, 7 December 2016, clause 10.16.

61 Financial Services Council, *Submission 26.2*, pp. 2, 5.

62 Financial Services Council, *FSC Standard No. 11 Genetic Testing Policy*, 7 December 2016, clause 10.16.

63 Financial Services Council, *FSC Standard No. 11 Genetic Testing Policy*, 7 December 2016, clause 10.16.

64 Financial Services Council, answers to questions on notice, 31 August 2017 (received 27 September 2017).

65 Financial Services Council, answers to questions on notice, 31 August 2017 (received 27 September 2017).

9.50 It is the FSC's understanding that where genetic information is used by life insurers for underwriting decisions, it is common for the decision to be made by a Chief Underwriter with the potential involvement of a Chief Medical Officer or a specialist reinsurance company with access to geneticists and other medical specialists.<sup>66</sup> The Chief Medical Officer or specialist reinsurer may also consult with external geneticists.<sup>67</sup>

9.51 Life insurers submitted that, in line with FSC standards, they only ask consumers whether they have had a genetic test.<sup>68</sup> Insurers do not request consumers to undergo genetic testing or inform insurers of results from anonymous research trials.<sup>69</sup>

9.52 Life insurers such as TAL and Zurich also told the committee that circumstances where genetic information has to be provided by the consumer is uncommon. For example, Mr Brett Clark, Chief Executive Officer and Managing Director of TAL, stated that out of 33 000 applications for retail insurance, only 750 applications contained genetic information.<sup>70</sup> Likewise, Mr Tim Bailey, Chief Executive Officer of Zurich, commented that it would be extremely rare for genetic information to be disclosed at the time of underwriting.<sup>71</sup>

9.53 Furthermore, Ms Helen Troup, Managing Director of CommInsure, explained that where genetic information is provided, the credibility of the information, including whether it was analysed in an accredited testing facility, would be considered prior to deciding how much credence to place on such information.<sup>72</sup> Ms Troup noted that a pre-disposition to an illness would not in itself preclude a person from having a successful claims outcome unless the condition had been formally diagnosed.<sup>73</sup>

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66 Financial Services Council, *Submission 26.2*, p. 5.

67 Financial Services Council, *Submission 26.2*, p. 5.

68 Ms Helen Troup Managing Director, CommInsure, Commonwealth Bank, *Committee Hansard*, 8 September 2017, p. 21.

69 Mr Tim Bailey, Chief Executive Officer, Zurich Financial Service Australia Limited, answers to questions on notice, 26 May 2017 (received 9 June 2017); MLC Life Insurance, answers to questions on notice, 26 May 2017 (received 9 June 2017).

70 Mr Brett Clark, Chief Executive Officer and Managing Director, TAL, *Committee Hansard*, 18 August 2017, p. 12.

71 Mr Tim Bailey, Chief Executive Officer, Zurich Financial Service Australia Limited, *Committee Hansard*, 26 May 2017, p. 41; See also, Mr Philip Anderson, Chief operating Officer, Life and Investments, Zurich Financial Service Australia Limited, *Committee Hansard*, 26 May 2017, p. 41.

72 Ms Helen Troup Managing Director, CommInsure, Commonwealth Bank of Australia, *Committee Hansard*, 8 September 2017, p. 22.

73 Ms Helen Troup Managing Director, CommInsure, Commonwealth Bank of Australia, *Committee Hansard*, 8 September 2017, p. 22; See also, Mr Craig Harrison, General Manager, Life Product and Distribution, Commonwealth Bank of Australia, *Committee Hansard*, 8 September 2017, p. 22.

9.54 While the FSC acknowledged that the debate over whether life insurers should use genetic information was complex, the FSC was of the view that self-regulation, through the Code and standards, was the most appropriate way to manage the use of genetic information.<sup>74</sup>

9.55 Moreover, the FSC believed that countries that have introduced legislation in response to the issue of genetic information do not have the same 'robust self-regulation mechanism' as Australia.<sup>75</sup>

9.56 The FSC submitted that their regime of self-regulation also allows for the industry to quickly respond to any developments in technology and research relating to genetic testing, unlike legislation which could take years to reflect any changes.<sup>76</sup>

9.57 The FSC also informed the committee that placing limits on, or banning the use of, genetic information will have consequences for consumers. One such consequence is that a consumer will not be allowed to use a negative test result to demonstrate to an insurer that they are not at risk of developing a condition.<sup>77</sup>

9.58 In terms of a moratorium type response to the use of genetic information, Mr Kirwan explained that the FSC does not support such an approach as it provides no certainty to consumers about what will happen with their genetic test results or any future test results once the moratorium concludes.<sup>78</sup>

9.59 Another consequence identified by the FSC and other insurers was the potential for anti-selection and information asymmetry. This position was examined in chapter 8 of this report on access to medical information by insurers.

9.60 Life insurers such as AMP, CommInsure, MLC and Zurich supported the FSC's position that the use of genetic information by insurers is a developing and complex area that requires further debate.<sup>79</sup>

9.61 MLC opposed any changes in legislation that would prohibit the use of genetic information by life insurers and, like the FSC, noted that genetic test results could benefit a customer by demonstrating to an insurer that they are not at risk.<sup>80</sup>

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74 Financial Services Council, *Submission 26.2*, p. 9.

75 Financial Services Council, *Submission 26.2*, p. 9.

76 Financial Services Council, *Submission 26.2*, p. 9; See also, Mr Nick Kirwan, Policy Manager, Financial Services Council, *Committee Hansard*, 1 December 2017, p. 32.

77 Financial Services Council, *Submission 26.2*, p. 7; See also, Mr Nick Kirwan, Policy Manager, Financial Services Council, *Committee Hansard*, 1 December 2017, pp. 31, 32.

78 Mr Nick Kirwan, Policy Manager, Financial Services Council, *Committee Hansard*, 1 December 2017, pp. 31, 32.

79 Mr Craig Meller, Chief Executive Officer, AMP, additional information received 5 September 2017, pp. 7–8; Ms Helen Troup Managing Director, CommInsure, Commonwealth Bank, *Committee Hansard*, 8 September 2017, p. 21; MLC Life Insurance, answers to questions on notice, 26 May 2017 (received 9 June 2017); Mr Tim Bailey, Chief Executive Officer, Zurich Financial Service Australia Limited, *Committee Hansard*, 26 May 2017, p. 41.

9.62 Likewise, AMP explained to the committee that, as the use of genetic information by the industry is not common at the moment, a full discussion on the appropriateness of a ban with stakeholders should take place before decisions are made on how to respond to the issue.<sup>81</sup>

### **Arguments for reform**

9.63 In summary, the arguments presented to the committee for reform of how life insurers use genetic information recommended that the use of such information should ideally be banned in order to protect consumers against genetic discrimination. In addition, concerns were raised about the FSC's current regime of self-regulation, the accuracy and interpretation of genetic test results, and how the use of genetic information by insurers affects participation in research.

### ***Concerns about self-regulation***

9.64 Professor Margaret Otlowski, Dean of Law at the University of Tasmania and Chair of the Australian Genetic Non-Discrimination Working Group (AGND Working Group) called for legislation that would restrict or ideally ban the use of genetic information by life insurers and a moratorium prohibiting the use of genetic information until such legislation is enacted.<sup>82</sup>

9.65 The AGND Working Group argued that a legislative response was necessary due to the inherent conflicts of interest within a self-regulatory regime such as the FSC's Code and Standards. The AGND Working Group argued that a conflict exists between the benefits that accrue to the life insurer from obtaining as much information as possible, and the consumer's loss of privacy and potential exposure to genetic discrimination.<sup>83</sup>

9.66 As noted earlier in this chapter, the update made to FSC Standard 11 in December 2016 included a question about whether a consumer is considering taking a genetic test. The AGND Working Group argued that the appropriateness of this

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80 Mr Andrew Hagger, Chief Customer Officer, National Australia Bank, answers to questions on notice, 26 May 2017 (received 9 June 2017).

81 Mr Craig Meller, Chief Executive Officer, AMP, additional information received 5 September 2017, pp. 7–8.

82 Professor Margaret Otlowski, Law Dean, University of Tasmania; and Chair, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, pp. 59, 62.

83 Australian Genetic Non-Discrimination Working Group, answers to questions on notice, 26 May 2017 (received 9 June 2017); Professor Margaret Otlowski, Law Dean, University of Tasmania; and Chair, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, pp. 59, 62; See also, Ms Jane Tiller, Legal and Social Adviser, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, pp. 67–68.

question was not subject to independent oversight, and saw it as allowing insurers to obtain more information than is necessary.<sup>84</sup>

9.67 While the FSC informed the committee that a geneticist was consulted in the revising of Standard 11, the AGND Working Group claimed that the geneticist community is not adequately represented in consultations undertaken by the insurance industry.<sup>85</sup>

9.68 The AGND Working Group also claimed that, due to self-regulation, it is unclear whether there is a systematic use of expert geneticists when reviewing and developing actuarial modelling to assess risk associated with predictable genetic disease.<sup>86</sup>

9.69 Both the Australian Medical Association (AMA) and the Royal Australian College of General Practitioners (RACGP) agreed that the self-regulated way in which insurers may or may not use genetic information obtained from a consumer is problematic.<sup>87</sup>

9.70 In relation to industry arguments that information is needed in order to prevent anti-selection and increased premiums, the AGND Working Group stated that no evidence had been provided by the life insurance industry to substantiate these claims.<sup>88</sup>

9.71 Furthermore, the AGND Working Group noted that the two reports commissioned by the Office of the Privacy Commissioner in Canada found that there would be no significant impact on the life insurance industry or insurance markets as a result of a ban on life insurers using genetic information.<sup>89</sup>

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84 Professor Margaret Otlowski, Law Dean, University of Tasmania; and Chair and Ms Jane Tiller, Legal and Social Adviser, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 67; Australian Genetic Non-Discrimination Working Group, answers to questions on notice, 26 May 2017 (received 9 June 2017)

85 Dr Paul Lacaze, Head, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Founding Member and Ms Jane Tiller, Legal and Social Adviser, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, pp. 67–68.

86 Professor Margaret Otlowski, Law Dean, University of Tasmania; and Chair, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, pp. 66–67.

87 Ms Anne Trimmer, Secretary General, Australian Medical Association, *Committee Hansard*, 8 September 2017, p. 32; Dr Edwin Kruys, Vice President and Chair, RACGP Queensland, answers to questions on notice, 8 September 2017 (received 26 September 2017).

88 Australian Genetic Non-Discrimination Working Group, answers to questions on notice, 26 May 2017 (received 9 June 2017).

89 Professor Margaret Otlowski, Law Dean, University of Tasmania; and Chair, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 64.

### ***Accuracy of genetic testing***

9.72 Dr Paul Lacaze, the Head of Public Health Genomics at Monash University and a founding member of the AGND Working Group, claimed that more research was needed to understand genetics and its relationship to the future prediction of disease risk, and that the information presently obtained from genetic testing is not sufficiently robust to justify its use in actuarial modelling.<sup>90</sup>

9.73 Dr Kate Stockhausen, Manager of Ethics at the AMA, also highlighted issues around the accuracy of genetic results, particularly from direct to consumer tests.<sup>91</sup>

9.74 While genetic test results obtained in Australia are subject to oversight and quality control, direct-to-consumer genetic tests are not regulated in terms of how the results are interpreted or where the testing occurs.<sup>92</sup>

9.75 Dr Lacaze advised the committee that direct-to-consumer test results are based on risk calculations that are not scientifically supported. Additionally, no genetic counselling is provided for such results and there is no medical oversight of how the results are interpreted.<sup>93</sup> Ms Jane Tiller, a Legal and Social Adviser in Public Health Genomics at Monash University and a member of the AGND Working Group observed, however, that despite the absence of these counselling and oversight processes, such test results would still need to be disclosed to an insurer.<sup>94</sup>

### ***Adverse impact on potentially life-saving genetic testing and participation in research***

9.76 The committee was told that the ability of life insurers to use genetic information is also adversely impacting the public's willingness to undergo genetic testing due to fears that their access to appropriate insurance may be compromised.

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90 Dr Paul Lacaze, Head, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Founding Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, pp. 61, 63.

91 Dr Kate Stockhausen, Manager, Ethics, Australian Medical Association, *Committee Hansard*, 8 September 2017, p. 31; see also Royal Australian College of General Practitioners Queensland, answers to questions on notice, 8 September 2017 (received 26 September 2017).

92 Australian Genetic Non-Discrimination Working Group, *Submission 60*, pp. 2, 6; Dr Paul Lacaze, Head, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Founding Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 65.

93 Dr Paul Lacaze, Head, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Founding Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 65.

94 Ms Jane Tiller, Legal and Social Adviser, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 65.

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According to the AGND Working Group, such fears may lead to an additional burden on the public health system as people avoid being tested and therefore cannot make the necessary lifestyle changes to be healthy.<sup>95</sup>

9.77 Similarly, Dr Stockhausen told the committee that the AMA does not want a situation arising where the actions, or potential actions, of a third party might cause a person to avoid having genetic testing.<sup>96</sup>

9.78 Ms Tiller told the committee that life insurers having access to genetic test results negatively impact on the number of people participating in research studies. Unlike the United Kingdom, where individuals can participate and obtain their results from the public 100 000 genomes research project without insurance implications, this is not currently possible in Australia.<sup>97</sup>

9.79 Likewise, Dr Simon Longstaff AO, Executive Director of The Ethics Centre, believed that people should not have to fear the insurance implications of participating in research as research has an inherent community benefit.<sup>98</sup>

9.80 Dr Lacaze also noted that a lack of participation in research may affect the future competitiveness and progress of the Australian research industry as well as the identification of emerging health issues. He provided evidence that in one study over half of the individuals who choose not to participate indicated that insurance concerns were the reason why.<sup>99</sup>

9.81 Dr Longstaff explained to the committee that, at its core, insurance is a means to respond to the uncertainty of life. Individuals pool their risk so that when an adverse event occurs, the pool's resources can be used to respond to the event.<sup>100</sup>

9.82 In Dr Longstaff's view, the insurance industry's trend towards trying to determine with greater precision the likely fate of an individual will, at some point,

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95 Australian Genetic Non-Discrimination Working Group, *Submission 60*, p. 5.

96 Dr Kate Stockhausen, Manager, Ethics, Australian Medical Association, *Committee Hansard*, 8 September 2017, pp. 28–29.

97 Ms Jane Tiller, Legal and Social Adviser, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, p. 62.

98 Dr Simon Longstaff AO, Executive Director, The Ethics Centre, *Committee Hansard*, 26 May 2017, pp. 70–71.

99 Dr Paul Lacaze, Head, Public Health Genomics, Department of Epidemiology and Preventative Medicine, School of Public Health and Preventative Medicine, Monash University; and Founding Member, Australian Genetic Non-Discrimination Working Group, *Committee Hansard*, 26 May 2017, pp. 62–68; See also, Productivity Commission, *Data Availability and Use*, No. 82, 2017, p. 5.

100 Dr Simon Longstaff AO, Executive Director, The Ethics Centre, *Committee Hansard*, 26 May 2017, p. 70.

become at odds with the purpose of insurance and the community benefit it provides.<sup>101</sup>

9.83 Dr Longstaff advised the committee that while the current situation regarding life insurers' use of genetic information is appropriate, he would be cautious about allowing insurers to 'push too far in terms of either demanding testing or using the results of testing in order to risk-weight the individual'.<sup>102</sup>

### **Committee view**

9.84 The committee is of the view that the evidence to the inquiry indicated that, at present, genetic data is not presently sufficiently accurate or reliable, particularly in relation to the increasingly popular direct to consumer genetic testing, for a duty to disclose to be appropriate.

9.85 Evidence presented to the committee indicated that an individual's genetic information can be used by insurers to charge a higher premium, exclude insurance cover for certain conditions or deny insurance. This has occurred even in instances where individuals have taken proactive steps to reduce their likelihood of having a certain condition. However, it was never used to reduce premiums.

9.86 While it may be difficult to ascertain the prevalence of genetic discrimination, the continual developments in the area of genetics, as well as costs reductions, means 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 The committee notes the reasoning underlying the insurance industry's need for genetic information. However, 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. In addition, the Canadian Office of the Privacy Commissioner found that the sustainability of the Canadian insurance industry is not likely to be affected at this time by a ban on the use of genetic information. Life insurers did not provide strong evidence to the contrary.

9.88 Though the committee considers the fears overstated, the committee acknowledges adverse selection as a phenomenon in insurance. The committee's primary concern in that regard is the potential for higher costs for consumers if information asymmetry between insurers and insureds causes insurers to seek to put up premiums to compensate. However, on balance, the committee believes there is presently greater benefit to consumers in preventing a duty of disclosure from arising in respect of predictive genetic tests for the reasons referred to above.

9.89 Furthermore, the committee is concerned that the use or perceived use of genetic information by life insurers has impacted on participation in public health

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101 Dr Simon Longstaff AO, Executive Director, The Ethics Centre, *Committee Hansard*, 26 May 2017, p. 70.

102 Dr Simon Longstaff AO, Executive Director, The Ethics Centre, *Committee Hansard*, 26 May 2017, p. 71.

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research projects and other forms of research. The committee is also concerned that 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.

9.91 The committee notes that the FSC were unable to provide the committee with the exact number of its member's of life insurance applications that involved genetic information since the approval of Standard 11.

9.92 Nevertheless, given that it appears that the use of genetic information by life insurers remains low, and the understanding of genetic testing and its predictive accuracy is developing, the committee is not persuaded that legislation should be the first response.

9.93 As a first step, the committee considers that the FSC, in discussion with the AGND Working Group, should update the Code and Standards 11 and 16 in order to 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 ASIC Enforcement Review Taskforce Position Paper, particularly the requirements for industry codes to be registered. The committee is firmly of the view that some of the concerns regarding self-regulation would be alleviated if the government provided ASIC with the appropriate enforcement powers to implement a co-regulatory approach.

9.95 In terms of the recommendations made in this chapter regarding the Code and Standards 11 and 12, 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.

### **Recommendation 9.1**

**9.98 The committee recommends that the Financial Services Council, in consultation with the Australian Genetic Non-Discrimination Working Group, assess the consumer impact of imposing a moratorium on life insurers using predictive genetic information, unless the consumer provides genetic information to a life insurer to demonstrate that they are not at risk of developing a disease.**

### **Recommendation 9.2**

**9.99 The committee recommends that the Financial Services Council make any updates as necessary to Standard 16—Family History and the *Life Insurance Code of Practice* to support the recommended changes to Standard 11—Genetic Testing Policy as outlined in Recommendation 9.1.**

### **Recommendation 9.3**

**9.100 The committee recommends that life insurers be banned from using predictive genetic information while the Financial Services Council is updating Standard 11—Genetic Testing Policy, Standard 16—Family History, and the *Life Insurance Code of Practice* to align with Recommendation 9.1.**

### **Recommendation 9.4**

**9.101 The committee recommends that if the Financial Services Council and life insurers have adopted a moratorium on the use of predictive genetic information as outlined in Recommendation 9.1, the Australian Government should continue to monitor developments in genetics and predictive genetic testing to determine whether legislation or another form of regulation banning or limiting the use of predictive genetic information by the life insurance industry is required.**