

# **FSC Standard No. 11**

## **Genetic Testing Policy**



**December 2005**

**Main features of this Standard are:**

- **The Genetic Testing Policy to be adopted by a Member in the operation of its life insurance business; and**
- **Guidance in the interpretation and application of those Standards.**

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## Title

- 1.1 **This Standard (The “Standard”) may be cited as FSC Standard No. 11 ‘Genetic Testing Policy’.**
- 2 **Standards and Commentary**
  - 2.1 **The standards set out in this Standard are shown in bold print. Commentary is shown in normal print immediately after the standard to which it relates, as an aid to interpretation of the standard.**
- 3 **Date of Issue - This standard was approved by the IFSA Board on 13 December 2001 to take effect from 1 January 2002. The IFSA Board approved Standard No.16 Family Medical History Policy on 26 October 2005. Standard No.11 has been modified to bring both this Standard and Standard No.16 into line. There has been no change to the Genetic Testing Policy in paragraph 10 of Standard No.11.**
- 4 **Effective Date – 1 January 2002**
  - 4.1 **This Standard should be applied in relation to a Member’s operations on or after 1 January 2002. Earlier application of this Standard is permitted and encouraged.**
- 5 **Application**
  - 5.1 **This Standard applies to all Members who are a registered life insurance company or have a subsidiary that is a registered life insurance company.**
  - 5.2 **All life insurance companies registered by APRA who are not FSC Members are encouraged to follow this Standard.**
  - 5.3 **Where there is a conflict between the requirements of this Standard and any applicable legislation, the requirements of this Standard should, having regard to the purpose of the Standard, be modified appropriately so that, as far as is practicable, the registered life insurer complies with the requirements of this Standard.**
  - 5.4 **This Standard should be read in conjunction with FSC Standard No.16 Family Medical History Policy and FSC Standard No.1 Code of Ethics & Code of Conduct**
- 6 **Statement of Underlying Principles**
  - 6.1 **In establishing this Standard, the industry acknowledges the following underlying principles:**
    - **that life insurance should remain available to the vast majority of people at standard premium rates;**

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- that risk classification should be free to evolve and reflect the continual development of medical knowledge ;
- that the price at which standard cover life insurance is offered should be an affordable price for average Australians;
- that, given the long term nature of the contracts, the industry must remain viable over the long term. Viability requires prudential management, management of risk including minimal cross-subsidisation between customer groups and provide reasonable returns to shareholders;
- that the Insurer maintain consumer confidence and is accountable and transparent so that nothing the industry does negatively impacts on a consumer's decision to take a genetic test or undergo appropriate medical intervention, nor impact on a person's decision to participate in a research program.

## 7 Statement of Purpose

7.1 The purpose of this Standard is to specify Standards relating to the handling of genetic test results to be adopted by a Member in the operation of its business;

7.2 Because of the significance individuals place on genetic test results, Members should meet the highest standards in relation to the handling of genetic test results within their operations. A variety of legislation imposes requirements on Members to meet objectives that are deemed important to consumers; therefore Members should closely monitor their obligations on an ongoing basis.

7.3 Experience has shown that, in addition to meeting regulatory requirements, there are other business principles and practices that should be followed in order to maintain a high standard of conduct in the operation and management of a Members' business.

7.4 This Standard, while based on the goal of an efficiently functioning life insurance industry, which remains viable in the long term, also acknowledges the industry's social responsibility to support the advancement and adoption of medical technologies, which improve health outcomes in the community.

## 8 Application of Materiality

8.1 The standards in this Standard apply to FSC Members. Failure by a Member to adopt or implement a Standard is material if such failure has the potential to adversely affect:

- an insured or potential insured person's confidence in the life insurer;
- other insured person's confidence in the Insurer or insurance;

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## 9 Definitions

### 9.1 In this Standard:

- **‘Applicant’ means the person to be insured;**
- **‘APRA’ means the Australian Prudential Regulation Authority;**
- **‘Authorised Representative’ means any person or entity authorised by the Member to provide information or advice to consumers in respect of the sale of a Member’s life insurance products.**
- **‘Genetic Test’ means “the direct analysis of DNA, RNA, genes or chromosomes for the purpose of determining inherited predisposition to a particular disease or group of diseases, but excluding DNA, RNA, gene or chromosome tests for acquired disease”;**
- **‘Insurer’ means a member of the Financial Service Council (FSC);**
- **‘Member’ means a member of the Financial Service Council (FSC).**

## 10 Genetic Testing Policy

### 10.1 Insurers will not initiate any genetic tests on applicants for insurance.

10.1.1 An applicant will not in any circumstances be asked by a Member to undergo a genetic test to support an application for insurance.

### 10.2 Insurers may request that all existing genetic test results be made available to the insurer for the purposes of classifying the risk.

10.2.1 This requirement to disclose relevant information is in line with the duty imposed by the Insurance Contracts Act 1984. This Act places applicants under both a contractual and statutory duty to disclose all relevant facts to an insurer.

10.2.2 Genetic information, like all health status information, may influence a person’s motivation to apply or not to apply for insurance cover.

10.2.3 Unless the insurer is in possession of the same information about the risk profile of an applicant as an applicant has about him or herself, the insurer cannot set a fair price for the insurance cover being applied for, which can result in a significant increase in the cost of claims, leading in turn to an increase in premium rates for all insured lives. In some circumstances the deliberate withholding of significant information amounts to material non-disclosure or fraud, with adverse consequences for the individual under existing legislation.

10.2.4 Assessing individual applications for insurance and applying the appropriate classification of risk and pricing is essential for the maintenance of a viable voluntary life insurance industry.

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- 10.3 In order to prevent indirect coercion to undergo genetic tests, insurers will not use genetic tests as the basis of 'preferred risk underwriting', (i.e. offering individuals insurance at a lower than standard premium rate).**
- 10.3.1 A genetic test will either indicate a future risk of a disease developing or not, the results of which may be unfavourable and distressing, or favourable and welcomed. It should be borne in mind that an unfavourable result will often allow early medical treatment. A person has a choice whether to know about their risk or not and some may choose not to know if there is no immediate prospect of a condition's prevention or its cure. Others may wish to know in order to take control of their lives and to consider the effect on other family members, particularly children.
- 10.3.2 Members should respect an applicant's right not to know and will not, in any circumstance, encourage or coerce an applicant to undertake a genetic test, even if this means that an application will be subject to a loading or modification to the contract's terms as a consequence of a family history of a genetic disease or disorder.
- 10.3.3 Where an applicant advises a Member that they are considering volunteering to take a genetic test for the purpose of obtaining insurance then the Member should issue a prominent warning statement similar to the following statement to the applicant: "Insurance companies are always prepared to review any assessment for insurance, on the basis of the provision of new or additional information. However, you should be aware that having a genetic test is a serious decision, which has implications for you and your family. FSC member companies encourage you to seek professional advice from your doctor or a qualified genetics counsellor to ensure you have a thorough understanding of the possible ramifications before you consider a test.FSC member companies also encourage you to discuss this decision with your family."
- 10.4 Members must provide their employees and Authorised Representatives who represent them with sufficient information and training so that those employees and Authorised Representatives can reasonably be expected to understand the content and meaning of this Standard so far as it relates to their particular jobs and responsibilities.**
- 10.4.1 Member's Authorised Representatives must be aware of the need to seek specialist advice before responding to applicant's questions, as the types of genetic tests and their potential impact on the applicant differ enormously.
- 10.5 When assessing the overall risk associated with a particular genotype (genetic make-up), insurers will take into account the benefits of special medical surveillance, early medical intervention and the likelihood of successful treatment.**
- 10.5.1 Members should ensure that they have access to appropriately informed experts (either internal or external) to assist in the underwriting assessment where a genetic test result is likely to be a factor in the assessment of an application.

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- 10.5.2 Members will keep themselves informed of wider developments in genetics likely to affect insurance and risk assessment through relevant courses and publications.
- 10.5.3 Members must incorporate into their procedures new information, which affects the way certain genetic diseases are underwritten, as quickly, as is practicable.
- 10.6 Insurers will ensure that results of existing genetic tests are only obtained with the written consent of the tested individual.**
- 10.6.1 Members will not ask a third party for an applicant's genetic test result without first having obtained the applicant's written consent.
- 10.7 The results of genetic tests will only be used in the assessment of an insurance application in respect of the individual on whom the test was conducted. The result will not be used in the assessment of insurance applications of relatives of the tested individual.**
- 10.7.1 It may be possible to draw inferences about the genetic status of relatives of a person who has had a genetic test performed. However, Members will only use the results of a genetic test to classify the risk of the person on whom the test was conducted. The genetic test result of an applicant will not be used by Members to assess applications from any of the applicant's relatives.
- 10.8 Insurers will ensure that strict standards of confidentiality apply to the handling and storage of the results of genetic tests.**
- 10.8.1 Members must maintain strict standards of confidentiality in the handling and storage of all medical information including genetic test results.
- 10.9 Access to the results of genetic tests in a form identifiable to particular individuals will be restricted to the insurer's underwriters and reinsurers. The results will be made available to other third parties only with the written authorisation of the applicant/insured or in the normal course of discovery during legal proceedings.**
- 10.9.1 Members will always respect the privacy of the applicant in any of its dealings with third parties.
- 10.9.2 Statistical records may be kept in a de-identified form to allow trends to be monitored.
- 10.10 Insurers will limit access to genetic test results to their Chief Underwriters (or their delegates) who are responsible for underwriting the application, for maintaining the confidential files for genetic tests and collecting the insurer's statistics on genetic tests results disclosed on applications for insurance. Where necessary, access to the results of genetic tests will be extended to other appropriately informed experts (including Company's Medical Officers and reinsurers) who are involved in the underwriting assessment.**

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- 10.10.1 Members will institute internal policies to control access to genetic test results by limiting access to the test results to authorised staff.
- 10.10.2 Member's authorised staff that have access to genetic test results will sign a confidentiality agreement, which acknowledges their understanding of the need to keep genetic test results, like all other information gained in their job, confidential.
- 10.11 All underwriting decisions, involving a genetic test, whether or not the test was a significant factor in the decision, should be thoroughly documented, so that adequate information can be provided to the applicant on request (subject to 10.12.2).**
- 10.12 Insurers will provide reasons for offering modifications or rejections to applicants in relation to either new applications or requests for increases on existing policies.**
  - 10.12.1 Members will inform applicants in a clear and meaningful way of the reasons for their decision in relation to the application.
  - 10.12.2 Where a Member is of the opinion that the decision is more appropriately explained by the applicant's own doctor, the reasons will be provided to the doctor. In these cases, the applicant will be given the decision and asked to discuss the reasons with their doctor.
  - 10.12.3 Members, when informing an applicant of their decision, will include information about how the applicant can lodge a complaint about the decision.
- 10.13 After assessing an application, a Member may conclude that the risk is too great to insure. In these circumstances, Members should endeavour to offer alternative terms (as may be actuarially justifiable) or alternative products.**
  - 10.13.1 Insurers will exercise care to ensure they are not providing Personal Advice contrary to Financial Services Reform Act 2001 (Chapter 7 Corporations Act 2001).
- 10.14 Insurers will have a competent & efficient internal dispute resolution system to deal with complaints relating to underwriting decisions involving a genetic test result. Responses to any complaints must include a reference to the legal remedies available to the applicant.**
  - 10.14.1 Members receiving any complaints from applicants will ensure that the complaint is referred to its internal dispute resolution system, which should investigate and deal with the complaint promptly
  - 10.14.2 After a Member has considered the complaint lodged by the applicant, and where the dispute with the applicant remains unresolved, then the Member's response must include a statement on the applicant's legal rights to further challenge the decision

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- 10.15** **Members' compliance with the Standard must be certified annually according to the terms of FSC Standard No 1 Code of Conduct and Code of Ethics.**
- 10.15.1 Members must monitor their staff's and authorised representative's compliance with this Standard and must take action where there has been a breach
- 10.16** **Subject to compliance with the Privacy Act, Members agree to participate in FSC's regular collection of de-identified data on applications involving a genetic test. Further, members agree to allow FSC to make such de-identified data public in order to aid any future research initiatives.**