Important points

- In Australia, premiums for private health insurance are not based on a risk assessment of an applicant’s present or past health or their family history. Applicants simply choose the type of coverage they wish to purchase and are charged a set fee, regardless of age or health status – a system known as ‘community rating’
- Premiums are based on an assessment of the applicant’s future health risks according to their present and past health, any genetic information including family history or any genetic test result, as well as other risk factors such as smoking, dangerous hobbies, etc (the insurance is risk-rated i.e. underwritten)
- Life insurance products include cover for life, disability, trauma, business and bank loans
- The Financial Services Council (FSC; see www.fs.org.au) has an industry standard for its members on genetic testing and life insurance that states that no applicant will be required to undergo a predictive or presymptomatic genetic test for the purpose of obtaining a life insurance policy. Similarly, no inducements to undertake the testing such as reductions in premiums will be offered.
- Under the law (Insurance Contracts Act 1984), an applicant for a life insurance product is required to disclose to the insurer any health or genetic information known to them that might impact on the insurance policy being applied for.
  - The industry standard covering collection of family history now states that you are only required to provide information (medical and genetic test results if known) about your living or deceased parents, brothers and sisters (first degree relatives)
- Insurance policies offered by life insurance companies in Australia are ‘guaranteed renewable’: once the applicant has received acceptance of the policy in the mail, no further health or genetic information needs to be provided
- The insurance premium —and even the ability to obtain an insurance policy— may vary between different companies depending on their calculation of the health risk as well as commercial factors. Applicants may wish to make applications to a range of companies at the same time; an insurance broker or agent may be helpful in this process
- Applicant’s should involve their family doctor, medical or genetics specialist if necessary in negotiations with the insurance company and document any screening and prevention strategies, where applicable
- If the predictive genetic test result was received before securing insurance cover, the applicant is required to make the results available to the insurer. Where an applicant’s relative has had a predictive genetic test and the test result is known, disclosure of this information is required—but not any other personally identifying information, such as the relative’s name or contact details
- An insurance policy may be secured before having genetic testing and the premium charged will be based on the information disclosed to the insurer, including the family history
- Some insurers ask whether it is the applicant’s intention to undergo a genetic test in future. Where it is intended, this will usually result in the insurer postponing the application until the test is performed and the result known. The result will then be used by the insurer in the underwriting of the risk. Importantly, an intention to seek genetic counselling, or having had genetic counselling, is not an intention to have a genetic test
- If a blood sample for a predictive genetic test has been given, but the sample has not yet been analysed by the laboratory, the person may withdraw from the testing. While this information should be disclosed, the insurer should underwrite the risk on the basis of the family history and other respective disclosures made in the application. The insurer may request a statement to clarify that there is no immediate intention to request the result of the disclosed genetic test. Similarly, if a person provides a sample for the DNA to be stored for future testing (DNA banking), then they have not yet undergone a genetic test
- If the laboratory has analysed the sample and a result is pending, the insurance company may delay assessing the application until the result is available
- Research Projects: The life insurance industry does not want to see potential research impeded by an individual’s fears that their participation may have an adverse impact on obtaining future life insurance. As always, full disclosure of any genetic test undertaken in any context needs to be made in an application. However, if a personal result will not be provided from the project, which means that you will not have anything to disclose relevant to your risk, the insurer will not use the fact that you have had a genetic test in the assessment of your premium
- Dealing with insurance companies:
  - Ensure any information provided by brokers or agents is in writing from the insurer
  - The complaint system provided by the insurance company or any other official process may be helpful if an applicant is concerned about how their application was assessed
  - Enlist the support of the family doctor, medical or genetics specialist with addressing these concerns

Genetic information, which includes your family medical history and the results of predictive genetic tests, might have implications for risk-rated life insurance options. Life insurance products include cover for:
- Life
- Disability (income protection)
- Trauma
- Business and bank loans which require a policy for life, disability or trauma

Life insurance can be obtained through direct application to the insurance company, through other distribution channels such as an insurance agent, by direct marketing without the assistance of an agent or financial adviser, or may be available through a superannuation plan.

Predictive genetic testing refers to testing of an individual who currently does not have symptoms or signs of a condition, but who might be at an increased risk due to their family history.
If the genetic test result shows that you have inherited the faulty gene (the result is ‘positive’), you will have an inherited predisposition (susceptibility i.e. you are at increased risk) for developing the condition over your lifetime. Importantly, you may never develop the condition unless other, often unknown triggering factors are also present. Examples of such conditions include some cancers, some cardiac conditions and hereditary haemochromatosis (see Genetics Fact Sheets 47-51, 53-55 & 36).

There are however some other rare conditions where inheriting the faulty gene means that you will develop the condition in your lifetime (if you live long enough) but it is not possible to determine with any accuracy at what age the condition may manifest itself, or its severity. Examples of such conditions include Huntington disease and early onset Alzheimer disease (see Genetics Fact Sheets 44 & 45).

Predictive genetic testing is currently possible for a limited number of inherited conditions (see Genetics Fact Sheet 21).

**Concerning insurance**

The Financial Services Council (FSC), representing life insurance companies in Australia, has an industry standard (Standard No. 11) that applies to genetic testing and life, disability and trauma insurance (see FSC’s fact sheet ‘Life Insurance and Genetic Testing in Australia’ at www.fsc.org.au).

Under FSC’s standard No. 11, you will not be required to undergo a predictive genetic test in order to obtain a life insurance product or make a change to an existing insurance policy.

Applications for a life insurance policy usually require the disclosure of any known genetic information which includes personal and family medical history and you and your relative’s genetic test results (where known). Recent changes to the industry Standard No. 16 that covers collection of family history information, requires you only have to disclose medical and genetic test information about yourself and your parents and brothers and sisters (first degree relatives).

Depending on the health condition involved, the use of this information in the underwriting process may or may not lead to:

- Higher (non-standard) insurance premiums;
- A reduced period of coverage;
- An exclusion for one or more medical conditions;
- The offer of an alternate insurance product;
- Deferral of the decision whether to offer coverage; or
- Outright denial of an offer for insurance.

Costs of insurance, and the ability to obtain insurance cover, may vary between different companies depending on your risk. You might wish to make applications to a range of companies at the same time. An insurance broker or agent may be helpful in this process.

Insurance policies offered by Life Insurance companies in Australia are *guaranteed renewable*. This means that you only have to apply for the cover once and you are not subject to providing any other information for the duration of the policy—unless you request to alter the policy and there is a need for the insurer to re-underwrite (reassess) the risk. In the event of the reassessment resulting in a premium loading or policy exclusion being imposed—or even the risk being declined and this is not acceptable to you—the original policy will remain in force upon your continued payment of the original policy premiums.

Other important points to note are:

- Under the law (*Insurance Contracts Act 1984*), you are required to inform the insurer of any changes you know that might impact their offer of insurance from the time of completing the application to the time of receiving the policy document in the mail
- Once a guaranteed renewable policy has been issued, there is no longer any obligation to inform the company of any changes in circumstances, such as the result of a predictive genetic test
- The *Insurance Contracts Act* also requires you to abide by a “duty of disclosure to the insurer where every matter that is known to the applicant, or could reasonably be expected to be known, that is relevant to the insurer’s decision must be disclosed. Some companies will ask for more details than others. You are obliged to provide answers to the questions asked honestly and to the best of your knowledge”. The disclosure requirement relates only to you and your first degree relatives
- If a predictive genetic test result indicates that you are lower risk than previously estimated based on your family history alone, you should inform the insurance company so that the policy can be reassessed with this new information
- Insurance policies that are offered by general insurance companies covering ‘sickness and accident’ are renewable during the time of cover of the policy. At every renewal period, disclosure of any information that you now have, including any change in genetic information (family medical history or genetic test results) must be disclosed. With these policies, each renewal period is like making a new application.

**Involve your family doctor, medical or genetics specialist if necessary in negotiations with the insurance company and document your screening and prevention strategies, where applicable.**

**Group Insurance**

Insurance cover for a limited amount (up to a predetermined level referred to as an ‘automatic acceptance level’ [AAL]) might be available, for example, as part of a superannuation plan. This is called ‘group insurance’. Eligibility to obtain such insurance up to the AAL amount requires you to be working and carrying out your usual duties at the time of the application. As this insurance has a limited cover, you are not individually ‘underwritten’ i.e. no individual health information, including family history and genetic testing results is required.

If however, you need or want insurance for a higher amount than the AAL, then your personal health and that of your parents, brothers and sisters (family history of your first degree relatives) as well as any genetic testing information will be required. This information will be used in the assessment of your premiums (underwritten).

It is advisable to investigate the options available to you with regard to the types of insurance available through group insurance. Life insurance, disability cover and even trauma cover can now usually be obtained via this insurance option for most employers in Australia. Your employer might be able to assist you with this.
If you are a sole proprietor of a business, you should consult your insurance broker or agent for advice.

If you leave your employer and your group insurance cover is still in place, you should talk to your current and prospective employer about your options with regard to carrying your insurance cover into your superannuation plan with your new position. This can often be done by taking up what is commonly known as a ‘continuation option’ which might be available to you. Alternatively, your new employer may well offer similar cover for which you might be eligible as long as you are at work on the day you make your application.

**Applying for insurance**

There are a number of situations that are relevant for people regarding predictive genetic testing and life insurance.

1. **Where a blood sample has not yet been taken for a predictive genetic test:**

You might wish to investigate your insurance options before considering predictive genetic testing. Securing a policy could take several weeks or more. **What you know** about the health of your parents, brothers and sisters (i.e. first-degree relatives) should be provided to a potential insurer.

Some companies might ask if advice and/or counselling have been sought about health or future health. In answer to this question, if **genetic counselling** had been attended to discuss risks based on a family medical history (but where a sample was not taken for a predictive genetic test), you must disclose that you had attended.

Sometimes genetic counselling can clarify that your family history does not indicate that you are at potentially high risk for a certain condition, and this can be helpful when applying for insurance.

2. **Where a blood sample for a predictive genetic test has been taken**

(a) **A test sample has not yet been analysed by the laboratory:**

As with all types of medical treatment, you can withdraw your consent for a procedure at any time. It is possible to withdraw consent to a sample being analysed at any time prior to the laboratory starting the process. In this situation, disclosure is still required to a potential insurer about the fact that a sample was provided for a genetic test but that you had withdrawn from the testing process without a result.

Where this has occurred, insurance companies are bound, under FSC’s genetic testing standard No 11, to respect your right ‘not to know’ your predictive genetic test result (see point 6 below, **Dealing with insurance companies**) and should underwrite the risk accordingly on the basis of your family history and the other respective disclosures made in your application. The insurer may request a statement to clarify that you have no immediate intention to request the result of the disclosed genetic test.

Sometimes an individual will give a sample for testing to be done in the future. This is sometimes called ‘DNA banking’. If you provide a sample for DNA banking you have not yet undergone a genetic test.

(b) **A laboratory has analysed your sample and a result is pending:**

Disclosure of undertaking such a test is required by a potential insurer. In this situation, an insurance company may await a result before proceeding with the application.

(c) **The laboratory has analysed your sample but you have chosen not to know your result:**

There may be a number of reasons why you might choose not to have your genetic test result. For example, you might have a test only for the benefit of other family members but do not wish to know your own result.

- In these circumstances you should disclose that a genetic test has been undertaken and that you have not chosen to obtain the test result. The insurer may request a statement from you to clarify that you have no immediate intention to request the result of the genetic test and should then underwrite the risk accordingly on the basis of your family history and the other respective disclosures made in your application.
- The insurance companies are bound, under FSC’s genetic testing policy, to respect an individual’s right ‘not to know’ their predictive genetic test result (see point six, **Dealing with insurance companies**).

3. **Where a predictive genetic test result has been received before securing insurance cover:**

The insurance company will require that the results of any genetic test be made available.

4. **Where a relative has had a predictive genetic test and the test result is known by the insurance applicant:**

When applying for insurance, it is required to disclose any **health information** that is **known**, about yourself, your parents and siblings. This is relevant to an assessment of your risk.

- This would include past and present health problems and predictive genetic test results, but would not include providing personally identifying information like the relative’s name.
- The insurer may also request written consent from you to access your medical records from your doctor.
- If there is information about a relative’s genetic test result in your medical record, your doctor may be obliged to disclose the test result information but in the written consent it is possible to request that a doctor does not disclose any personally identifying information about relatives.

5. **Research Projects**

The life insurance industry does not want to see potential health and medical research impeded by an individual’s fears of the impact that their participation may have in obtaining future life insurance.

How the insurer uses the fact that you have had a predictive genetic test as part of a research study will depend on how the research project is being conducted:

(a) **You will not receive any personal or family information from the research.**

As always with the requirement for full disclosure, you need to disclose that you have had the test, but as you will not be able to tell them the result, the insurer will not use the fact that you have had genetic testing in an assessment of your risk.
(b) You will not be given a personal genetic test result but you might be told that the research has indicated that a family test result could be important to your future health.

The opportunity to investigate options further through a clinical service will be made available:

- If you are advised of the above scenario, you are now aware of a matter that an insurer might consider relevant, and are therefore expected to disclose the information in an application for a policy
- If you choose to undergo a further predictive genetic test in a clinical setting, similar obligations to disclose apply.

(c) You will receive a personal result from the research.

This is perceived as no different to having the test conducted in a clinical setting and the insurer may take into account your research participation in the assessment of your risk.

6. Dealing with insurance companies

If the insurance company is a member of FSC, it will be bound by the FSC standards.

- If the company is not a member of FSC, you should enquire about their policy regarding genetic testing
- If advised by an agent/broker that an insurance offer might be declined, deferred, offered at non-standard rates or impacted on the basis of a particular genetic test result:
  - You should check that this advice is received from the company’s underwriter in writing and a copy requested
  - A genetics specialist may be able to explain the reasons for a decision, and if necessary might discuss the decision with the company’s Chief Underwriter or Chief Medical Officer
  - If there are difficulties with an insurance company over an application or renewal, it is possible to follow the Internal Disputes Resolution process that each company has documented in their product disclosure brochure (this is the brochure that contains the application form).

Other Genetics Fact Sheets referred to in this Fact Sheet: 21, 36, 44, 45, 47, 48, 49, 50, 51, 53, 54, 55

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