



LDG MEETING - 18TH MAY 2011

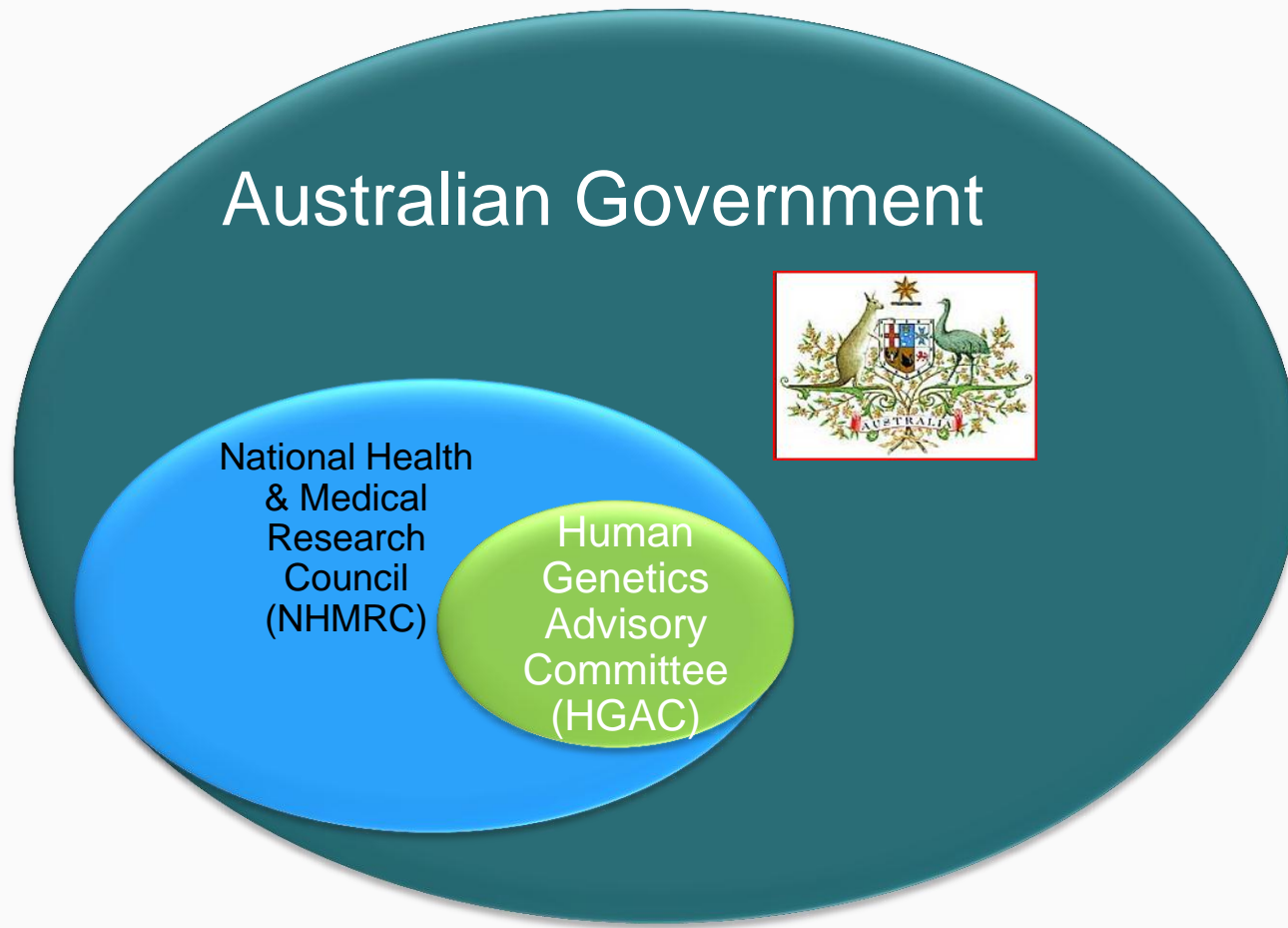
Genetics – “Under the microscope”

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Chief Underwriter

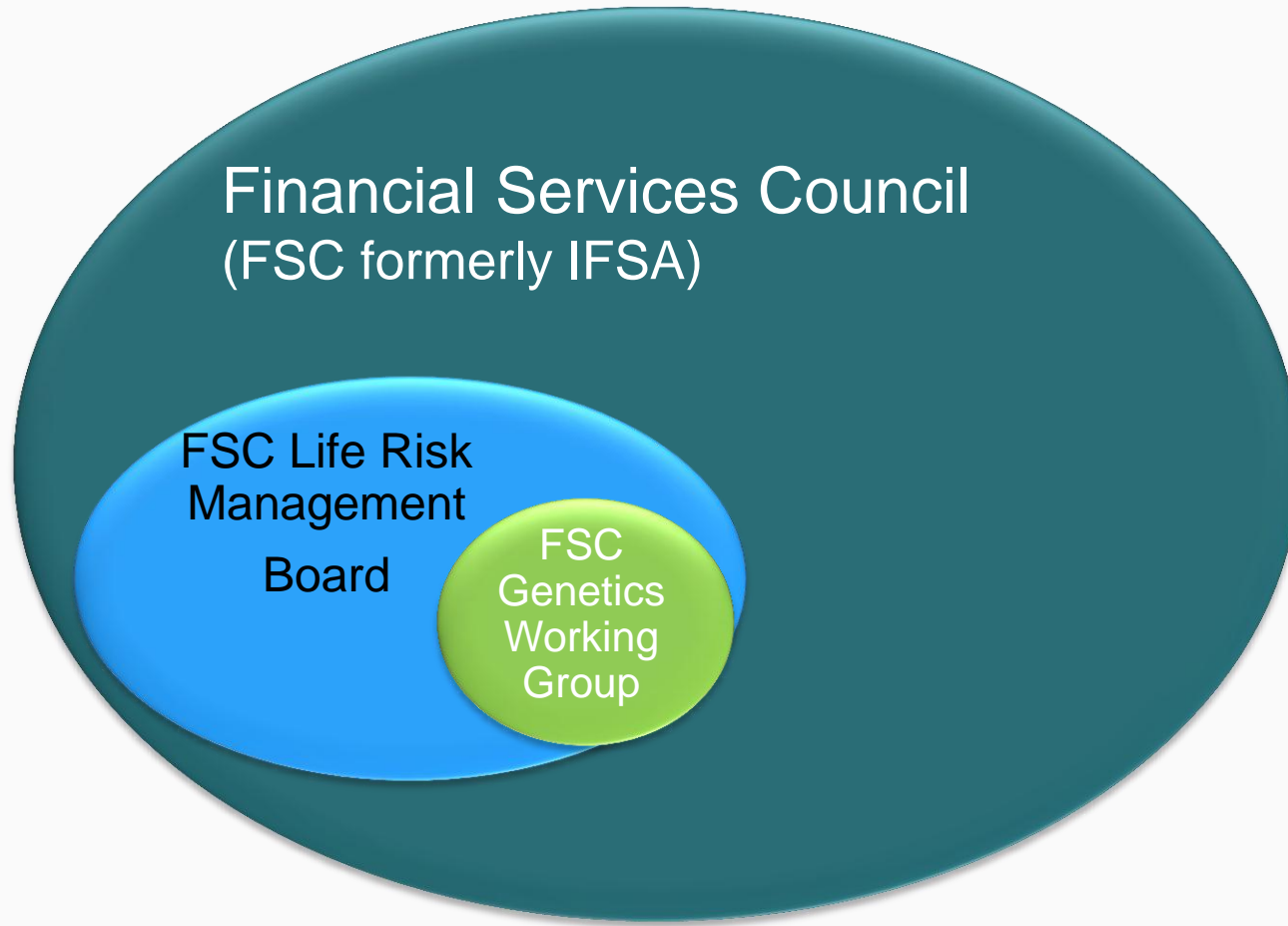
Session Overview

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1. Human Genetics Advisory Committee (HGAC)
 2. Financial Services Council (FSC)
 3. Industry Challenges
 4. Discussion / Questions

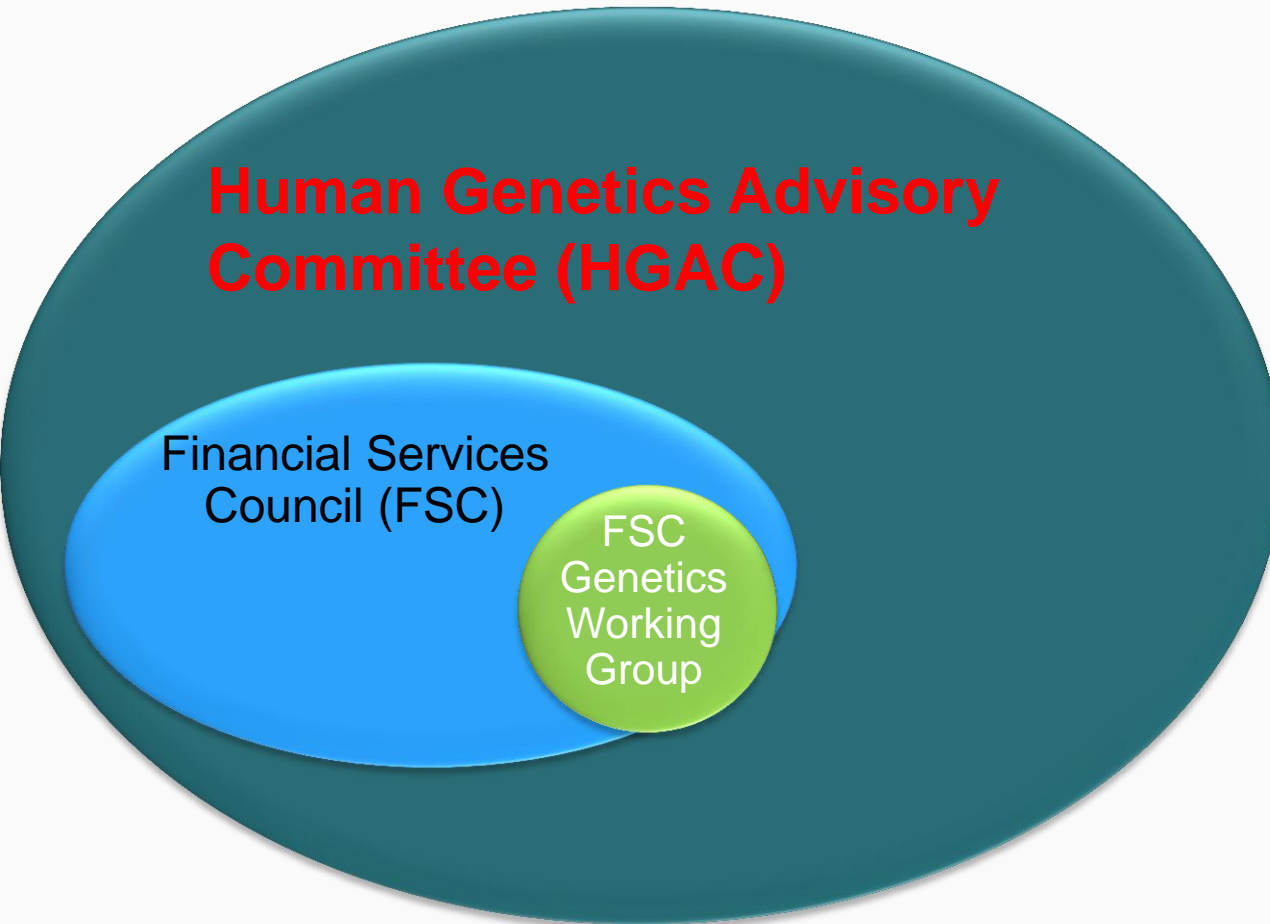
Who Fits Where ? – The big picture



Who Fits Where ? – Life Ins. Industry



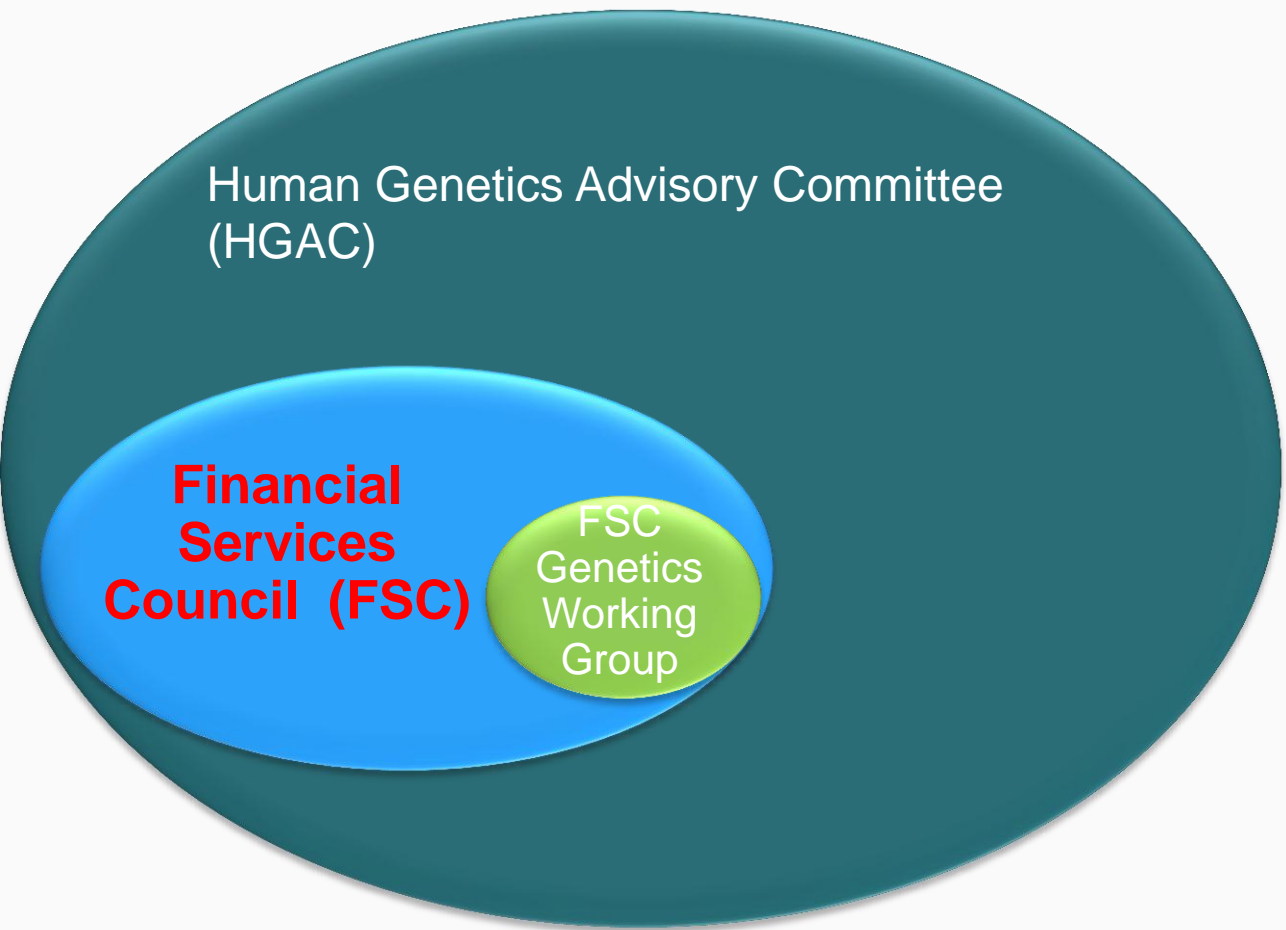
Who Fits Where ?



HGAC

- Ministerial (Aust. Govt) appointment (triennium)
- Committee advise on:
 - current & emerging issues in human genetics & related technologies particularly the expected impacts on human health & healthcare
 - ethical, legal & social implications arising from developments in human genetics & related technologies

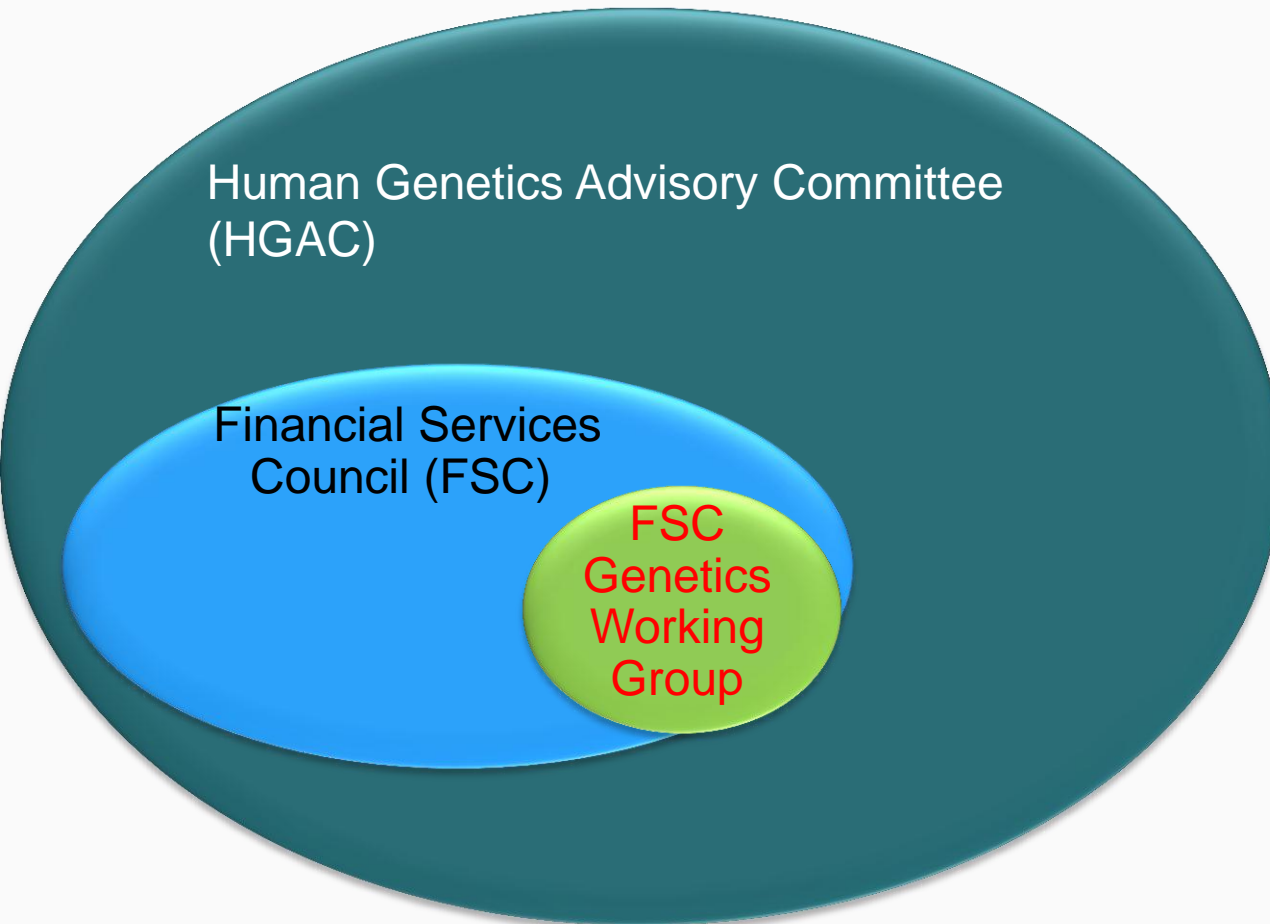
Who Fits Where ?



FSC

- National peak body representing the Australian retail and wholesale funds management, superannuation and life insurance industries.
- Plays significant role in the development of the social, economic and regulatory framework in which we operate, thereby assisting us to serve our customers better

Who Fits Where ?



FSC Genetics Working Group

- Working group comprised of life insurance risk technicians from Australian life insurance companies
- Advise the IFSA Life Risk Management Board on risk insurance matters involving genetics

Human Genetics Advisory Committee



Australians refused insurance because of poor genes

Deborah Smith
Science Editor

AUSTRALIANS have been refused insurance protection because of their genetic make-up, researchers have shown in the first study in the world to provide proof of genetic discrimination.

Most cases were found to relate to life insurance. In one instance, a man with a faulty gene linked to a greater risk of breast and prostate cancer was denied income protection and

trauma insurance that would have let him claim if he developed other forms of cancer.

The findings have led to renewed calls by experts for policies to ensure the appropriate use of genetic test results by the insurance industry.

The director of the Centre for Genetics Education at Royal North Shore Hospital, Kristine Barlow-Stewart, said the research also showed consumers needed to be better informed about their rights.

"Eighty-five per cent of the people in the study didn't know where to go to seek assistance if they had been discriminated against," she said.

Associate Professor Barlow-Stewart and her colleagues surveyed more than 1000 people who had attended clinical genetic services about their experiences of discrimination.

In a long, complex process that was only possible because of the assistance of organisations and companies that had carried out the

GENETIC DISCRIMINATION

- ▶ Life insurance 42%
- ▶ Family context 22%
- ▶ Health services 20%
- ▶ Social life 11%
- ▶ Employment 5%

discrimination, the researchers were able to verify 11 cases of genetic discrimination, and their results are published in the journal *Genetics in Medicine*.

Previous to this paper, only

anecdotal reports of genetic discrimination have been available, with some commentators questioning whether or not the phenomenon actually existed," Dr Barlow-Stewart said.

In one case, two women with the same genetic fault linked to breast cancer applied for income protection to the same insurer three years apart.

One was denied any type of cover, while the other was offered insurance with an exclusion of breast cancer.

The different decisions were justified by the Insurance and Financial Services Association on the grounds of updated scientific information. "But I don't believe consumers should be penalised while the insurance companies are learning," said Dr Barlow-Stewart.

An expert assessment panel should be established to advise on which tests were sufficiently well understood to be used for insurance purposes, she said.

This was one of the recommendations of a 2003

report by the Australian Law Reform Commission. "And it still hasn't happened."

Under industry guidelines, insurers cannot compel people to have a genetic test, but those who have been tested must reveal their results.

It is legal for companies to use this information only if they can justify their decisions.

In the case of the man with the breast cancer gene, genetic experts judged his exclusion from claims relating to all forms of cancer was too broad.

INSIDE

Step it up war: NATO

NATO officials say Australia overstating its commitment in the war in Afghanistan is failing to take a greater role in planning the campaign, an official said. The Government official said the European countries were not sharing the burden as "past its use date".

WORK

Derailed: Criminal claims irrelevant, says girl's father

Campuses n poor student

Elite Sydney universities to do more to attract poor students, the report says.


MONITORS

ack



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MTWTFSS-

THE AGE

ESTABLISHED IN 1854

Gene testing exposes us all to discrimination

Loss of privacy and risk of penalties can outweigh benefits.

IT IS 10 years since the human genome was mapped. Genetic testing is big business. However, by 2000, most European countries and American states had enacted laws on the use of such tests for employment and insurance purposes. At the time, *The Age* warned that Australians lacked privacy protection and faced economic and social assessments of their genetic "stamp". Despite some

superannuation products. If tests indicate a higher risk, a person may be charged more, offered a shorter period or more limited form of cover, or refused cover (but health insurance premiums cannot be adjusted for individual risk). If a customer conceals a test, the insurer may refuse to pay out. A member of the federal government's Human Genetics Advisory Committee, Kristine Barlow-Stewart, studies genetic

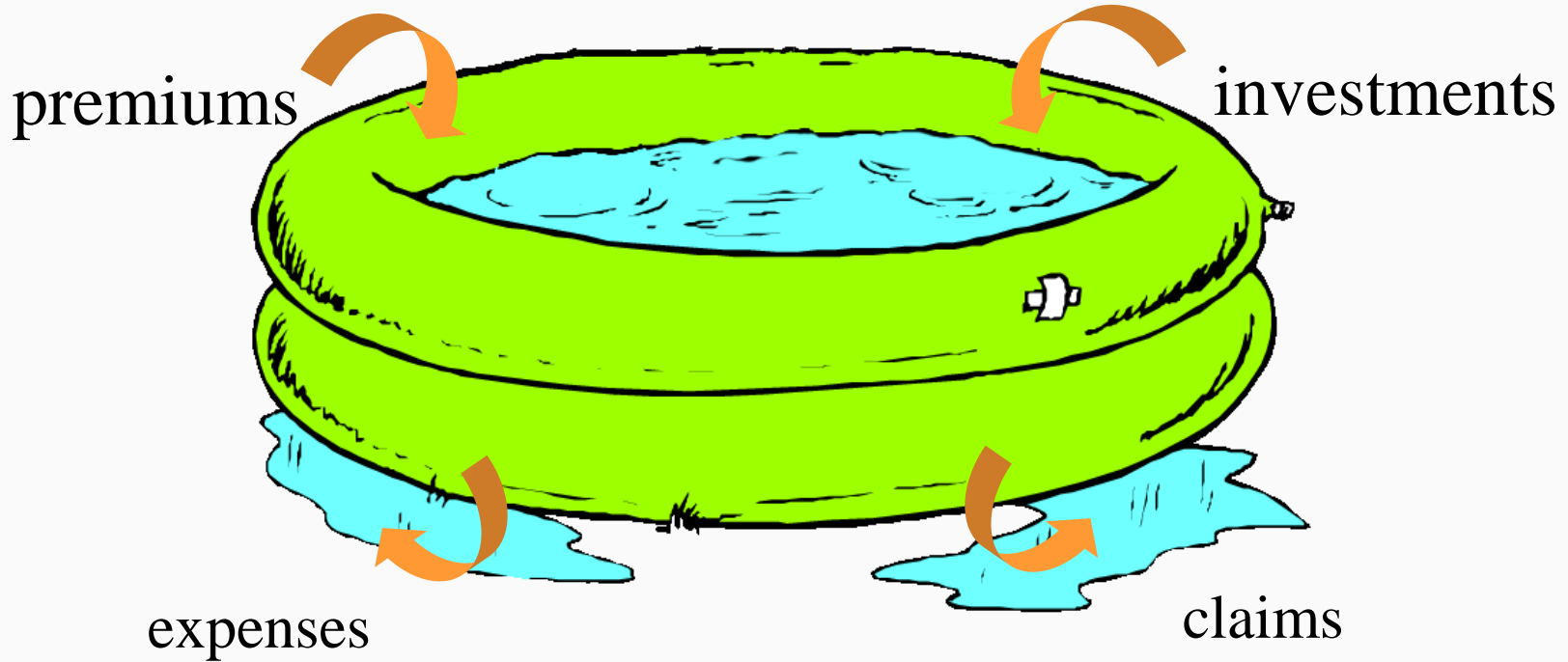
to use results of genetic testing against people. Last year, the Disability Discrimination Act was amended to cover genetic predispositions to disability, but the definition of a disability is far narrower than the range of genetic conditions that expose people to discrimination.

This is much more than an issue of medical risk and insurance. As *The Age* stated in 2005: "We all hold information in our

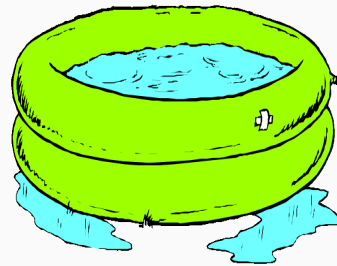
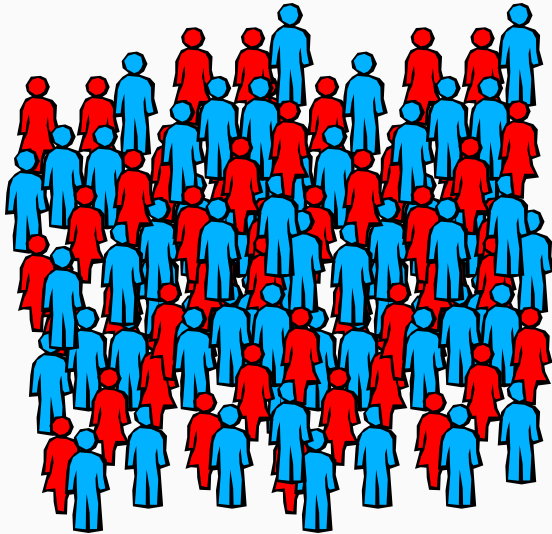


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- Feb 2001 - Aust Law Reform Commission (ALRC) undertook inquiry into matters relating to protection of human genetic information in Australia
 - Final report “Essentially Yours – the Protection of Genetic Information in Australia” issued March 2003
 - Australian Govt response handed down April 2006
 - Essentially Yours Report was catalyst for the formation of the HGAC & remains the driver for the HGAC with regards to matters life ins.
 - * Interest in how insurers use genetic information
 - * How insurers underwrite / price risks involving genetic information
 - * Keen interest in whether insurers unlawfully discriminate
 - * Disability Discrimination Act
 - * Allows discrimination where it is based on statistical data / research
 - My involvement - very much been education process of what we do & why ?

Life Insurance – How is it priced?



All being equal - That is if all lives have the same risk of claim then....

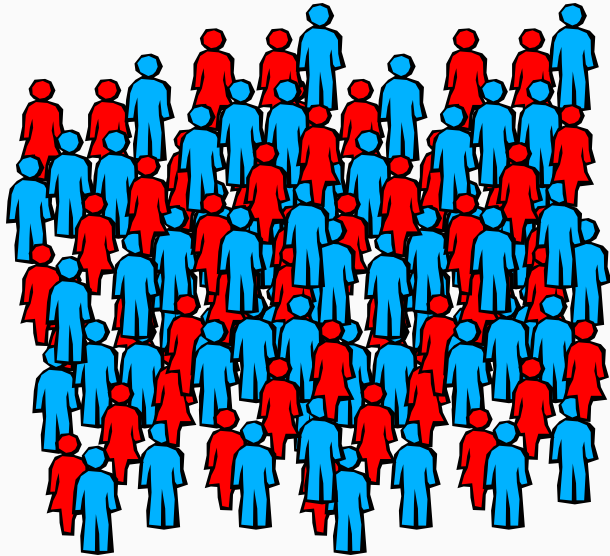


**\$500 000 in
the pool**

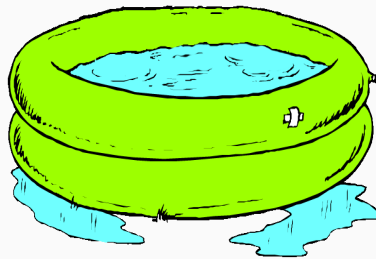
**Sufficient funds
in pool to meet
the expected 1x
claim of \$500,000**

**If 1 death per annum will
occur from 1000 people (with
the same risk factors) aged 40
and each insures for \$500,000
sum insured
Each life pays a \$500 premium
to the insurer**

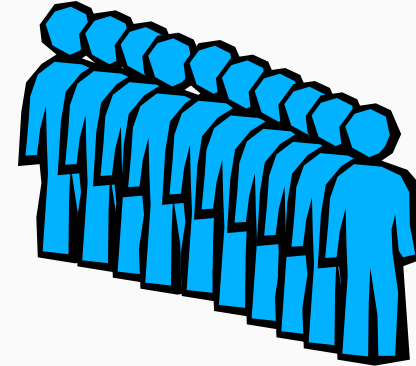
If anti-selection occurs or we ignore material risk factors



1000 people pay \$500 each for a \$500,000 sum insured policy but....9 lives know they are more likely to die or have additional risk factors to the rest of the pool



\$500,000
in the pool



Total of 10 death claims (Ie, 9 additional to the 1 claim expected) means \$5 million is required in the pool to meet claims costs.

Insufficient funds in pool of \$4.5 million

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1. Mid way through 2nd year of current triennium for HGAC
 2. During first 18 months there has been a number of Life Ins related matters tabled requiring our attention, consideration and action :
 3. CEO NHMRC Professor Warwick Anderson wrote to FSC in later stages 2010 requesting a meeting with FSC to discuss –
 - desire to establish independent expert panel to determine suitability of genetics tests for use in risk rating by the insurance industry
 - provision of guidance on clinical & actuarial relevance of particular tests
 - assist in dispute panel for cases involving genetic tests



In addition : other key areas of concern for HGAC centre on what needs to be disclosed to the insurer by an applicant :

- (a) Genetic counsellors report uncertainty regarding Insurance Personal Statement questions Vs applicant's Duty of Disclosure (duty to disclose known risk factors relative to the risk!)

- (b) Applicant's involved in medical research projects or trials
 - debate on whether research related genetic tests should be disclosed

- (c) Pharmacogenomics

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“Quick Wins” for the industry may be achieved to demonstrate our willingness to address perceived problems and ensure greater transparency by:

- re-structuring (and standardising) the P/S questioning across the industry
- and / or updating respective FSC Standards on Genetic Testing (11) & Family History (16)

Recommended GWG Solutions -

(i) For applicant's involved in medical research or trials :

“Have you ever had or are you considering having a genetic test where you received (or are currently awaiting) an individual result?”

Doesn't cater for pharmacogenomic genetic testing.

(ii) General Family Hx wording in P/S

Has your mother, father or any brother or sister

Inclusion of following foot note -

“Note: you are only required to disclose any family history information pertaining to first degree blood related family members – living or deceased. (mother, father, sisters, brothers)”

_FSC Genetics Working Group Activity

- Instrumental in the development of industry guidelines (“Standards”) with regard to:
 - FSC Genetic Testing (Standard 11)
 - FSC Family Medical History (Standard 16)
 - GWG undertaken review both standards wordings
- Instrumental in industry’s ongoing collection of data involving applications Hx genetic testing is disclosed
- Investigating most efficient and cost effective collection and reporting of data

FSC Genetics Working Group Activity

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- Approx 400 (genetic test) applications p.a
 - >750,000 applications p.a

Latest draft report (Rice Warner) based on data collected from 1 Dec 2007 to 30 Nov 2009:

- Haemochromatosis most commonly disclosed genetic test (approx 56%)
- Approx 58% of total applications involving disclosed genetic tests were offered “standard” premium rates
- 27% “non-standard”
- 15% deferred or declined

FSC Genetics Working Group Activity

Of those applications where the disclosed genetic test was “Positive” :

- 43% UW on “standard” premium terms
- 29% “non - standard”
- 28% deferred or declined

Of 144 applications not offered “standard rates”

- 7 (or only 5%) were cases where the insurer indicated the genetic test was the sole reason for the UW decision

FSC Genetics Working Group Activity

- GWG has established a framework for a “Genetics Information Review Panel” (as recommended by ALRC “Essentially Yours” report)
 - Draft format – Requires FSC Life Risk Board and then member approval
- Ongoing FSC education (on all matters genetics) needs to continue including distribution channels

Australian Industry Challenges

“Moratorium Model” debate - Why not ?

- Aust Govt response to ALRC “Essentially Yours” report
- Rapid scientific/medical advancements in genetics
- Growing number “compulsory” insurance options now available in Australian market
- Leaves “door ajar” for other lobby groups to request similar concessions

**Ongoing FSC member training / education
(including distribution)**

Wider Industry Challenges (Worldwide)

Growing Direct To Consumer (DTC) Testing market

- validity of testing
- risk of “anti-selection”

Rapid scientific/medical advancements in genetics

- Genetics → Genomics (single gene Vs multi gene)
- Envisaged availability of entire human genome testing
- Risk Assessment / Actuarial modeling
 - Reasonable for common single gene mutations
 - Challenge is for multi gene mutations - Will we be ready ?



THANK YOU

Discussion / Questions