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GENETIC TESTING &  
LIFE INSURANCE  
CONSUMER  
PERCEPTION  
RESEARCH

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# 1. Research context

## 1.1 Background

The Australian Law Reform Commission and the Australian Health Ethics Committee are currently undertaking an inquiry into the protection of human genetic information. The terms of reference of the inquiry were announced in February 2001, and the Law Reform Commission and Australian Health Ethics Committee are required to report back to the Commonwealth Government by 30 June 2002.

An issues paper was released shortly after the November 10 Federal election, and submissions to the inquiry are required by mid-January 2002.

IFSA held a meeting with stakeholders, including consumers, researchers, doctors and hereditary disease interest groups. Some stakeholders expressed concerns regarding the potential misuse of results of genetic tests by life insurance companies. These concerns include:

- That individuals may decline to enter into public genetic test screening or research programs for fear of adversely influencing their standing with life insurers
- That genetic test results should not be released to life insurers because the results reveal information not only about the patient, but also about the patient's immediate family
- That life insurers do not have the knowledge or expertise to underwrite individuals who present with a particular genetic test result

An Insurance Council of Australia study in late 2000 found strong consumer opposition to allowing insurance companies access to the results of genetic tests.

In August 2001 IFSA commissioned Eureka Strategic Research to conduct quantitative research. The aim of the research was to allow IFSA to extend its understanding of consumer knowledge and attitudes to genetic testing and life insurance. The quantitative research raised several issues that were then explored in more detail in consumer group discussions. The groups were held in early December 2001.

The results of the research will also be used to inform and support IFSA's submission to the joint inquiry into the protection of genetic information.

## 1.2 Research objectives

The main aim of the research was to explore consumers' attitudes to allowing insurance companies to access results of genetic tests for the purpose of risk assessment and premium setting. More specifically, the objectives of the research were:

- To explore consumers' understanding of life insurance companies' use of different factors in assessing risk.
- To understand consumers' attitudes to life insurance companies' use of different factors in assessing risk.
  - These factors included sex, age, smoking status, current and past health, family history of cancer or heart disease, and genetic make-up.
- To determine if the use of genetic test results by life insurance companies would deter consumers from having such tests.
- To explore consumer attitudes to disclosure of information to insurance companies.
  - Attitudes to voluntary and involuntary disclosure.
- To gain an understanding of why consumers hold particular attitudes.
- To collect information on consumers' current ownership of life insurance products, and demographic information.

## 2. Methodology

### 2.1 Quantitative research

The objectives of the first phase of this project lent themselves very well to a structured survey approach. Several open-ended questions were also included to explore why consumers hold particular attitudes.

The aim of this phase of the research was to gain an understanding of the attitudes of the general community, so the target population was defined as all people aged 18 years or older.

A short questionnaire was designed in conjunction with IFSA. The survey was administered using Computer Assisted Telephone Interviewing (CATI) by NCS Pearson, a specialist fieldwork company. The sample size was 784, and the average interview length was 8 minutes.

The fieldwork was conducted from August 28 to September 3, 2001.

**Exploration of education effects** An hypothesised mediator of consumer attitudes to life insurer's use of results of medical tests and other pertinent information in risk assessment was consumers' understanding of the concept of risk assessment. That is, it was felt that, if consumers had a basic understanding of some of the factors influencing the cost of life insurance premiums, they would be more likely to agree that life insurance companies should be able to gain access to pertinent information such as results of genetic tests.

To this end, a random 50 percent of respondents were read a brief description of life insurance risk assessment procedures at the beginning of the interview.

## 2.2 Qualitative research

The exploratory nature of the second phase of the research meant that a qualitative group discussion approach was most appropriate.

Four group discussions were conducted on December 5 and 6 2001. Details of the groups were as follows:

- Two in Sydney CBD:
  - 25-39 year-olds who do not currently have life insurance, white collar;
  - 40-60 year olds, who have life insurance, white collar.
- Two in Parramatta:
  - 40-60 year-olds who do not currently have life insurance, blue collar;
  - 25-39 year-olds who have life insurance, mix of blue and white collar.

There were eight (8) respondents per group. Each respondent was provided with a cash incentive of \$70, to cover any costs incurred, and as consideration for their time.

The groups contained a mix of males and females.

A discussion guide was developed by Eureka Strategic Research in conjunction with IFSA.

## 3. Results

This report presents the main findings from the two phases of research conducted in August/September and December 2001.

### 3.1 Ownership of life insurance

Overall, 37% of respondents had some form of life insurance, and a further 7% planned to take out a life policy in the next 12 months. Seventy-two percent of those with life insurance said that the cover was voluntary, and 35% said they had group cover, implying that at least 8% of those with life insurance have both voluntary and group policies. It was clear from the group discussions that a significant proportion of people have little knowledge of the details of their policies.

#### Why life insurance?

There was a general consensus that people have life insurance to provide financial security for other family members in the event of the death or disablement of the main income earner in a family unit. It was also seen to provide peace of mind to the individual insured. Specific benefits of having life insurance were mainly associated with paying off a mortgage, and providing for children. However, some with group life see their life insurance simply as “something that came with the employment package”.

In the younger age groups, there was general agreement that life insurance was for people with “responsibilities” – for example, dependents, a mortgage, or a husband or wife.

For others, a clear decision had been made against taking out life insurance, even where financial burden exists:

“Well I’m married and I’ve got heavy burdens on my finances but I still haven’t got life insurance. I think I’m fairly prudent in saving a bit on the side that I might

need to look after my dependents. Discussed the mortgage with my wife, we decided that a house is just a house – it can be sold, you can still exist, so we don't have it”

There is also a widely held view that life insurance is expensive. Those who do not know the true cost of life insurance premiums tend to over-estimate the cost, some by significant amounts:

“I'd consider it if it was cheaper – but how much is it??”

“If it was \$30 a month I'd go for it, but I think it's \$200-\$300 per month”

“I discussed it with my husband the other day – like most Australians, we've got a mortgage the size of Texas, he's insured and I'm not. You're just paying the whole time – food, school fees, internet, pay TV – they're all \$30 a month, but it adds up”

The typical premium for a \$100,000 term life policy for a male non-smoker varies from \$130 to \$800 per annum, depending on age. Premiums for female non-smokers are lower.

**Knowledge about life insurance** There is, at best, only a moderate level of knowledge about life insurance among consumers. This knowledge tends to extend to the ability to name ‘death & disability’ and to a lesser extent ‘income protection’ as different types of life insurance products. There is also a widespread belief that premiums are invested by insurers to earn profits.

Perhaps surprisingly, there is not a significantly greater level of understanding among those who have life insurance. Life insurance is frequently confused with general insurance, health insurance, and (particularly among older groups) endowment products. As a result of this, any odium surrounding these other companies (especially general insurers) spills over to life insurance companies.

There is also odium generated from within the life insurance industry, mainly due to perceived unscrupulous behaviour by life insurance sales agents. Many people hold strongly negative perceptions of life insurance salespeople. This can act as a barrier to inquiring about the product, thus inhibiting product knowledge and ultimately, purchase.

### 3.2 Attitudes to use of risk factors by insurers

Most people think that insurance companies should be able to use age, current health, and smoking status when determining life policy premiums. However, only 23% believe that insurers should be able to use gender. Factors, such as smoking status, age and current and past health are fairly obvious risks. It is not intuitively obvious, however, that gender is a risk factor – hence the relatively low level of agreement. It may also be the case that consumers are unwilling to tolerate discrimination of any kind on the basis of gender.

A similar proportion (though not necessarily the same people) believes that insurers should be able to use genetic make-up.

Attitudes to the use of specific risk factors are discussed below.

**Smoking status** Smoking status is the least controversial risk factor - even among smokers. Over three quarters of the population (77%) believe that life insurance companies should be able to use smoking status when setting life insurance premiums.

**Current & past health** Although there is widespread agreement (67%) that it is fair for insurers to use a person’s current and past health, there is a significant minority that felt that previous health status should have no bearing on premiums – even if a prior condition was serious:

“Past health should not be relevant – if you had cancer and recovered, it should be based only on your *current* health”

The more typical view was that, fundamentally, health is the core issue at stake in life insurance premium setting:

“That’s the main risk – how healthy you are when you take the policy out”

“That’s the fundamental basis of what they provide”

**Age** Approximately two-thirds (62%) of people believe that insurers should be able to use age when setting premiums.

“It’s reality – you breakdown as you get older”

**Family history of disease**

A majority (62%) of people are opposed to the use of family history by life insurance companies. The most prevalent view is that lifestyle factors must also be considered, and that a family history of a particular ailment does not predestine the offspring to inherit the affliction – effectively, the view is that ‘the sins of the father should not be visited upon the son’:

“If your father lived on bacon and eggs and beer for sixty years and you’re a gym junkie, I don’t think you should be punished for his cholesterol count”

A related view is that a family history may in fact be beneficial as a preventative measure, through increased vigilance:

“We have a history of breast cancer in my family, so I get checked very regularly and because of that I actually think that I have *less* risk of dying of breast cancer”

Those who support the use of family history take a ‘drier’ or more rational view of the process of risk assessment:

“If you had a father and 2 brothers who all died of heart attacks at about age 50 – you’d have to look at that”

**Gender**

As mentioned above, only 23% of the population believe that insurers should be able to use gender when setting premiums. Those who support the use of gender highlighted the fact that women, on average, outlive men.

Opposition to the use of gender focused on its use being a form of discrimination:

“It’s sexist – discrimination - it just doesn’t determine risk”

“We’re all going to die – it should be the same – where do you draw the line?”

**Genetic test results** Genetic test results were by far the most controversial risk factor examined in the research. Part of the controversy undoubtedly stems from a lack of knowledge and understanding of genetic testing.

Even though they may not understand the issues surrounding the use of genetic information by life insurance companies, the vast majority of people are opposed to the use of such information. A variety of reasons were provided for this opposition.

**Reasons for opposition to use of genetic test results** Those who said that insurers should not be allowed to require people to disclose results of genetic tests (78% of the sample) were asked why they held that view. The most frequent responses are shown in the following table.

Reasons for opposition to use of genetic test results by life insurance companies	Percent (base n=612)
Invasion of privacy / confidentiality	42%
May not get sick even if have gene	17%
Unfair / genes not under your control	13%
Shouldn't be based on health status / everybody who wants insurance should be covered	11%
Insurers should have to take risks	5%
Stigmatisation	5%
Don't believe in genetic testing / morally opposed	3%
Insurers might misuse the information	3%
Don't know / don't understand the issues fully, but think it is wrong	3%
A form of discrimination	1%
People would avoid having genetic tests	1%

There is, however, a minority (22% of the sample) in favour of the use of genetic test results by life insurance companies, usually because of the duty of disclosure.

This more rational view is based on the use of existing genetic test results. It is evident that some people’s fears are related to the possibility of being forced to undergo a genetic test in order to obtain life insurance. This fear further highlights the need for education regarding the life insurance industry’s policy regarding the use of human genetic information.

Can an insurer cancel your policy if you become sick?

There is a high degree of uncertainty about this issue, and in the presence of this uncertainty there is a tendency for people to use heuristics, such as ‘life insurance companies are nasty, profit-driven ogres’, when forming perceptions and making judgments. The quantitative research revealed that just under one in five (18%) of the population erroneously thinks that a life insurance company can cancel a policy if the insured becomes sick. The typical reaction to this question in the group discussions was “I’m not really sure, but knowing insurance companies, they’d find a way out of the policy if they could”. A high level of cynicism towards life insurance companies was evident when discussion turned to this issue:

“I think they probably can cancel your policy if you become sick – but that’s probably my mistrust of insurance companies”

“There is probably something in the contract in small print on the 47<sup>th</sup> page that says *The obligation is on you to inform us if you get sick* – I would say definitely that they can cancel your policy if you get sick”

### 3.3 Medical tests and genetic tests

Genetic tests vs other medical tests

Genetic tests are not perceived to be “just another medical test”. The common feeling is that a medical test, such as a blood test, reveals something about a person’s current state of health, whereas a genetic test reveals information about the future. There is also the perception that genetic tests are more ‘personally invasive’ than other medical tests (a number of people expressed the view that they would not want to live with the threat of cancer or some other future catastrophe hanging over their head).

### Refusal of genetic tests

Less than 5% of the population claimed to have refused a medical test that had been recommended by their doctor. More importantly (from the insurers perspective), less than one quarter of one percent of the population have refused a medical test due to concerns about adversely affecting their standing with life insurance companies.

It is important to note that this low level of reported refusal of medical tests was made in a research context where a higher, or exaggerated level of refusal might have been expected.

This qualitative research confirmed this finding. There was no evidence found in this research to support the view that people would refuse to have a genetic test due to fears about adversely affecting their standing with insurers. In fact, most people would have any test recommended by their doctor:

“If you trust your doctor and they recommend something, you have it”

“If there’s something wrong with you, you’re just focused on fixing that up, the last thing you’re going to think about is life insurance”

## 3.4 Attitudes to privacy of personal information

Attitudes to revealing personal information ranged from the mildly concerned to the paranoid. It is likely that attitudes in the community have shifted to the ‘more concerned’ end of the spectrum recently, due to blanket media coverage of the new Privacy Act. There may be a temptation to dismiss the conservative shift as a temporary phenomenon. However, it is a very real phenomenon, and it would be difficult to overstate people’s concerns about privacy.

Forty-two percent said (spontaneously) that concerns about privacy / confidentiality were the reason for their objection to the use of genetic test results by life insurance companies.

Concerns about the privacy of personal information can be grouped into two categories: concerns about revealing information to a company; and concerns about the potential for abuse of that information by the company.

**Concerns about disclosing personal information** There is a feeling that companies already have an inordinately large amount of information about individuals: from banks’ knowledge of customers’ transactions, to a phone company’s knowledge of customers’ phone calls.

These concerns are even greater when genetic information is involved – there is a feeling that it is a more personal invasion:

“[Credit card] details – it’s just money. Your genes – it’s yourself, can be used against you in too many ways – job, insurance, marriage”

**Concerns about abuse / misuse of personal information** The main concern in this area is the potential for the information to be passed on to a third party, and then used for purposes for which it was not intended. The issue is the potential loss of control of personal information.

Of concern to life insurance companies (and indeed any company that holds customer information) should be the very high level of scepticism surrounding any claims of confidentiality of information made by companies. Most people do not believe companies when they claim they will keep details confidential:

“I don’t believe the bank, insurance company or whatever if they said they would guarantee that your information is kept confidential. No one can guarantee that”

“I’m an auditor for different types of companies. There is always scope for things going awry, data being lost, people leaving files lying around”

### 3.5 A system of ‘universal life cover’

Three-quarters of Australians think that life insurance companies should be required to sell basic cover to all people, even if they are already sick – and over half report being willing to ‘practice what they preach’, with 57% saying they are prepared to pay higher premiums to have a system where everyone is covered.

**Coverage of high-risk individuals** A large proportion of people believe that insurance companies should be required to offer life insurance to high-risk individuals. Indeed, just under half of the population believes insurers should be required to offer life cover to people with a terminal illness. Even more (57%) think that insurers should be required to offer cover to people with a life-threatening illness, and the vast majority (74%) believe that life insurance companies should be required to offer cover to people who are not currently sick, but are known to carry a gene that definitely leads to a terminal illness.

These results (particularly the “terminal illness” finding) betray a lack of understanding among consumers about life insurance.

It should be noted that the rather general term “life insurance” was used in these questions, without elaboration as to the specific type of cover.

At the same time, there is an acknowledgement that differential pricing of premiums should apply where certain risks are either present or absent. Fifty-eight percent think that people with a known illness or risk should pay more than the average policyholder, and 49% think that people without a known illness or risk should pay less than average.

At a superficial level, a universal life insurance system is attractive, as it appeals to people’s sense of ‘fairness’. However, with even the scantest consideration of the implications of such a system, the majority of people agree that there will always be people who are ‘uninsurable’, or at least people who would have to pay prohibitively high premiums in order to get cover.

The issue of increased premiums to fund a universal life insurance system deters most people, unless the increase was trivial.

The consensus seems to be that people are willing to pay only slightly higher life insurance premiums (perhaps 5% higher) for a more inclusive system, but that there are people who are simply too great a risk for a life insurance company to insure.

### 3.6 Malleability of attitudes

**Effect of ‘education’** The preamble used in the quantitative research (regarding the concept of pooled risk) appears to have influenced attitudes, to a small extent, in a number of important areas (despite the preamble being only a very basic explanation of the concept of pooled risk). Those exposed to the preamble were more likely to agree that “Charging people according to their risk of getting sick keeps the costs of life insurance down for healthy people” (69% in the ‘educated’ group versus 59% in the baseline comparison group). This is hardly surprising, given that the meaning of this statement is very similar to the gist of the preamble. However, this suggests that some of those in the ‘educated’ group did in fact process the information contained in the preamble. It can be concluded from this that attitudes in this area are to some extent malleable. That is, there is some scope for informed discussion to change attitudes.

### 3.7 Communications strategy

This research highlights the fact that there are rather large knowledge deficits among consumers in the areas of life insurance and genetic testing. Indeed those who participated in the group discussions were very aware of their combined paucity of knowledge, and asked numerous factual questions in the course of the groups.

At the end of the sessions, the question was asked “do you want to know more about these issues”, and the overwhelming majority of responses were “yes”:

“We care about these issues, we should know, we need more information”

For life insurance companies, it is important that consumers are better informed, because in an atmosphere of uncertainty, people make judgments based on perceptions and stereotypes – and the perceptions and stereotypes surrounding life insurance companies are not particularly positive.

There is also an important role for government to play. The relatively high level of cynicism towards life insurance companies is likely to act as a barrier to effective communication, in the absence of support from an ‘independent’ government voice. It is clearly in the interests of the government to address the uncertainty and misinformation that

exist in the community regarding life insurance generally, and in relation to the use of genetic information in particular.

Education is critical in overcoming significant knowledge gaps and uncertainty in the community about the following issues:

1. Differentiating life insurance from other products, including general insurance, health insurance, and endowment products.
2. Differentiating between different life products.
3. The costs of different life insurance products.
4. Life insurers' use of genetic information.
5. The scope of the life insurers' genetic testing policy.
6. Gene technology and genetic testing.

The first three of these areas are clearly fundamental to the success of the life insurance industry, and, as such, would be best addressed by life insurers. The areas numbered 4 and 5, regarding the use of genetic information by life insurance companies, should be addressed by government as well as by the life insurance industry, as they are new policy areas, and may be covered by a regulatory framework.

The sixth 'knowledge gap', regarding gene technology, and genetic testing in particular, is the area of expertise of the medical research community. The most credible and effective communication about developments in this area will come from government and the medical community.

**Media and form of communication**      People tend to have idiosyncratic media preferences. As such, both above- and below-the-line communications could play important roles in an education campaign.

A brief brochure (for example, double sided A4 or similar) distributed through traditional channels (such as intermediaries, insurance offices / branches, and banks) could be particularly effective. The content of the brochure should also be made available on the internet – through

life insurance companies' websites, or from links on their websites to a centralised industry website.

Despite cynicism towards life insurance agents, other intermediaries could play a significant educative role. Financial planners (incentive issues aside) could be very useful educators.

## 4. Conclusions

Life insurance is a relatively low involvement product, even for those who have voluntary cover. It is not something that occupies consumers' minds at times other than the time of consideration / purchase. The result of this is a low level of awareness and understanding of life insurance products, and more generally, of the operation of life insurance companies.

There is confusion in the minds of consumers between life insurance, general insurance, health insurance, and some investment products (such as endowment products). Life insurance companies, therefore, are subject to odium emanating from problems in the general insurance sector, such as the collapse of HIH, increasing general insurance premiums, and obscenely large director salaries and bonuses. This is the case even among apparently erudite individuals.

In this knowledge vacuum, people make incorrect assumptions and attributions about life insurance. These ill-formed and uninformed attitudes then act as barriers to life insurance product take-up.

A similar line of reasoning is applicable to genetic testing. A lack of knowledge about the details and potential benefits of genetic testing leads people to associate genetic testing with unrelated areas such as organ farming, human cloning, 'Dolly the sheep' and so on.

It should not be surprising, therefore, that there is a significant level of opposition in the community to the use of human genetic information by life insurers. It is effectively the fusion of two areas of uncertainty, coupled with cynicism towards financial institutions.

However, the picture is not altogether bleak. There is evidence in this research suggesting that attitudes to life insurance and genetic testing are, to some extent, malleable. In the course of the group discussions, the attitudes of numerous people changed, in some cases dramatically. In the quantitative research, a brief explanation of the concept of pooled risk was able to significantly alter attitudes to a number of issues. While it is the case that some people are more easily led

than others, these two pieces of research suggest that a communications program has the potential to influence attitudes in the area of life insurance and genetic testing. Our belief is that given the relatively low involvement nature of life insurance, an attitude change program should target the time of greatest involvement – that is, the time around product consideration and purchase. We believe that a communication program would be most effective if it was a joint life insurance industry and government initiative.