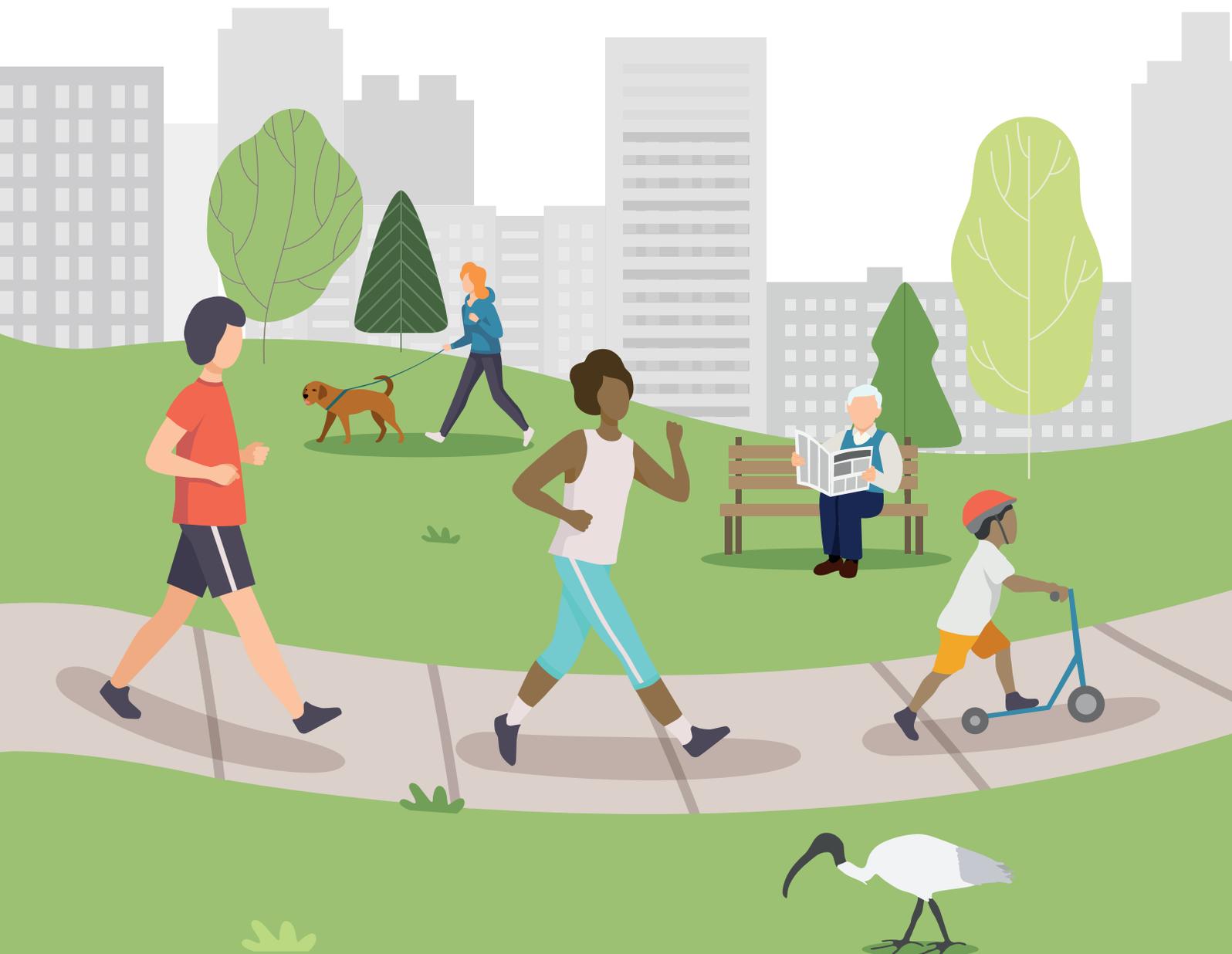


# WHAT'S THE RISK?

Access to insurance for people living  
with health conditions



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## About Legal Aid NSW

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The Legal Aid Commission of New South Wales (**Legal Aid NSW**) is an independent statutory body established under the *Legal Aid Commission Act 1979* (NSW). We provide legal services across New South Wales through a state-wide network of 24 offices and 221 regular outreach locations, with a particular focus on the needs of people who are socially and economically disadvantaged.

We assist with legal problems through a comprehensive suite of services across criminal, family and civil law. Our services range from legal information, education, advice, minor assistance, dispute resolution and duty services, through to an extensive litigation practice. We work in partnership with private lawyers who receive funding from Legal Aid NSW to represent legally aided clients.

We also work in close partnership with LawAccess NSW, community legal centres, the Aboriginal Legal Service (NSW/ACT) Limited and pro bono legal services. Our community partnerships include 29 Women's Domestic Violence Court Advocacy Services.

The Legal Aid NSW Civil Law Division focuses on legal problems that impact most on disadvantaged communities, such as credit, debt, housing, employment, social security and access to essential social services. There are also specialist teams, working with Aboriginal communities, children, prisoners and refugees, including a team which assists with insurance issues affecting disadvantaged people. Consumer issues, including insurance, are the largest category of service provided by our Civil Law Division.

## Acknowledgements

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We would like to thank everyone who gave their time so willingly to help us prepare this report.

### Survey participants

First and foremost, we thank those who generously shared their stories, expertise and lived experiences with us. Without them, this report would not have been possible.

### Partners

We thank Cancer Voices NSW and Cancer Council NSW for informing us of the issues addressed in this report, for sharing their experiences and for their ongoing support of this project.

We are also grateful to the stakeholders who provided feedback about the issues raised in this report, and who promoted our survey to their members. In particular:

Bernie Banton Foundation	Lung Foundation of Australia
beyondblue	Lymphoedema Action Alliance
Brain Tumours Alliance Australia	McCabe Centre for Law and Cancer
Breast Cancer Network Australia	Public Interest Advocacy Centre
Cancer Council NSW	Rare Cancers Australia
Cancer Voices NSW	Unicorn Foundation
Choice	WMozzies (Australian Support group for everyone affected by Waldenström's Macroglobulinemia)
Heart Foundation	
Hepatitis NSW	

### Experts

We would also like to thank everyone who helped us develop the survey, particularly Maria Karras (Law & Justice Foundation of NSW), John Berrill (Berrill Legal), Kat Lane and Alex Kelly (Financial Rights Legal Centre), Denis Nelthorpe (Footscray Community Legal Centre), Michelle Cohen, Laura Lombardo and Mary Flanagan (Public Interest Advocacy Centre), and Tony Robinson (Brotherhood of St Laurence). We are very grateful for their time, knowledge and experience.

### Contributors

We would also like to thank everyone at Legal Aid NSW who assisted with this project, including Lillian Leigh, Rebekah Doran, Robyn Gilbert, Jo Evans and Dana Beiglari.

## Glossary

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- Australian Financial Complaints Authority (AFCA)**
- Australian Financial Services Licence (AFSL)**
- Australian Human Rights Commission (AHRC)**
- Australian Institute of Superannuation Trustees (AIST)**
- Australian Prudential Regulation Authority (APRA)**
- Association of Superannuation Funds of Australia (AFSA)**
- Australian Securities and Investments Commission (ASIC)**
- Breast Cancer Network Australia (BCNA)**
- Chronic Obstructive Pulmonary Disease (COPD)**
- Credit and Investment Ombudsman (CIO)**
- Disability Discrimination Act 1992 (Cth)* (DDA)**
- Financial Ombudsman Service (FOS)**
- Financial Services Council (FSC)**
- International Classification of Functioning, Disability and Health (ICF)**
- Insurance Council of Australia (ICA)**
- Product Disclosure Statement (PDS)**
- Public Interest Advocacy Centre (PIAC)**
- Total and Permanent Disablement (TPD)**

## Foreword

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The issue of access to insurance—particularly life insurance, income protection and travel insurance—is an area of increasing concern to people affected by cancer. In 2015, the Cancer Voices team identified the issue as a key priority, so we were delighted when Lillian Leigh, a solicitor at Legal Aid NSW and cancer survivor, joined the Cancer Voices Executive Committee, at the invitation of our then Chair, Sally Crossing AM. Lillian and Legal Aid NSW agreed this was a priority issue; so what began for Cancer Voices as a focus on travel insurance for those affected by cancer, was then expanded by Legal Aid NSW to insurance issues affecting those with a range of health conditions. Not surprisingly, the cancer community has much in common with people living with health conditions such as mental illness when it comes to securing insurance at a reasonable premium.

Legal Aid NSW has worked collaboratively with key stakeholders to develop, conduct and analyse a comprehensive online survey, the results of which are recorded in the report which follows. The results confirm that those with health conditions frequently experience difficulty and frustration in securing insurance at a reasonable premium and on occasions face outright denial. People with health conditions also need to be prepared to endure a cumbersome and lengthy process in sourcing medical reports in support of their application, and are frequently unaware of their legal rights when it comes to making a claim on their insurance.

The report identifies the opportunity for further ongoing collaborative work between insurers and industry representatives, consumers and advocates, and government and regulatory bodies to improve the insurance experiences of people living with health conditions.

Cancer Voices NSW is a leading state volunteer, not for profit advocacy organisation and provides the independent voice of people affected by cancer in NSW, to improve the cancer experience of the more than 48,000 people who are diagnosed each year.

Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. We work with member input in partnership with decision makers and providers of these services, ensuring that the patient perspective is heard from planning to delivery. We are grateful to consumers who raised the issue, for the support of our survey participants, and to the partners and advisors who provided their expertise and experience in developing and analysing the online survey, which forms the foundation of the report. We wish to extend our thanks and gratitude to Legal Aid NSW for compiling such a valuable resource, which will form the basis of our ongoing work in progressing the resolution of the insurance issue on behalf of our cancer community of interest.

Cancer Voices is proud to commend Legal Aid NSW's *What's the Risk?* report and we look forward to advancing the cause for accessible, affordable, hassle free insurance for people living with cancer and other health conditions, in collaboration with other key stakeholders.

Elisabeth Kochman  
Chair Cancer Voices NSW

## Executive summary

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Legal Aid NSW conducted the Health Conditions and Insurance Project to better understand the experience of people living with health conditions who access general and life insurance products. The project included a survey of 281 people, a literature review, consultation with consumer and industry representatives, and analysis of case law, legislation and codes of practice. Survey participants reported difficulty obtaining appropriate insurance, particularly life and travel insurance, and also reported challenges when making claims. Some of these people perceived their treatment as discriminatory, but most people experiencing problems with insurance did not take any legal or other action.

It is unlawful to discriminate against a person because of their disability, although there are exceptions for decisions based on actuarial or statistical data on which it is reasonable for the insurer to rely. This report recommends that the insurance industry, government and consumer advocates should work together to

- prevent unlawful discrimination, and
- ensure that, if unlawful discrimination does occur, people with health conditions are empowered to assert their rights.

### Key findings of the survey

Two thirds of survey participants reported difficulty in obtaining insurance because:

- the insurer refused to sell them a policy that covered their health conditions
- they were charged an extra premium because of their health conditions
- the insurer refused to sell them a policy at all, or
- they were not able to find products that suited their needs.

Some survey participants reported that:

- they did not receive reasons for the decision to refuse cover
- they purchased insurance but did not receive a product disclosure statement (PDS), or the PDS was confusing
- the medical assessment process was inappropriate, or
- they perceived that they were being discriminated against.

Survey participants reported the following challenges when making claims:

- being discouraged from making a claim
- having their claim denied because of their health condition
- not being given information that the insurer relied upon to refuse the claim, not being given information about complaints processes, and not being given the decision in writing
- onerous procedural requirements for making a claim, including multiple forms and repetitive requests for information, and
- negative attitudes of some medical professionals towards insurance claims.

While survey participants agreed that their insurers were honest, efficient and transparent, they did not consider that insurers accommodated for their health.



Of those survey participants who had a problem with insurance, few took any action to resolve it. The reasons for their lack of action included

- those who had difficulty getting insurance did not necessarily identify this as an insurance or legal problem
- feeling disheartened, despondent, or unsure of their options
- lack of physical, emotional and financial capacity to take action
- accepted the status quo but still find it unfair, and
- fear of negative implications if action is taken.

## Pathways to improved access to insurance for people with health conditions

Improving access requires collective efforts from all stakeholders. The following recommendations are based on our survey results, existing research and advocacy, case law and the experience of health and consumer advocates.

### **Recommendation 1:**

**Insurers should review all policies that exclude coverage for health conditions and ensure that the exclusion is justified on the basis of actuarial or statistical data upon which it is reasonable to rely.**

### **Recommendation 2:**

**The General Insurance Code of Practice should include an obligation to comply with the requirements of anti-discrimination law, with a provision similar to the Life Insurance Code of Practice section 5.17.**

### **Recommendation 3:**

**The General Insurance Code Governance Committee and the Life Code Compliance Committee should monitor and enforce compliance with anti-discrimination law.**

### **Recommendation 4:**

**Codes of Practice should require insurers to report to the Code Committee if an allegation of discrimination is made against them.**

### **Recommendation 5:**

**The General Insurance Code of Practice should require that, where an insurer decides to refuse cover, offer cover at a higher premium, or to refuse a claim, the insurer must:**

- **give reasons**
- **inform applicants/consumers about their right to receive the information the decision was based on, and**
- **inform applicants/consumers about their right to seek a review of a decision.**

### **Recommendation 6:**

**The Australian Financial Complaints Authority (AFCA) should publish an industry guideline setting out its approach to disability discrimination in insurance.**

### **Recommendation 7:**



The Australian Human Rights Commission (AHRC) should conduct a national public inquiry into whether there is systemic unlawful discrimination by the insurance industry against people with health conditions.

**Recommendation 8:**

The Australian Securities and Investments Commission (ASIC) should incorporate findings from this research into consumer messaging on MoneySmart.

**Recommendation 9:**

ASIC should conduct inquiries relating to potential breaches of license obligations by insurers in relation to the findings of this review, including in thematic industry reviews.

**Recommendation 10:**

When insurer obligations are expanded to include a ban on unfair contracts terms, ASIC should review travel and life insurance policies to identify unfair terms relating to consumers with pre-existing health conditions and disabilities.

**Recommendation 11:**

Consumer and health advocates should work together to:

- Establish clear, consistent communications about consumer rights in relation to insurance decisions and where to seek legal help, and
- Target communications to health and other services working directly with people living with health conditions.

**Recommendation 12:**

Government, industry and consumer advocates should encourage the development of market innovations, including consumer collectives for people with health conditions.

# 1. Introduction

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## About the Health Conditions and Insurance Project

The Health Conditions and Insurance Project was funded by Legal Aid NSW for 12 months over 2016 / 2017 to better understand the experience of people living with health conditions when accessing general and life insurance products. The Project involved a survey of 281 people with health conditions and experience with insurance, a literature review, consultation with consumer and industry representatives, and analysis of case law, legislation and codes of practice.

This report outlines the findings of the project, with particular emphasis on the results of the online survey.

The project was a response to the growing body of evidence that consumers with health conditions face challenges accessing insurance. For example, the McCabe Centre for Law and Cancer found that people affected by cancer find access to insurance challenging but do not take action to address this.<sup>1</sup> A survey conducted by the Mental Health Council of Australia, in collaboration with *beyondblue*, raised similar issues affecting Australians living with mental health conditions. These studies support the anecdotal experience reported to us by health and consumer advocates that access to insurance is a significant and serious issue for people with a range of health conditions.

Legal Aid NSW hopes that this report will raise awareness about these issues and contribute to an ongoing discussion about improving access to insurance for people with a range of health conditions. Our recommendations are directed to both preventing discrimination against people with health conditions, and ensuring that people with health conditions and problems with insurance are aware of their options for redress.

We note that preventing discrimination in insurance will not mean that all people with health conditions will have access to insurance. The underlying difficulty remains that if the person faces significant health risks, an insurer may make a commercial decision not to insure. This report has not resolved that problem and we consider that stakeholders should continue to work towards a resolution.

## About the online survey

The purpose of the survey conducted by Legal Aid NSW was to gain a better understanding of the insurance experiences of people affected by health conditions generally, and through their stories, identify barriers to accessing insurance.

When designing the survey, we posed four key questions:

- A. What were these people's buying experiences like?
- B. What was it like for them when they make a claim?
- C. How did they rate the insurer's customer service?
- D. When insurance problems arise, what actions did these people take and why?

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<sup>1</sup> Lawson, D. and Davoren, S. (2014). *Making the Law Better for People Affected by Cancer – 2013 Report*. McCabe Centre for Law and Cancer: Cancer Council Victoria.

Details about the privacy and ethics of the survey, and the survey itself, can be found at Appendix 2.

The survey was conducted through an online survey platform called *Qualtrics* (<http://qualtrics.com>) and distributed by over 20 organisations to their members and networks (see Appendix 1). These organisations were predominantly health, not for profit and legal advocacy agencies. The survey was conducted online because this is the most cost effective mode of survey research. Participants in the survey self-selected to participate and did not receive an incentive in return for their participation. Legal Aid NSW acknowledges that there are limitations with this methodology, for instance, the total population of Australians living with health conditions is not known, and so a sample size has not been identified. Also, the online survey would not reach population groups with no access to the internet. Therefore, the survey is not a representative sample of all Australians living with health conditions.

894 people started to respond to the online survey. However, 506 people failed to complete it. 450 of these people dropped out when asked to provide details of their health conditions. A further 107 complete responses were excluded from data analysis because they did not report any experience with insurance.

Only the 281 responses from completed surveys, where participants reported experience with insurance, were analysed.

## Defining “disability” and “health condition”

Disability can be defined in many different ways. According to the World Health Organisation’s *International Classification of Functioning, Disability and Health* (ICF), “disability” is an umbrella term for “impairments, activity limitations and participation restrictions”.<sup>2</sup> In other words, disability is the dynamic interaction between individuals with a health condition (such as cancer or depression) and personal and environmental factors (such as limited social supports or inaccessible buildings). This ICF definition is used in Australia for many data collection purposes.<sup>3</sup>

In this report, we use the term “disability” as defined in the *Disability Discrimination Act 1992* (Cth) (DDA) when referring to the law or official data. Under this definition, “disability” is defined as:

- total or partial loss of the person’s bodily or mental functions
- total or partial loss of a part of the body
- the presence in the body of organisms causing (or capable of causing) disease or illness
- the malfunction, malformation or disfigurement of a part of the person’s body
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction, or
- a disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgment, or that results in disturbed behaviour;

and includes disability that:

- presently exists
- previously existed but no longer exists

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<sup>2</sup> World Health Organisation. (2016). Factsheet: Disability & Health. Online. Available at: <http://www.who.int/mediacentre/factsheets/fs352/en/>.

<sup>3</sup> Australian Institute of Health and Welfare & Australasian Association of Cancer Registries. (2017). Cancer in Australia: in brief 2017. Cancer series no. 102. Cat. no. CAN 101. Canberra: AIHW.

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- may exist in the future (including because of a genetic predisposition to that disability), or
  - is imputed to a person.

This definition is sufficiently broad to capture people living with a range of health conditions that would not consider themselves as having a “disability” – for example those who have survived cancer. Legal Aid NSW therefore uses the phrase “people living with health conditions” to refer to the broad group of people falling under the DDA definition of disability.

## 2. Survey results: what are the issues?

### Summary

This chapter reports on the results of the online survey conducted by Legal Aid NSW in March 2017. There were 281 participants who were affected by health conditions including cancer, lung diseases, cardiovascular diseases, mental illnesses and multiple sclerosis. The types of insurance most commonly mentioned by participants were travel insurance and life insurance. Two thirds of participants reported difficulties obtaining insurance. A significant number of claims were denied due to the health condition. Very few of those who reported having a problem with insurance took any action to resolve it, largely because they were unsure of their options or did not expect a positive outcome.

### Survey participants

Of the 281 participants, 83% were personally affected by health conditions. 9% were carers and 8% of participants were both carers and personally affected. The average age of participants was 56 years old. 74% of participants were female. 55% were not currently employed.

65% of all participants were affected by cancer (n=183). Participants reported a number of other health conditions, including lung diseases (n=38), cardiovascular diseases (n=27), mental illnesses (n=24), diabetes (n=17), multiple sclerosis (n=4), and various other conditions (such as arthritis, sleep apnoea, and chronic fatigue syndrome; n=58). A total of 28 participants were affected by multiple health conditions. Figure 1 below shows the *primary* health condition of participants.

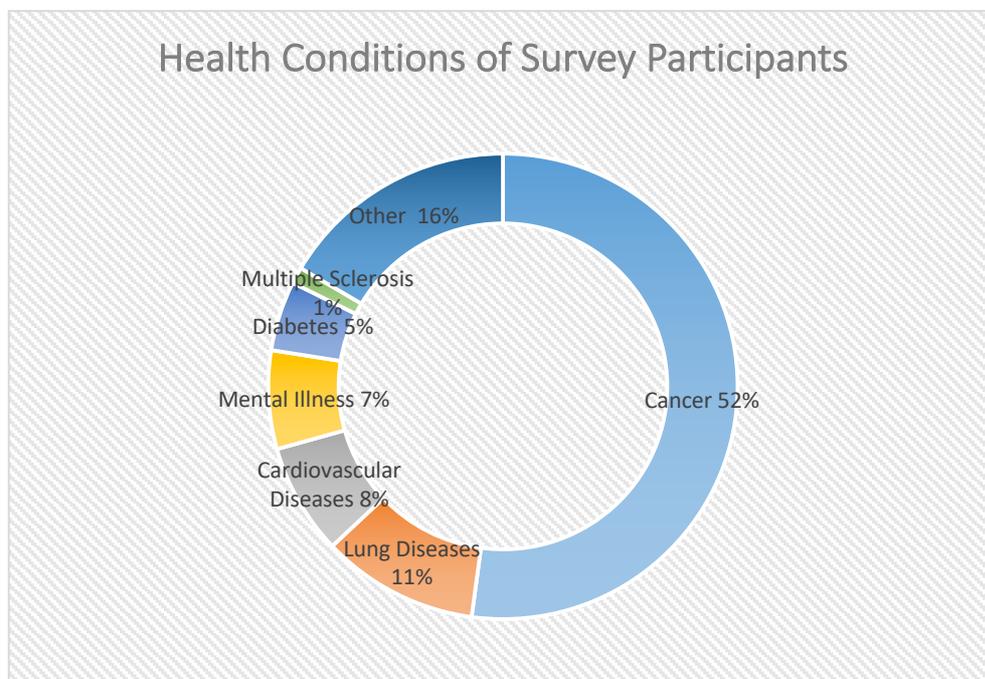


Figure 1: Breakdown of survey participants' primary health condition

Given that more than half of the total participants are affected by cancer, we provide results of this group separately in some parts of this report. These participants are referred to as the “Cancer Group”.

## What insurance products did participants share about?

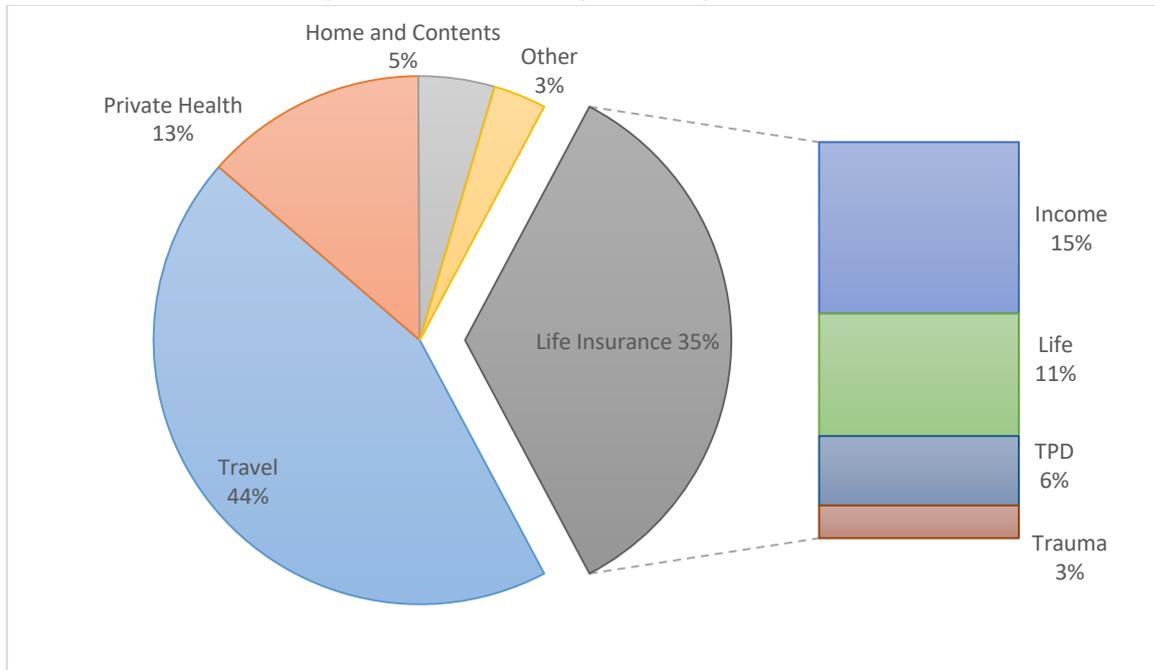


Figure 2: The type of insurance products participants shared stories about

Participants shared their experiences with a variety of insurance products:

- 44% travel insurance (n=124)
- 35% various life insurance products (n=97), in particular:
  - income protection (n=42)
  - life insurance (n=30)
  - total and permanent disability (n=17)
  - trauma insurance (n=8).
- 13% private health insurance (n=38),
- 5% home and contents insurance (n=13), and
- 3% other types of products (n=9).

A similar trend was found in the Cancer Group, where 43.7% of the Cancer Group shared their experience with travel insurance (n=80), 41% shared their life insurance stories (n=75) including income protection (n=30), life insurance (n=23), TPD (n=14), and trauma insurance (n=8), and 10% of participants talked about private health insurance products (n=18).

## Buying experience

### Key results

Two thirds of participants had difficulty obtaining insurance because:

- the insurer refused to sell them a policy that covered their health conditions
- they were charged an extra premium because of their health conditions
- the insurer refused to sell them a policy at all, or
- they were not able to find products that suited their needs.

Some consumers:

- did not receive reasons for the decision to refuse coverage, or
- did not receive a product disclosure statement when purchasing insurance.

### Difficulty obtaining insurance

Of the 203 survey participants who deliberately purchased insurance,<sup>4</sup> 30% or 61 people were happy with their buying experience, while 66% had difficulty obtaining insurance. Difficulties included:

- the insurer refused to sell them a policy that covered their health conditions (26%, n=53)
- they were charged an extra premium because of their health conditions (22%, n=44)
- the insurer refused to sell them a policy at all (18%, n=36), and
- they were not able to find products that suited their needs (2.5%, n=5).

Comparing participants with cancer (the Cancer Group) with other participants, the Cancer Group was more likely to report being refused cover for their particular health condition (31% vs 19%) and less likely to be charged extra premiums (16% vs 30%). They reported being declined cover at similar rates (17% vs 19%).

These results are consistent with the reports of health advocates to Legal Aid NSW that people living with health conditions find that they are either subject to a premium loading (and potentially priced out of the market); deemed partially uninsurable with an exclusion of their medical conditions; or totally uninsurable and cannot find a product at all.

Some people reported that they are not able to find any suitable insurance product. The size of the market and range of products available can be confusing, despite the rise of price comparison websites. The survey results also indicate that some people do not even attempt to buy insurance because they believed they would not be covered.

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<sup>4</sup> Other survey participants had default insurance policies through a linked credit card or superannuation policy (n=45), had obtained cover so long ago they did not specify how they purchased their policies (n=27), or did not attempt to obtain insurance because they thought they would not be covered.

"I called so many travel insurers before settling on [my current travel insurer]. When I told them about my pre-existing condition, the premiums sky rocketed with five [insurers] before I found [the current insurer], even though now I am totally fit and well. Grossly unfair and discriminatory practices at play here."

"I did not go on the holiday as the company stated I could not get insured full stop. It was complex and hard to compare products. I sold my tickets to someone else... and now I will only travel to a country with a reciprocal health agreement with Australia which is restricting."

"The policy was reviewed at my 10 year anniversary as I had been advised the loading may be reduced or removed at that point but the outcome was that the loading would remain. I cancelled my trauma policy in absolute disgust and frustration – I'm 10 years clear and healthy as anything yet I'm paying twice as much for my protection. Furious!"

## No reasons given for refusals and exclusions

Some survey participants reported a lack of explanation as to why they had been denied a product, as well as a lack of suggested alternatives. This can lead to future self-limiting behaviours and financial exclusion.<sup>5</sup>

"It wasn't worth the effort ... who would want to insure me anyway? I have cancer. I felt so angry and hurt ... They were blunt ... No reasons given."

"[A] total lack of transparency. [The travel insurer] would not discuss evidence/information on which they based their decision. I doubt they even understood my illness. If the cancer did return, it would be a very slow process and would not affect the short trip I was planning to undertake. The companies would not move, even when I presented a doctor's letter stating that there was very little likelihood of a recurrence."

## Product disclosure

Of those participants who deliberately purchased insurance, 16% (n=32) reported that they did not receive a copy of the Product Disclosure Statement (PDS). This is despite statutory obligations under the *Corporations Act 2001* (Cth) to provide a PDS.

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<sup>5</sup> See further Chapter 4 and Rowe, B., De Ionno, D., Peters, D. and Wright, H. (2016). *Mind the gap. Consumer research exploring experiences of financial exclusion across the UK*. London: ESRO/FCA.

Several participants reported finding it difficult to understand the benefits, costs and exclusions of the product, and indicated that the PDS was confusing and contradictory.<sup>6</sup>

“Lots of legal jargon. Difficult to understand what is covered.”

“Lack of understanding of what they insure and what they wouldn't.”

“Confusing and contradictory. Took our money but we were not covered.”

### Medical assessment process

A number of participants commented on the inadequacy of the medical assessment process when seeking cover for their health conditions.

“Unable to get reasonable cover for pre-existing conditions ... Restrictions on coverage was non-negotiable ... medical assessment forms are ridiculously complex and often require GP consultation and extensive medical reports.”

“Some questions were ambiguous and did not cover my situation. I rang the company and was directed to state my cancer had been cleared by surgery when in fact it was cleared by chemo and radiotherapy. I was concerned this may have impacted on any claim I may have made. Fortunately I didn't need to make a claim.”

“The medical form had limited flexibility - they didn't take into account the type of drug I was on, just that I was on treatment.”

“Standardised question did not allow for more specifics on my condition.”

### Insurers' practices are perceived as discriminatory

A number of survey participants considered their inability to get insurance as a discriminatory practice of insurers.

“There is a discriminatory element to the judgments made about who can/cannot get travel insurance. Just because I live with cancer doesn't mean that I shouldn't be covered when I am well enough to travel.”

“Grossly unfair and discriminatory practices at play here.”

“I felt discriminated against, but was at a loss on where and what to do.”

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<sup>6</sup> This finding is consistent with the findings of the research commissioned by the UK Financial Conduct Authority and conducted by the research company ESRO which looks at barriers to accessing insurance: Rowe, B., De lonno, D., Peters, D. and Wright, H. (2016). Mind the gap. Consumer research exploring experiences of financial exclusion across the UK. London: ESRO/FCA.

“The insurance companies are not keeping up to date with the advances made in treating cancers. Most cancers can be classed as chronic conditions. I feel that insurance companies switch off when they hear the word 'Cancer' and don't want to know anything else about how your overall health is.”

## Claims experience

### Key results

- Of those who did not claim, 16% did not claim because their insurer told them that they would not be covered.
- 17% of claims were denied, the majority because of the health condition.
- Some participants reported not being given information that the insurer relied upon to refuse the claim, not being given information about complaints processes, and not being given the decision in writing.
- More than half of the participants who had a claims experience reported that insurers were transparent, honest and efficient.
- Some participants felt that the procedural requirements for making a claim were too onerous.
- Very few of those people who considered that they had an insurance problem did anything about it.

## The decision to claim

When participants were asked whether they had made a claim on their insurance policies:

- 48% (n=134) had made a claim, and
- 52% (n=147) had not made a claim

A similar trend is found with the Cancer Group, with 51% of people making a claim (n=93) and 49% of people who did not (n=90).

The 147 participants who did not make a claim on their policy were asked why they did not do so. Their responses were:

- 60% (n=89) had no incident to claim
- 16% (n=23) did not claim because their insurer told them that they would not be covered
- 15% (n=22) did not claim because they had been unable to acquire a suitable policy
- 7% (n=10) did not claim for various other reasons e.g. the excess being too high to justify a claim, and
- 2% (n=3) assumed they would not be covered.

The claims experience of the Cancer Group is again broadly consistent with the experience of participants overall.

23 participants were told by their insurers not to make a claim because they would not be covered by the policy. Of those 23 participants, 17 were affected by cancer. This is of concern because where no claim is made, the consumer does not have the benefit of a written, considered and reviewable decision and does not have access to internal and external dispute resolution. It also means that the

claim payment and refusal rates reported by insurers may not accurately reflect the experience of consumers.

“The insurer initially told me that I have no right to claim. I’m still trying to get a resolution. The insurer’s claim forms are very complicated. I’m nervous to sign their documents because they are unclear.”

“The insurer didn’t know much when it came to what I was exactly covered for ... I was initially told I wasn’t covered, when I had a policy in front of me telling me otherwise.”

## The response to claims

Of those participants who made a claim on their insurance policy (n=134), 75% reported that their claim was accepted by their insurer (n=101).

For those whose claims were denied (17%, n=23), the majority reported that the claims were denied because of the relevant health conditions (n=18).

Very few denials were unrelated to their health conditions (n=5). One participant stated that he was waiting for his insurer to process his claim, and another participant stated that she withdrew her claim.

## When claims are denied

Of the participants whose claims had been denied, responses indicated that:

- 52% were not informed that they could get details about the information their insurer relied on to deny their claim (n=12)
- 43% were not given any information by the insurer about the complaints process (n=10), and
- 22% did not receive the insurer’s decision in writing (n=5).



Figure 3: Experiences of the 23 participants whose claims had been denied

The General Insurance Code of Practice and the Life Insurance Code of Practice provide that consumers will receive decisions in writing, information about the right to ask for the information relied upon, and information about complaints processes.<sup>7</sup> Receiving information about adverse decisions allows consumers to understand their rights and have those decisions reviewed.

While the sample size for consumers with denied claims is small, it appears that some insurers may not be meeting industry standards or community expectations.

<sup>7</sup> General Insurance Code of Practice sections 7.19, Life Insurance Code of Practice sections 8.19 and 14.6.

## Barriers to making a claim

Procedural barriers may create obstacles for people with health conditions. For example, the provision of required documentation can be a challenge for survey participants. Some survey participants (many in relation to their life insurance experience) complained that the claim forms asked for too much information, and the process seemed repetitive and onerous.

“Rang the insurance section of my superannuation to advise them that because of the length of time since I finished working, I cannot locate a copy of my last group certificate. I am still waiting for them to get back to me because the person who was handling my claim has been moved to another department and they don't know who will be taking on that claim now.”

“[The claims process is] not very easy to work out. I got the two specialist and GP forms completed quickly but it's the other details they are now requesting that are creating my problems.”

“Awful long, repetitive very minor subtle but important word changes with each form. So many required. My doctor started to resent filling them out. I dreaded asking him. Horrible process.”

“Tediously repetitive, especially when it was necessary to fill in on a monthly basis, both self and doctor. Then stretched to three months, and then eventually six months.”

“Continued to request more information after receiving full details from two highly qualified specialists - surgeon and oncologist.”

Physical access challenges or digital exclusion can also cause barriers for consumers to access financial services. Those people who are most likely to be affected by this category are older people, those living with disabilities, and those living in rural, regional or remote areas.<sup>8</sup>

“We don't [deal with our insurers] as they are no longer in our town. Everyone is expected to use the internet, even though I am a pensioner who can't afford internet, let alone a computer that I don't know how to use.”

The negative attitudes of some medical professionals towards insurance claims can also pose a challenge for consumers.

“Stressful. The insurance doctor was very unsympathetic and unhelpful.”

“Initially overwhelming, then ok a relief to finally get some money after a three month wait. Then the longer I was on it the harder it became doctor and psychologist reports were required so often, no help

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<sup>8</sup> Rowe, B., De lonno, D., Peters, D. and Wright, H. (2016). *Mind the gap. Consumer research exploring experiences of financial exclusion across the UK*. London: ESRO/FCA.

retraining, made to feel like I was doing something wrong being unethical no empathy or understanding.”

## Customer service experience: How did insurers rate?

Participants were asked to rate their insurer’s customer service on the basis of five characteristics by rating their level of agreement to the statements: fair, transparent, efficient, honest, and accommodating for my health. A Likert scale of rating is used: 1 = Strongly Disagree, 2 = Disagree, 3 = Neutral, 4 = Agree, 5 = Strongly Agree.

The results were that participants:

- Slightly agree that insurers were:
  - efficient (mean = 3.27)
  - honest (mean = 3.27)
  - transparent (mean = 3.09)
- Neutral to the statement that insurers were fair (mean = 3.00), and
- Disagreed that insurers accommodated for their health (mean = 2.48).

The characteristics of fair, efficient and honest were selected as they are consistent with the general obligations of Australian Financial Services Licensees under section 912A of the *Corporations Act 2001* (Cth). The characteristic of transparent was selected as it is consistent with obligations under the General Insurance Code of Practice, the Life Insurance Code of Practice, and the Private Health Insurance Code of Practice.



Figure 4: Average rating by participants on their level of agreement to the statement “The insurer’s customer service was...” as it applies to each of the 5 characteristics

135 participants disagreed or strongly disagreed that their insurer accommodated for their health. However some of this group provided contrasting feedback in relation to other aspects of the insurers customer service:

- 10% agreed or strongly agreed that the insurer was fair
- 28% people agreed or strongly agreed that the insurer was transparent
- 33% people agreed or strongly agreed that the insurer was efficient, and
- 34% people agreed or strongly agreed that the insurer honest.

This indicates that while survey participants on average believed their insurer failed to accommodate for their health, many of them still agree that their insurer was honest, efficient and transparent.

The response results show that survey participants are generally satisfied with the insurers' level of honesty, efficiency and transparency. This is encouraging as these are all industry standards expected under the General Insurance Code of Practice (see sections 1.3, 4.4, 7.2 and 10.4), and the Life Insurance Code of Practice (see Key Code Promise 1, and sections 1.5 and 1.6). The survey participants were neutral as to whether their insurer was fair, despite fairness being an industry standard under both Codes.

Some participants commented that insurance representatives were polite, understanding and sympathetic, even where the insurer's decision was not as hoped for. However, there were many negative comments in relation to the conduct and manner of insurance representatives. There were concerns about lack of politeness and sympathy.

"The insurer was quite rude at one point and made the already difficult process harder."

"They have been abusive, rude, it's been extremely stressful for both of us."

"Hard hearted and totally unsympathetic in my dealings with them."

Insurers' efficiency was rated the highest out of the factors in the survey. However, analysis of participants' comments about efficiency revealed concerns about both quick refusals and delays in processing claims regarding life insurance products.

"5 minute outright refusal."

"Most denied coverage for these conditions immediately."

"Rather quickly—claim resulting from cancer excluded."

"Instant refusal."

"[It's been] nearly 12 months. Unable to contact them. Very slow at processing the next part of the claim so you are repeating some of the examinations. A lot of procrastination."

"Had to be off work continuously for 3 months before could lodge a claim, then it took them another 2 months to process the claim, with me having to contact them a number of times to find out the status. To me, this seemed very slow and inefficient."

## Dealing with insurance problems

### *What actions did people take?*

When survey participants were asked what they did about their insurance problems:

- 48% reported that they did not have any insurance problem (n=134)
- 43% said they had a problem, but have not done anything about it (n=120), and
- 9% had a problem and took some action to resolve it:
  - 5% sought legal or financial advice (n=14)
  - 4% lodged a complaint through the insurers' internal dispute resolution (IDR) process (n=10)
  - 1% lodged a complaint through an external dispute resolution scheme (n=3) (*Note: these participants also appear in the IDR figures above*).

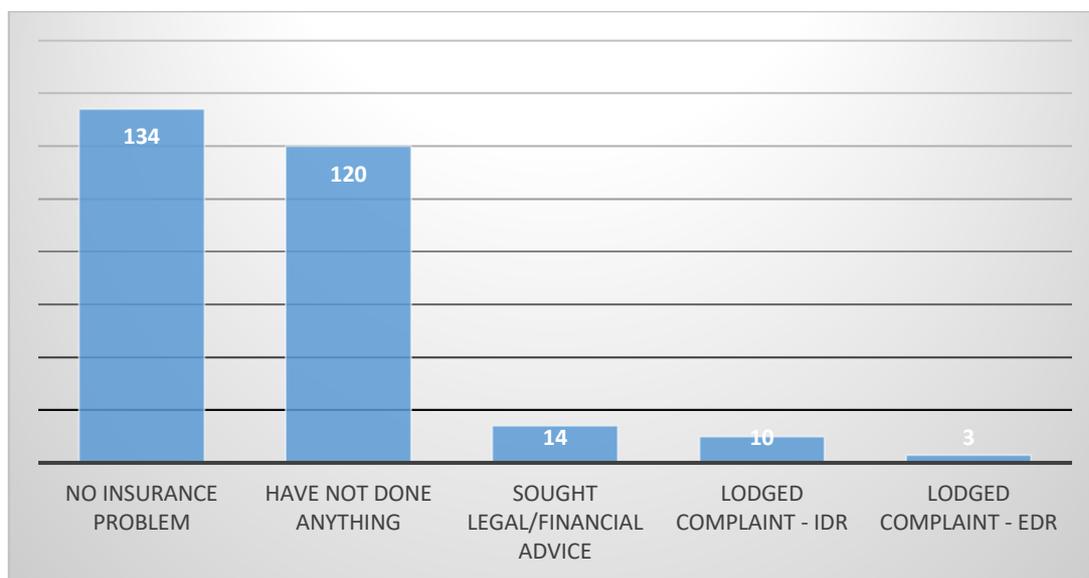


Figure 5: What participants did about their insurance problems

A similar trend was found in the Cancer Group (n=183), where 51% didn't have an insurance problem (n=93), and 42% said they have not done anything about their problems (n=77). Only 4% of survey participants in the cancer group had sought legal or financial advice (n=8), 2% had lodged a complaint through internal dispute resolution (n=3), and 1% through external dispute resolution (n=2).

Notably, while 66% of participants reported that they had difficulty obtaining insurance; only 51% identified having an insurance problem. This disparity suggests that some consumers do not identify their inability to obtain appropriate insurance as a problem, let alone a legal problem with possible legal solutions.

### *What are the reasons for inaction?*

Only 14 participants with an insurance problem made an informed decision to not act, and gave reasons such as "I am waiting for the insurer to get back to me" and "I eventually found an insurer who would cover me". The remainder (n=106) felt constrained by factors such as:

- Feeling disheartened or despondent
- Unsure of their options

- Lack of physical, emotional and financial capacity to take action
- Accepted the status quo but still find it unfair, and
- Fear of negative implications if action is taken.

#### **Feeling disheartened or despondent**

“Because when I first tried to get income protection insurance in my 20’s, I got a broker who approached every insurer. I was denied by each one. Since then I have acquired other benign health issues, and I don’t have the heart to try again.” Female, 44 yrs, with stable and lifelong hydrocephalus.

“No insurer that I contacted was willing to cover me (due to the risk of recurrence?). I could not take on the whole of the travel insurance industry.” Male, 64 years, rare cancer survivor.

“I gave up. I'm not saying it's fair, but it is what it is. I'm very fearful on what is going to happen when I want to purchase travel insurance. I'm stuffed...” Female 53 years, breast cancer survivor.

#### **Unsure of their options**

“I don't know what to do. I have been treated for cancer and no longer have evidence of it in my body but they still won't insure me to travel... I have not had it for a year but still no approval given.” Female, 53 years, lung cancer survivor.

“At the time they removed me from the insurance cover... I felt discriminated against, but was at a loss on where and what to do.” Female 55 years, breast cancer survivor.

#### **Lack of financial, physical or emotional capacity**

“Because it's too hard. When I got refused cover I asked for an assessment, then I was still refused cover. The insurer then said if I wanted to dispute it I had to provide about 10 different documents from different health professionals. They make it so difficult and time consuming that people walk away.” Male 47 years, rare cancer survivor.

#### **Accepted status quo but still find it unfair**

“I’ve contacted various insurance companies, I can never get covered for Bronchiectasis. Insurance companies don't understand exactly what the condition is or take into account how it doesn't affect my everyday life at all. I have travelled overseas extensively for a total of 4 months over the past 6 months [with] no incidents requiring medical treatment.” Female 70 years, with a lung condition for over 20 years.

  
**Negative implications if action taken**

“My insurer has recently started refusing to pay ongoing costs. In the past when I've complained they've punished me by refusing to pay other things which have been converted [compensated] in the past. I'm concerned that if I take my complaint further they will find enough things to refuse payment on.” Female 55 years, cancer survivor.

Overwhelmingly, survey participants identified insurance problems, but did not take any action to address their problems. Very few people sought legal or financial advice. Fewer people lodged a complaint to the insurer through internal dispute resolution processes. Even fewer people lodged a complaint against the insurer at an external dispute resolution forum.

It is of concern that the legal framework which aims to protect consumers from unlawful discrimination and provide cost-free dispute resolution mechanisms, is not being effectively used by consumers in practice.

This suggests that there is a need to empower consumers by increasing their awareness of their legal rights and options, as well as providing support to take action where insurance problems arise.

## 3. Legal framework

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### Summary

Australia's anti-discrimination laws regulate the provision of goods and services, including insurance and superannuation. It is unlawful to discriminate against a person because of their disability. However, a person can be refused cover or a charged an additional premium if the decision is based on actuarial or statistical data on which it is reasonable for the insurer to rely, and is reasonable having regard to the matter of the data and other relevant factors. Insurers also have obligations to provide services efficiently, honestly and fairly, and to act in good faith. Complaints about breaches of anti-discrimination laws can be made in a range of forums.

### Disability discrimination is unlawful

The purpose of the *Disability Discrimination Act 1992* (Cth) (DDA) is to promote, as far as possible, the rights of people with a disability to participate equally in all areas of life.<sup>9</sup> It is unlawful to discriminate against a person because of their disability:

- by refusing to provide them with goods or services or make facilities available to them, or
- in the terms or conditions on which, or in the manner in which, the goods, services or facilities are provided.<sup>10</sup>

Discrimination can be direct or indirect. Direct discrimination is where a person with a disability is treated less favourably than a person without that disability in the same or similar circumstances. Indirect discrimination is often less obvious. It occurs when practices, conditions or requirements that appear to equally apply to everyone have the effect of causing a disadvantage for a person because of their disability.

Sections 4 and 5 of the DDA require reasonable adjustments to be made to allow people with disability to access goods, services or facilities such as insurance.

### Partial exemption for insurance contracts and superannuation

A partial exemption to the prohibition on discrimination applies to insurance policies and superannuation. The exemption allows insurers to refuse to cover a person with disability or to modify the person's insurance policy if the decision:

- (i) is based on actuarial or statistical data on which it is reasonable for the insurer to rely, and
- (ii) is reasonable having regard to the matter of the data and other relevant factors.<sup>11</sup>

If no reliable data is available or reasonably obtainable, the decision to refuse to insure or to modify the policy is not unlawful discrimination if the discrimination is reasonable having regard to any other relevant factors.<sup>12</sup> The onus of proof is on the insurer to demonstrate that the exemption applies.

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<sup>9</sup> Australian Human Rights Commission Guidelines for providers of insurance and superannuation under the Disability Discrimination Act 1992 (Cth) (2016).

<sup>10</sup> Disability Discrimination Act 1992 (Cth) section 24.

<sup>11</sup> Disability Discrimination Act 1992 (Cth) section 46(1)(f).

<sup>12</sup> Disability Discrimination Act 1992 (Cth) section 46(1)(g).

The operation of this exemption has been considered in *Xiros v Fortis Life Assurance Ltd (Xiros)*,<sup>13</sup> *QBE Travel Insurance v Bassanelli (Bassanelli)*<sup>14</sup> and *Ingram v QBE Insurance (Australia) Ltd (Ingram)*.<sup>15</sup>

In *Xiros*, the Federal Magistrates Court found that the insurer had sufficiently justified the exclusion of HIV/AIDS from the mortgage protection insurance purchased by the applicant.

In *Bassanelli*, the insurer declined to issue Ms Bassanelli a travel insurance policy for a short holiday to Japan. Another insurer subsequently issued a policy to Ms Bassanelli that excluded any claims relating to her pre-existing medical conditions. The Federal Court found that in declining Ms Bassanelli cover, the insurer had not acted reasonably, and did not base its decision to discriminate on relevant factors. The Federal Court held that a person cannot be discriminated against for having a pre-existing condition, such as cancer, when the insurance sought does not relate to the condition.

In *Ingram*, the insurer had denied Ms Ingram's travel insurance claim after she was hospitalised with depression and had to cancel her overseas school trip. The insurer refused the claim because of an exclusion in the policy for claims relating to mental illness. The Victorian Civil and Administrative Tribunal decided that the insurer discriminated against Ms Ingram, in breach of the *Equal Opportunity Act 2010 (Vic)*, a state-based anti-discrimination statute that is similar to the DDA. The insurer attempted to rely on the statutory exemptions to justify the discrimination, but the Tribunal found that the insurer failed to prove that:

1. the discrimination was based on reasonable actuarial or statistical data,
2. it would have suffered unjustifiable hardship if the mental illness exclusion was not in the insurance policy, and
3. removing the mental illness exclusion would lead to price increase or financial loss.

The AHRC has published non-binding guidelines that provide the Commission's views on the interpretation of the DDA, when discrimination may be unlawful, and when it may be lawful.<sup>16</sup>

## General defence of unjustifiable hardship

A general defence of unjustifiable hardship is also available for insurance and superannuation providers.<sup>17</sup> This defence is available to all who provide goods, services or facilities in Australia and means that it is not unlawful for an insurer to discriminate against someone on the basis of disability if providing the insurance cover would cause unjustifiable hardship.

While a reduction in profits might be sufficient to amount to an unjustifiable hardship, the insurer must provide reliable evidence to establish that there would be a reduction in profits.<sup>18</sup>

The unjustifiable hardship defence was considered in *Financial Ombudsman Service Case No. 428120*,<sup>19</sup> where the applicant lodged a claim on a travel insurance policy after suffering a manic

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<sup>13</sup> *Xiros v Fortis Life Assurance Ltd* (2001) FMCA 15.

<sup>14</sup> *QBE Travel Insurance v Bassanelli* [2004] FCA 396.

<sup>15</sup> *Ingram v QBE Insurance (Australia) Ltd* [2015] VCAT 2936.

<sup>16</sup> Australian Human Rights Commission. (2016). Guidelines for providers of insurance and superannuation under the Disability Discrimination Act 1992 (Cth).

<sup>17</sup> Disability Discrimination Act 1992 (Cth) section 29A.

<sup>18</sup> *Ingram v QBE Insurance (Australia) Ltd* (Human Rights) [2015] VCAT 1936; adopting the approach of the Federal Court in *King v Jetstar Airways Pty Ltd (No 2)* [2012] FCA 8.

<sup>19</sup> *Financial Ombudsman Service Case No. 428120*, 31 March 2017.

episode during his overseas trip. The applicant had no history of mental illness prior to departure. The FOS Panel determined that the travel insurer in that case:

Is not entitled to rely on the general exclusion clause under the policy because:

1. the general exclusion for all claims arising from mental illness is contrary to the provisions of Section 5 and Section 24 of the *Disability Discrimination Act 1992*,
2. the insurer has not established an unjustifiable hardship under section 29(A) of the *Disability Discrimination Act 1992*, and
3. the insurer has not established that the discrimination is lawful under the exemptions within section 46(2)(f) or section 46(2)(g) of the *Disability Discrimination Act 1992*.

The insurer gave evidence that the anticipated extra cost to the insurer if it covered first presentation mental illness as well as pre-existing mental illness was \$5.60 per policy (or \$3.50 per insured). However, the FOS Panel found that the information provided by the insurer did not establish in this claim that it would suffer unjustifiable hardship within the meaning of the DDA, as no relevant information was provided concerning first presentation mental illness.

## Obligations of insurers as financial services providers

Insurers have a range of obligations under financial services laws which underpin their interactions with consumers. Key obligations that impact consumers with health conditions include duties under Australian Financial Services Licences (AFSLs), the duty of utmost good faith, and industry codes of practice.

### General duty as the holder of an Australian Financial Services Licence

Insurers are generally required to hold an Australian Financial Services Licence (AFSL). The Corporations Act sets out the general duties of AFSL holders, including the duty to:

- do all things necessary to ensure that the **financial services** covered by the **licence** are **provided** efficiently, honestly and fairly: section 912A(1)(a)
- comply with the **financial services laws**: section 912A(1)(c). “Financial services laws” as defined by the Act are most likely broad enough to include protections against disability discrimination in the provision of insurance.

### Duty of utmost good faith

The duty of utmost good faith is implied into all contracts of insurance by section 13 of the *Insurance Contracts Act 1984* (ICA 1984). A failure to comply with the duty of utmost good faith constitutes a breach of the ICA 1984. Gleeson CJ and Crennan J described the duty of utmost good faith in the matter of *CGU v AMP* [2007] HCA 36 (29 August 2007) at [15]:

In particular, we accept that utmost good faith may require an insurer to act with due regard to the legitimate interests of an insured, as well as its own interests. The classic example of an insured's obligation of utmost good faith is a requirement of full disclosure to an insurer, that is to say, a requirement to pay regard to the legitimate interests of the insurer. Conversely, an insurer's statutory obligation to act with utmost good faith may require an insurer to act, consistently with commercial standards of decency and fairness, with due regard to the interests of the insured.



These obligations are overseen by the Australian Securities and Investments Commission (ASIC).

## Industry codes of practice

Industry codes of practice are voluntary codes in which insurers agree to minimum standards of conduct.

The Life Insurance Code of Practice is owned and published by the [Financial Services Council](#) (FSC). All life insurance companies which are FSC members were required to be compliant with the Code by 1 July 2017.

The General Insurance Code of Practice is owned and published by the [Insurance Council of Australia](#). The latest version of the Code is effective from 1 July 2015. The Code was recently reviewed.

The Insurance in Superannuation Voluntary Code of Practice is the most recent industry Code, and commenced on 1 July 2018. It is owned by the Financial Services Council, Australian Institute of Superannuation Trustees (AIST) and Association of Superannuation Funds of Australia (ASFA).

Code governance committees oversee compliance with industry codes. Failure to adhere to a code can result in sanctions. AFCA, and its predecessor FOS, also plays a role in ensuring code compliance. FOS operated an independent business unit called the Code Compliance and Monitoring team (Code Team) which supported independent code governance committees of various industry codes to monitor compliance. The Code Team can investigate consumer concerns to help them to monitor insurers' compliance, and support them to remedy breaches of the code.

## Access to redress

Concerns about disability discrimination in insurance can be raised:

- with the insurer, via internal dispute resolution processes
- with AFCA, an external dispute resolution process
- in tribunals that handle complaints under state-based anti-discrimination laws
- at the AHRC, and
- in the state and federal courts.

## Complaints to the Australian Financial Complaints Authority

As a condition of their AFSL, insurers are required to be members of an external dispute resolution scheme. Almost all insurers are members of AFCA.

It is free for consumers to complain to AFCA. AFCA will attempt to resolve the complaint by conciliation. If this is not possible, AFCA will make a determination, or final decision, that is binding on the insurer. If the consumer is unsatisfied with the outcome the consumer can reject the decision and continue to pursue remedies in court. The AFCA process allows disputes to be resolved without the consumer needing to attend in person.

## State-based processes

There are anti-discrimination laws in all states and territories in Australia. They prohibit discrimination based on disability, but coverage varies between jurisdictions.<sup>20</sup> Complaints about breaches of these laws can be made to state agencies. In NSW, the Anti-Discrimination Board will attempt to conciliate the complaint.<sup>21</sup> If the conciliation is unsuccessful, the complaint may be referred to the NSW Civil and Administrative Tribunal for a legally binding decision.<sup>22</sup>

## Complaints to the Australian Human Rights Commission

Complaints about breaches of the DDA can be made to the AHRC, where conciliation will be attempted.<sup>23</sup> The AHRC does not have the power to order that an insurer take specific steps to remedy discrimination. Only 13 complaints were made to the AHRC under the DDA in relation to superannuation and insurance in the 2016–17 financial year. Case studies published by the AHRC show that complaints have been made by people with HIV, whiplash injury, mental illnesses, melanoma, visual impairment and diabetes.<sup>24</sup>

If conciliation is unsuccessful, complainants can apply to the Federal Court or the Federal Circuit Court for a binding decision. The court may order damages and other remedies.<sup>25</sup>

## A comment on complaint-based approaches

The current anti-discrimination framework relies heavily on individuals to make complaints for redress. Such mechanisms can be effective, particularly where the consumer is assertive and confident in their ability to navigate complaint systems, and where the systems are user-friendly and include supports for vulnerable users. However, complaint-based systems have been criticised as being reactive, focussed on the individual, privatising conflict and ignoring power dynamics.<sup>26</sup> Settlement of individual complaints can also avoid systemic practices being addressed. Chapter 5 of this report suggests ways to ensure compliance with anti-discrimination laws that do not rely on consumers to make complaints.

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<sup>20</sup> See further Australian Human Rights Commission *A quick guide to Australian discrimination laws* <https://www.humanrights.gov.au/employers/good-practice-good-business-factsheets/quick-guide-australian-discrimination-laws> accessed 10 September 2018.

<sup>21</sup> *Anti-Discrimination Act 1977* (NSW) s 91A.

<sup>22</sup> *Anti-Discrimination Act 1977* (NSW) s 93B.

<sup>23</sup> *Australian Human Rights Act 1986* (Cth) Part IIB Div 1.

<sup>24</sup> Australian Human Rights Commission (AHRC) *DDA conciliation: insurance*

<https://www.humanrights.gov.au/dda-conciliation-insurance>

AHRC *Conciliation Register*

<https://www.humanrights.gov.au/complaints/conciliation-register> accessed 10 September 2018.

<sup>25</sup> *Australian Human Rights Act 1986* (Cth) Part IIB Div 2.

<sup>26</sup> Maggie Smyth, Angelene Falk. (2013). "Addressing systemic discrimination in the public sector" *Occasional Paper of the NSW Anti-Discrimination Board* 17.

## 4. Background and Context

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### Summary

Almost one in five Australians report living with a disability, and this rate is likely to increase with the ageing of the population. People living in areas characterised by socio-economic disadvantage are more likely to live with disability. Insurance is an important way of managing the risk of unexpected economic loss that can occur as a result of the illness, injury or death of a family member, a car accident or a natural disaster. If access to insurance for people living with disability or health conditions is impeded, they have a greater risk of poverty. The shift to individualised risk pricing of insurance may be creating barriers for people living with disability or health conditions.

### Disability in Australia

Almost 1 in 5 Australians reported living with a disability in 2015 (18.3% or 4.3 million people).<sup>27</sup> This rate is predicted to increase with an ageing population.<sup>28</sup>

In Australia, cancer is the leading cause of disease burden.<sup>29</sup> By the age of 85, 1 in 2 people will be diagnosed with cancer at some stage in their life.<sup>30</sup> The majority of people (68%) diagnosed with cancer are alive five years after diagnosis.<sup>31</sup> Survival rates are improving, due to better diagnostic methods, earlier detection and improvements in treatment.<sup>32</sup> As treatments and survival rates improve, cancer is increasingly being viewed as a chronic disease that can be effectively managed.

There is a clear relationship between disability and socio-economic disadvantage, with people residing in areas with lower socio-economic conditions being more likely to experience severe disability in comparison to people from other areas.<sup>33</sup>

The Legal Australia-Wide Survey revealed that respondents with a disability were 2.2 times more likely to experience legal problems when compared to other respondents.<sup>34</sup>

### What is insurance

Insurance is an arrangement where a consumer transfers to the insurer financial loss that the consumer might suffer if an unexpected event happens during the period of the arrangement.

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<sup>27</sup> Australian Bureau of Statistics *A profile of people with disability in Australia – Information Sheet* (2016) ABS Cat No 4430.0. The definition of disability used by the ABS is 'a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities'.

<sup>28</sup> Australian Bureau of Statistics. (2009). *Disability, Ageing and Carers, Australia: Summary of Findings* Cat. no. 4430.0. Canberra: ABS.

<sup>29</sup> Australian Institute of Health and Welfare. (2017). *Cancer in Australia* Canberra: AIHW at ix.

<sup>30</sup> Australian Institute of Health and Welfare. (2017). *Cancer in Australia* Canberra: AIHW at 17.

<sup>31</sup> Australian Institute of Health and Welfare. (2017). *Cancer in Australia* Canberra: AIHW at 40.

<sup>32</sup> Australian Institute of Health and Welfare. (2017). *Cancer in Australia* Canberra: AIHW at 42.

<sup>33</sup> Louise O'Rance. (2009). *The geography of disability and economic disadvantage* Australian Institute of Health and Welfare.

<sup>34</sup> Christine Coumarelos, Deborah Macourt, Julie People, Hugh M McDonald, Zhigang Wei, Reiny Iriana and Stephanie Ramsey. (2012). *Legal Australia-Wide Survey: Legal Need in NSW*. Law and Justice Foundation of NSW at 68.

There are three broad categories of insurance products available to consumers:

1. general insurance (eg: home, contents, car, liability and travel insurance)
2. life insurance (eg: income protection, total and permanent disablement, term life insurance payable upon death)
3. health insurance.

While 13% of respondents to the survey raised concerns about health insurance, this report's analysis and recommendations focuses on general and life insurance products. Health insurance falls outside of the scope of legal services provided by Legal Aid NSW and is governed by a separate legal framework.

## Why insurance matters

Insurance protects individuals and families from financial crises following unexpected events. Real life blows, such as a car accident, the sudden death of a family member, an illness or a natural disaster, have a particular impact on an uninsured person, causing financial hardship and stress. People on low incomes often do not have the social or financial resources to help them withstand such shocks. The inability to manage the risk caused by such an event can perpetuate or lead to poverty. Insurance can prevent asset loss and poverty.

“Financial inclusion” means that individuals and businesses have access to financial products that meet their needs.<sup>35</sup> On the other hand, financial exclusion means that people find it difficult to access the products they need. This can result in or reinforce social exclusion.<sup>36</sup> Inability to access insurance can result in being unable to travel, or being unable to secure one's family's future in the event of illness, injury or death.

### ***Advice from the Department of Foreign Affairs and Trade***

“Organising travel insurance is an essential part of preparing for your overseas trip.”

“Check you're covered for your pre-existing medical conditions.”

“If you can't afford travel insurance, you can't afford to travel.”<sup>37</sup>

<sup>35</sup> World Bank, *Financial inclusion* <https://www.worldbank.org/en/topic/financialinclusion> accessed 30 August 2018.

<sup>36</sup> Mitton, L. (2008). *Financial inclusion in the UK: Review of policy and practice*. Joseph Rowntree Foundation at 2.

<sup>37</sup> Department of Foreign Affairs and Trade *Travel Smart Advice for all travellers* <https://smartraveller.gov.au/guide/all-travellers/everyone/Pages/advice-for-all-travellers.aspx> accessed 30 August 2018.

### **Accessing travel insurance**

“For many people with cancer, getting travel insurance can turn a dream holiday into a nightmare. Every day, we hear from people who have longed for a holiday as a chance to recuperate, to celebrate the end of their treatment, or to spend precious time with friends or family, only to have those plans shattered by issues with travel insurance.”

“It’s not good enough that they are being denied travel insurance or charged sky-high prices. Even those who were diagnosed a decade ago are being written off as ‘uncoverable’.”

“We want insurance providers to give people with cancer a break. Travel insurance policies should be clear and fairly priced for everyone, including people with cancer.”<sup>38</sup>

### **Advice from PriceWaterhouseCoopers**

“Life insurance plays a vital role in Australia’s social construct, and in providing financial protection to those policyholders in need, it truly has a noble purpose.”

“One thing that will not change is the core purpose of life insurance – to protect customers and offer them peace of mind in their time of greatest need.”<sup>39</sup>

### **Advice from ASIC**

“By setting up a way to support your loved ones after you die, you can ensure they can continue to pay the mortgage and school expenses, go on holiday and buy essentials.

Consider how much money your family would:

- Need – to pay your mortgage and any other debts, as well as child care, education and living expenses
- Receive – from superannuation, shares, savings and existing insurance policies, how much paid leave you have and what type of support your family could provide.

The difference between these is the amount of cover you should get.”<sup>40</sup>

<sup>38</sup> Lynda Thomas, Chief Executive, MacMillan Cancer Support (UK). “Thousands of holidaymakers denied travel insurance despite being diagnosed with cancer over a decade ago”. Media Release, 18 July 2017.

<sup>39</sup> pricewaterhousecoopers. (2017). *Future of Life Insurance in Australia*, at 3, 9.

<sup>40</sup> ASIC. *Life cover* Moneysmart website, <https://www.moneysmart.gov.au/insurance/life-insurance/life-cover> accessed 11 September 2018.

## Pricing insurance

There are (at least) two possible approaches to calculating premiums for insurance products:

1. **Mutuality:** where members pay money into a pool of funds that is then used to draw from when paying out valid claims. Those people who claim less end up subsidising those who claim more.
2. **Individualised risk-pricing:** where an individual's risk is estimated for the purpose of setting the premium they should pay.<sup>41</sup>

If risk is priced individually, low-risk people benefit, while others find their premiums rise significantly, and others may be uninsurable.<sup>42</sup> In recent times, there has been a move towards individualised risk pricing (sometimes called 'segmented markets'). The UK government has recognised that increasingly segmented markets in insurance has meant that those consumers who have, or have had, cancer as well as other pre-existing medical conditions face difficulties accessing insurance.<sup>43</sup>

In Australia, when calculating risk, insurers rely heavily on databases such as that provided by UK-based company Healix. The Insurance Council of Australia describes Healix as follows:

a configurable 'black box' system that allows the assessment of pre-existing medical conditions as part of the sales and underwriting process. The black box contains a medical dataset and risk algorithms, that are described (by Healix) as being continually updated to reflect the latest insurance claims data and trends in medical treatment. The information provided by systems, such as Healix, is essential to an underwriter making a decision to provide cover (and at what premium) or to exclude a pre-existing condition.<sup>44</sup>

## Evidence of difficulty accessing insurance

Existing research suggests a need to improve access to insurance to people with health conditions.

### Cancer and insurance

A 2014 report from the McCabe Centre for Cancer and the Law raised concerns about access to life and travel insurance by people affected by cancer.<sup>45</sup> It analysed the responses of almost 100 women in an online survey distributed by Breast Cancer Network Australia (BCNA), and found that despite 87% of respondents thinking that obtaining an insurance cover is a problem for people affected by

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<sup>41</sup> Mabbett, D. (2001). *Mutuality in insurance and social security: retrospect and prospect*. The New Mutualism in Public Policy. Johnston Birchall: Routledge.

<sup>42</sup> Collard, S., Coppack, M., Lowe, J. and Sarkar, S. (2016). *Occasional Paper No. 17: Access to Financial Services in the UK*. London: Financial Conducts Authority.

<sup>43</sup> Collard, S., Coppack, M., Lowe, J. and Sarkar, S. (2016). *Occasional Paper No. 17: Access to Financial Services in the UK*. London: Financial Conducts Authority.

<sup>44</sup> Insurance Council of Australia, letter to Cancer Voices NSW, published in *Cancer Voices NSW Newsletter of September 2016*.

<sup>45</sup> Lawson, D. and Davoren, S. (2014). *Making the Law Better for People Affected by Cancer – 2013 Report*. McCabe Centre for Law and Cancer: Cancer Council Victoria.

cancer, none of the respondents had made a complaint about discrimination in insurance. The McCabe Centre recommend<sup>46</sup>:

- Amending the *Insurance Contracts Act 1984* (Cth) to enable consumers to obtain information about an insurer's adverse decision, including details of the actuarial or statistical data relied by the insurer;
- More resources for people affected by cancer to better understand the protections under the DDA, and to support them to make a complaint where appropriate; and
- Facilitate research on the uptake and use of genetic information for the purposes of insurance.

In 2017, the United Kingdom's financial services regulator, the Financial Conduct Authority, stated that:

We have seen evidence from our work with stakeholders that these issues are present and significant in the travel insurance market for those with pre-existing medical conditions. These issues are particularly apparent for those with, or recovering from, cancer.<sup>47</sup>

The Brain Tumour Alliance Australia<sup>48</sup> and Cancer Voices NSW<sup>49</sup> have also raised concerns with the Insurance Council of Australia about their members' access to insurance.

## Mental health and insurance

In 2011, the Mental Health Council of Australia conducted a survey of people living with mental illness and accessing insurance. The results were remarkably similar to those of our health conditions survey, with both groups of survey participants reporting:

- Being offered insurance products with higher premiums and exclusions, and at times being refused cover completely
- Difficulties making claims
- Personal circumstances not being taken into account, and assumptions being made about them,
- A lack of awareness of their rights to appeal insurers' decisions.<sup>50</sup>

Over the past two decades, the life insurance industry and the mental health sector have worked together to improve life insurance outcomes for people with mental illness.<sup>51</sup> Significant progress has been made. Industry-wide guidelines relating to mental health conditions have been developed, and

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<sup>46</sup> Discrimination in Insurance <http://www.mccabecentre.org/focus-areas/treatment-and-support/making-law-work-cancer/insurance-discrimination> accessed 22 October 018

<sup>47</sup> Financial Conduct Authority. (2017). *Call for Input: Access to Insurance*, 3.

<sup>48</sup> Letter from Insurance Council of Australia to Brain Tumour Alliance Australia, 23 February 2015 at <https://www.btaa.org.au/page/13/documents-research>, accessed 10 September 2018.

<sup>49</sup> Cancer Voices NSW. "Travel Insurance - Progress Report" September 2016 *Newsletter* at <https://www.cancervoices.org.au/news-updates/>.

<sup>50</sup> Mental Health Council of Australia. (2011). *Mental Health, Discrimination and Insurance: A survey of consumer experiences 2011*.

<sup>51</sup> This partnership involves organisations such as the Australian General Practice Network, Australian Medical Association, Australian Psychological Society, *beyondblue*, Financial Planning Association, Financial Services Council, Mental Health Council of Australia, Royal Australian and New Zealand College of Psychiatrists, and Royal Australian College of General Practitioners.

useful resources such as the information guide *Mental illness and life insurance: What you need to know* have been distributed. This information guide states that, as a result of this collaborative work, there has been a decline in the rate of refusal of life insurance for those living with a mental illness.<sup>52</sup>

People suffering from mental health conditions are not excluded from cover in group insurance contracts as long as they meet the eligibility test when they first start work with an employer... Exclusions can be put in place for a medical condition based on a person's medical history, but **mental health conditions are treated no differently to any other medical condition by the insurer.**<sup>53</sup> (emphasis added).

Concerns remain regarding mental health exclusions in insurance, particularly regarding life, income protection, total and permanent disability and travel insurance.<sup>54</sup>

The Public Interest Advocacy Centre is working with beyondblue, Mental Health Australia and Victoria Legal Aid to address discrimination against people with mental illness in insurance.<sup>55</sup> PIAC said:

We believe insurers should make a genuine assessment of the risks posed by all applicants for insurance. Insurers should offer insurance that reflects the real risk posed by the application for insurance and not on generalised or outdated understandings of mental health conditions.<sup>56</sup>

The final chapter of this report considers ways to ensure that insurers do indeed make “a genuine assessment of the risks”.

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<sup>52</sup> Beyondblue, Lifewise, Mental Health Council of Australia, FPA. (undated) *Mental illness and life insurance – what you need to know – a brief guide* <http://www.lifewise.org.au/>.

<sup>53</sup> Comminsure general manager of wholesale life, Claire Roberts, cited in Chunn, J. “Life insurance for mental illness sufferers”. *Investment Magazine*, 26 November 2012.

<sup>54</sup> Misa Han. “Banking royal commission: Insurers might be breaking anti-discrimination laws”. *Australian Financial Review* 8 September 2018; Public Interest Advocacy Centre. Media Release “Banking Royal Commission: insurers must end mental health discrimination” 10 September 2018.

<sup>55</sup> Public Interest Advocacy Centre. *Mental health and insurance*. 11 August, 2016 <https://www.piac.asn.au/project-highlight/mental-health-and-insurance/>

<sup>56</sup> Public Interest Advocacy Centre. *Mental health and insurance*. 11 August, 2016 <https://www.piac.asn.au/project-highlight/mental-health-and-insurance/>

## 5. Opportunities to improve access to insurance

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### Summary

The survey (Chapter 2) and literature review (Chapter 4) indicate that there are widespread challenges for people with health conditions accessing insurance. This chapter proposes a systematic and proactive approach to improving access to insurance for people with all health conditions, and a collective effort from the insurance industry, government, consumers and their advocates. Insurers should examine their offerings to ensure exclusions and premiums are based on evidence upon which it is reasonable to rely. Codes of practice should include obligations to comply with anti-discrimination laws, and code compliance committees should ensure compliance with these obligations. AFCA should publish an industry guideline setting out its approach to disability discrimination in insurance. AHRC should conduct an industry review to examine compliance. ASIC should incorporate findings from this research into consumer messaging on MoneySmart, and conduct inquiries relating to potential breaches of license obligations by insurers in relation to the findings of this review, including in thematic industry reviews. When insurer obligations are expanded to include a ban on unfair contract terms, ASIC should review travel and life insurance policies to identify unfair terms relating to consumers with pre-existing health conditions and disabilities. Consumer advocates should raise awareness of legal rights and support consumers to lodge complaints. Finally, government, industry and advocates should support market innovations that improve access for people with health conditions.

### Systematic solutions for all health conditions

As noted in Chapter 4, advocates for people living with mental illness and cancer have worked to improve access to insurance for people with these conditions. However, the problem of access to insurance for people with disability or health conditions should not be solved one health condition at a time. Globally, rates of disability are increasing, in part due to population ageing and increases in chronic health conditions.<sup>57</sup> Solutions that address all health conditions are required.

### Moving beyond complaint-based approaches

The legal framework to respond to breaches of anti-discrimination law was outlined in Chapter 3. The legal options are complaint-based, requiring consumers (or potential consumers) to take action if they consider that they have been discriminated against. Such mechanisms can be effective when the consumer is assertive, literate and confident, but where the consumer is not aware of their legal options, or lacks confidence, discriminatory conduct can go unchallenged. Legal Aid NSW considers that the insurance industry and regulators should take proactive steps to ensure compliance with anti-discrimination laws. Some options are outlined below.

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<sup>57</sup> World Health Organisation. (2016). *Factsheet: Disability & Health*  
<http://www.who.int/mediacentre/factsheets/fs352/en/>.

## Opportunities for the insurance industry

### Examine exclusions and the price of products

Insurance expert Colin Pausey from Sparke Helmore Lawyers considered the issues raised in the VCAT decision of *Ingram* (discussed in Chapter 3), and made a number of recommendations to insurers.<sup>58</sup> Pausey advised that insurers should identify the historical reason as to why an exclusion was introduced, which means that insurers should first keep historical data. Insurers should then use statistical and actuarial data to price the cost of removing the exclusion.

“The mere fact that an exclusion is commonplace or market accepted may not be good enough.”<sup>59</sup>

It is currently unclear the extent to which this is happening across the insurance industry. The published complaints to the AHRC, FOS (now AFCA) and courts suggest that at least some insurers are not making decisions to decline coverage, exclude health conditions or impose higher premiums on people with health conditions on the basis of actuarial or statistical data upon which it is reasonable to rely. Legal Aid NSW considers that insurers should, as Pausey proposes, examine all policies that exclude coverage for health conditions to ensure that the exclusion complies with the law.

#### **Recommendation 1:**

**Insurers should review all policies that exclude coverage for health conditions and ensure that the exclusion is justified on the basis of actuarial or statistical data upon which it is reasonable to rely.**

### Use industry codes to ensure compliance with anti-discrimination law

#### *Extending Code obligations*

The new Life Insurance Code of Practice, which came into full effect on 30 June 2017, introduced additional obligations on insurers to comply with anti-discrimination law:

Our decisions on applications for insurance will comply with the requirements of anti-discrimination law. Our decisions will be evidence-based, involving relevant sources of information where this is available, and having regard to any other relevant factors where no data is available and cannot reasonably be obtained. We will regularly review our underwriting decision-making processes to ensure we are not relying on out-of-date or irrelevant sources of information.<sup>60</sup>

This new Code provides that consumers can report to the Life Code Compliance Committee which is the body responsible for monitoring and enforcing compliance with the Code.

Legal Aid NSW suggests that similar anti-discrimination requirements should be incorporated into the General Insurance Code of Practice.

<sup>58</sup> Colin Pausey. “Australia: rethinking mental health exclusions in the context of the Ingram decision” *Mondaq* 5 May 2016.

<sup>59</sup> Colin Pausey. “Australia: rethinking mental health exclusions in the context of the Ingram decision” *Mondaq* 5 May 2016.

<sup>60</sup> Life Insurance Code of Practice section 5.17.



Legal Aid NSW considers that the General Insurance Code Governance Committee should monitor and enforce compliance with any relevant anti-discrimination clauses. This might include own motion inquiries and desk-top audits. Our survey revealed that 23 survey respondents did not make a claim on their policy because they were told that they would not be covered.<sup>61</sup> We consider that particular attention should be paid to compliance with the Code requirement that potential claimants should not be discouraged from making claims.<sup>62</sup>

The monitoring committees would be assisted in their work if they were aware of allegations of discrimination made against insurers. As noted in Chapter 3, consumers may make a complaint of discrimination to the AFCA, to the AHRC, or to state-based tribunals. It is difficult to gather data about the incidence of claims of discrimination in insurance.<sup>63</sup> Codes of Practice should require insurers to report to the Code Committee if an allegation of discrimination is made against them.

### *Transparent decision-making*

Transparency around decision-making regarding insurance for people with health conditions can help to ensure that those decisions are made on the best available information. Legal Aid NSW considers that consumers should be given:

- reasons for decisions
- information about their right to receive the information the decision was based on, and
- information about their right to appeal / complain against the decision.

This should apply to the decision to refuse cover, to offer cover at a higher premium, or the decision to refuse a claim.

The Life Insurance Code of Practice protects all of the above consumer rights.<sup>64</sup> However the General Insurance Code of Practice only protects some of them. For example, the General Insurance Code of Practice requires providers to give reasons for a decision to refuse cover or deny a claim, but not to offer cover at a higher premium.<sup>65</sup> This Code only requires providers to give applicants the information relied upon in assessing their application if they request it, meaning that applicants who are unaware of their right to that information may not ask. Similarly, the Code only requires providers to inform applicants who are refused cover that they can complain ‘if you tell us you are unhappy with our decision’.<sup>66</sup> Legal Aid NSW suggests that the revised General Insurance Code of Practice should protect all of the above consumer rights.

### **Recommendation 2:**

**The General Insurance Code of Practice should include an obligation to comply with the requirements of anti-discrimination law, with a provision similar to the Life Insurance Code of Practice section 5.17.**

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<sup>61</sup> See further Chapter 2.

<sup>62</sup> General Insurance Code of Practice section 7.8; Life Insurance Code of Practice section 8.2.

<sup>63</sup> Discrimination in insurance straddles two areas of law, that is, consumer law and discrimination law. ASIC does not normally deal with discrimination law, while AHRC does not normally deal with consumer law.

<sup>64</sup> Life Insurance Code of Practice, section 5.14, 8.19.

<sup>65</sup> General Insurance Code of Practice 4.8, 7.19.

<sup>66</sup> General Insurance Code of Practice 4.8.

### **Recommendation 3:**

**The General Insurance Code Governance Committee and the Life Insurance Code Compliance Committee should monitor and enforce compliance with anti-discrimination law.**

### **Recommendation 4:**

**Codes of Practice should require insurers to report to the Code Committee if an allegation of discrimination is made against them.**

### **Recommendation 5:**

**The General Insurance Code of Practice should require that, where an insurer decides to refuse cover, offer cover at a higher premium, or to refuse a claim, the insurer must:**

- **give reasons,**
- **inform applicants/consumers about their right to their right to receive the information the decision was based on, and**
- **inform applicants/consumers about their right to seek a review of a decision.**

## **Opportunities for government and regulators**

As noted above, the burden of ensuring compliance with disability discrimination law as it applies to insurance services and products should not fall entirely upon consumers. Industry, government and regulators should also take steps.

AFCA provides an independent forum to resolve disputes, and must also identify systemic issues, refer them to the insurer for remedial action, and report them to ASIC. It also publishes reports reviewing compliance with Code requirements.<sup>67</sup> Legal Aid NSW considers that AFCA should publish an industry guideline setting out its approach to disability discrimination in insurance, in order to draw attention to the issue.

The Australian Human Rights Commission, in consultation with ASIC and the Australian Prudential Regulatory Authority (APRA), should conduct an inquiry to explore the extent to which the insurance industry complies with the DDA in making insurance decisions. ASIC should incorporate findings from this research into consumer messaging on MoneySmart.

Opportunities exist for the Australian Government to explore ways to improve access for Australians affected by cancer and other health conditions. However, actuarial or statistical data will sometimes reveal significant risk, meaning that insurers can legally refuse to offer cover. In those circumstances, the Australian Government plays a critical role in ensuring that the social safety net is sufficient to support people who do not have access to insurance.

### **Recommendation 6:**

**AFCA should publish an industry guideline setting out its approach to disability discrimination in insurance.**

### **Recommendation 7:**

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<sup>67</sup> See, for example *General insurance in Australia 2016–2017: Industry practice and Code compliance 2018*.

**The AHRC should conduct a national public inquiry into whether there is systemic unlawful discrimination by the insurance industry against people with health conditions.**

**Recommendation 8:**

**ASIC should incorporate findings from this research into consumer messaging on MoneySmart.**

**Recommendation 9:**

**ASIC should conduct inquiries relating to potential breaches of license obligations by insurers in relation to the findings of this review, including in thematic industry reviews.**

**Recommendation 10:**

**When insurer obligations are expanded to include a ban on unfair contracts terms, ASIC should review travel and life insurance policies to identify unfair terms relating to consumers with pre-existing health conditions and disabilities.**

## Opportunities for consumers and their advocates

### Raise awareness of rights and support for complaints

Survey participants who experienced discrimination or were otherwise dissatisfied with their insurance experience described constraints in seeking legal redress, including being discouraged or unaware of their options. Many did not identify their insurance issue as a legal problem.

There is a need for greater public awareness of legal rights and options, particularly for Australians affected by health conditions as they are vulnerable to discrimination. While there are currently limited community legal education materials, such as printed and online factsheets from Cancer Council Victoria and the Breast Cancer Network Australia, these materials can be more widespread to reach the relevant population. A national organisation such as the AHRC, or a network of consumer advocates such as National Legal Aid could work with health advocacy organisations to develop and distribute materials.

Greater support to lodge complaints is needed for those consumers who are discouraged or experience barriers such as literacy or technology limitations. Adequately funded and accessible legal services are essential. Consumer and patient advocates can collaborate in the delivery of support services for those seeking legal advice and assistance to lodge complaints. For example, Cancer Council NSW staff have been trained to identify early problems relating to insurance and regularly refer clients to the Cancer Council legal service or Legal Aid NSW.

**Recommendation 11:**

**Consumer and health advocates should work together to:**

- **Establish clear, consistent communications about consumer rights in relation to insurance decisions and where to seek legal help, and**
- **Target communications to health and other services working directly with people living with health conditions.**

## Market innovations - collective bargaining power

In order to fill the gaps in the insurance market, consumers with similar needs are coming together through intermediary websites and using their collective buying power to obtain better deals in insurance. The UK web-based company *Bought By Many* ([boughtbymany.com](http://boughtbymany.com)) created a platform for groups of people to purchase a variety of insurance products including travel insurance. In September 2018, there were over 300 groups of consumers with a total of over 583,000 members.

One group provides travel insurance specifically for people with Chronic Obstructive Pulmonary Disease (COPD). It is the name used to describe a number of health conditions, including chronic bronchitis and emphysema, whose sufferers have difficulty breathing because of long-term damage to their lungs. The website states that:

Provided you have been cleared to travel by a medical professional, the only thing that might stop you jumping aboard that cruise right away is the added cost to your travel insurance that some companies will expect you to pay. By joining our group you use the buying power you share with other COPD sufferers to get a better, fairer deal on travel insurance.<sup>68</sup>

The company also recognises the difficulties faced by people affected by cancer who are medically cleared for travel but are deemed uninsurable by the insurance market. *Bought By Many* recognises that:

The process of getting travel insurance can be difficult if you've been affected by cancer. It can involve a lot of shopping around and answering distressing questions relating to the grade, stage and prognosis of cancer. Travel insurance options of cancer patients are so poor that the Financial Conduct Authority (FCA) has called on insurers to do more to help consumers.<sup>69</sup>

**Recommendation 12: Government, industry and consumer advocates should encourage the development of market innovations, including consumer collectives for people with health conditions.**

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<sup>68</sup> <https://boughtbymany.com/offers/travel-insurance-for-people-with-copd/> accessed 7 September 2017.

<sup>69</sup> <https://boughtbymany.com/offers/travel-insurance-for-people-with-copd/> accessed 7 September 2017.

# Appendix 1

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## Organisations engaged as part of the *Health Conditions & Insurance Project*

### Consumer organisations

Bernie Banton Foundation  
beyondblue  
Brain Tumours Alliance Australia  
Breast Cancer Network Australia  
Cancer Council NSW  
Cancer Voices Australia  
CanRevive  
Choice  
Consumer Action Law Centre  
Financial Rights Legal Centre (Insurance Law Service)  
Heart Foundation  
Hepatitis NSW  
Kingsford Legal Centre  
Lung Foundation of Australia

Lymphoedema Action Alliance  
McCabe Centre for Law and Cancer  
Public Interest Advocacy Centre  
Rare Cancers Australia  
Unicorn Foundation  
Victorian Legal Aid  
WMOzzies

### Industry Representatives

Financial Planners Association  
Insurance Council of Australia  
Individual Financial Advisors

### Other

Anti-Discrimination Board of NSW  
Australian Human Rights Commission  
Australian Security & Investments Commission  
Financial Ombudsman Service



## Privacy and Ethics

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Legal Aid NSW has no formal research ethics approval process. Survey participants were advised that their participation is voluntary and participants were not pressured in any way to take part. The information collected by Legal Aid NSW through Qualtrics is password protected. Qualtrics also has a Privacy Statement that can be accessed online ([qualtrics.com/privacy-statement/](https://qualtrics.com/privacy-statement/)).

Pursuant to the Legal Aid NSW Privacy Management Plan 2013 and the *Australian Privacy Principles*, Legal Aid NSW took specific measures to ensure that personal information and the privacy of every participant was protected. A copy of the Privacy Management Plan 2013 was provided on request to partner agencies that promoted the online survey to their members.

Personal information collected can be found in the survey at Appendix 2. All participants provided their age and gender. Participants who specifically agreed to be contacted by Legal Aid NSW were asked to provide their name, telephone number and email address. This was voluntary. Participants were advised that Legal Aid NSW would not disclose this information to anyone else without their consent.

All participants were advised that their participation is anonymous and that while the information we collect will be made publicly available, no participant will be personally identified. Participants were then advised to click on a button on the screen to consent and start the survey. In this report, we have taken measures to ensure that the comments of participants that are quoted are de-identified.

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