

# Making the law work better for people affected by cancer

2013 Report



**Authors** Deborah Lawson and Sondra Davoren

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615 St Kilda Road  
Melbourne Vic 3004 Australia

**T** +61 3 9514 6100

**F** +61 3 9635 6800

**W** [www.cancervic.org.au](http://www.cancervic.org.au)

Cancer Council Helpline 13 11 20



# Contents

- 05** Making the law work better for people with cancer
- 06** Executive summary
- 09** Cancer in Victoria: A snapshot
- 10** The project
- 14** Access to treatment
- 23** Employment-related issues
- 32** Insurance
- 39** End of life decision-making
- 47** About us
- 48** Appendix
- 52** References





# Making the law work better for people with cancer

Reducing the impact of all cancers for all Victorians is Cancer Council Victoria's (CCV) mission, to be delivered through a combination of prevention, research, fundraising and support. CCV's Strategy and Support programs strive to reduce the impact of cancer by providing reliable information and compassionate support to people living with cancer, their family and friends. As part of *Making the law work better for people affected by cancer*, the strategy and support team have been able to examine legal issues across the cancer journey from transport and accommodation challenges for people undergoing treatment and their carers, to the challenges of returning to work, obtaining insurance following a cancer diagnosis, and for people who are having to make difficult choices in end-of-life situations.

With the commencement of this project, the Strategy and Support division have utilised the experience and capacity of the McCabe Centre to affect change at a law and policy level in order to reduce financial and emotional distress for people affected by cancer, and to enable better delivery of treatment services for health professionals. The project has built new capacity, relationships and networks around the relationship between law and cancer treatment and supportive care.

Working with a variety of partners and stakeholders has been a key focus of the project this year, in particular, engaging with Department of Health strategic objectives in relation to palliative care and access to transport and accommodation support. Other highlights included the close engagement between project staff and the Clinical Network.

In 2014 we look forward to engaging further with the Victorian government on key cancer supportive care issues, and expanding the capacity of the strategy and support division to deliver support for cancer patients, carers and health professionals who are impacted by the law.

**Nicola Quin**  
Head of Division, Strategy and Support  
Cancer Council Victoria  
December 2013

The law has a significant impact on health outcomes for people with cancer, their experiences of cancer, and those of their families and health professionals. This project, *Making the law work better for people affected by cancer*, recognises that there are many opportunities to improve laws and policies, and their understanding and implementation, to enhance the health outcomes and experiences of people affected by cancer.

This report provides an overview of the major legal and policy issues across its focus areas of access to treatment, employment, insurance discrimination and end of life decision-making and recognises the significant stakeholder engagement and partnership development that have occurred in the project's first year.

In 2014, we will be disseminating the report and following up on its main findings and recommendations, and broadening the focus of our work to include regulation of complementary and alternative treatment, and the operation of principles of informed consent, areas that have been identified as meriting further attention. We will continue to build partnerships with NGOs,

government and health agencies, the legal profession and academia, in Victoria, Australia and internationally.

Through the McCabe Centre's international networks, we are sharing information, knowledge and experiences with colleagues in other countries, particularly in Europe, through the Norwegian Cancer Society, the McCabe Centre's network hub for Europe. Not surprisingly, we are finding that our colleagues in other countries are grappling with similar issues, and there is much we can learn from one another.

We are fortunate that UICC's biennial World Cancer Congress will be held in Melbourne in December 2014. The Congress will provide a wonderful opportunity for us to share our major findings, and learn from our colleagues in Victoria, Australia and around the world.

We look forward to continuing to work with our partners through 2014, and to seeing many of you through the year and at the Congress in December.

**Jonathan Liberman**  
Director, McCabe Centre for Law and Cancer  
December 2013

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# Executive summary

This project examined how identified areas of law impacted on experiences and outcomes for people affected by cancer. In relation to these areas, our key findings and recommendations for further work are:

## Access To Treatment: The Victorian Patient Transport Assistance Scheme

The costs of transport and accommodation for treatment represent a significant burden for people affected by cancer living in rural and remote areas, and contribute to the context in which decisions are made about treatment and recovery.

### Key findings

- Many patients and carers who are eligible for the VPTAS are grateful that the scheme exists, and for the financial support it provides them at a difficult time.
- Almost all stakeholders agreed that the VPTAS subsidy levels are too low. Many stakeholders informed us that the subsidies were not making much of a dent in their travel costs and were unrealistic in light of how much petrol and accommodation actually costs.
- Almost all stakeholders agreed that the distance eligibility thresholds (100 kilometres, or 500 kilometres per week for five weeks) seem arbitrary and are unfair, particularly for those who fall just outside the criteria despite having the same needs as eligible users of the scheme. Ineligibility for accommodation support acutely impacts those having block treatment who are just short of the 100 kilometre threshold.
- Lack of awareness of the scheme is a key challenge. Many people told us that they did not hear about the VPTAS until after they had already made several trips for treatment – or that the first time that they heard about it was through our consultation process.

### Recommendations

1. That the Victorian government:
    - a. Increase the VPTAS subsidies from:
      - 17 cents per kilometre to 30 cents per kilometre for private vehicle usage; and
      - \$35 (+ GST) per night to \$75 (+ GST) per night for accommodation
- With annual increases to the subsidies indexed against the Consumer Price Index;
- b. Change the VPTAS distance criteria from 100 kilometres each way/500 kilometres over five consecutive weeks to a single cumulative threshold of 200 kilometres per week; and
  - c. Improve administration of the scheme, to allow for online processing and prepayment for accommodation costs.
2. That GPs' offices, public and private hospitals and other cancer care treatment centres:
    - a. Prominently display VPTAS posters, brochures and forms, to increase the likelihood that patients and carers who need to travel for treatment know about the VPTAS before they travel;
    - b. Ask patients and carers about their likely need to travel as part of routine information gathering and needs screening, and provide VPTAS information for those who require it.

### Employment-Related Issues

Retaining, returning to or finding new employment can be problematic for some people who have or have had cancer, and for people who care for someone affected by cancer. While cancer remains a leading cause of death in Australia the survival rate for many common cancers has increased by 30 per cent in the past two decades; as screening services and treatment options improve, it is likely that people will be living longer with a cancer diagnosis. Many people choose to continue working or to return to work after a cancer diagnosis, and/

or treatment, but current approaches to facilitate working with cancer or a return to work after cancer may not be sufficiently sensitive to cancer patients', survivors' or carers' needs.

### Key findings

- Assessing the extent of employment problems for people affected by cancer remains a challenge, although we are now better informed about some of the challenges and priority issues for people affected by cancer in the workplace.
- Feedback on the issues paper revealed that discrimination is a problem for some people affected by cancer, while others' employers have been very supportive when they were diagnosed and having treatment.
- Among those affected, there is concern about taking time off, losing opportunities and losing their jobs.
- Many people who provided feedback on our issues paper referred to relationship and communication problems with employers and colleagues, which were often related to taking time off. These concerns were not limited to patient experience; it appears that some carers also experience difficulties at work.
- Very few people take formal action about being treated unfairly at work.
- For people affected by cancer, suggested improvements for the workplace include:
  - greater flexibility, including flexible hours or the ability to work from home;
  - more knowledge, understanding and sympathy among employers and colleagues regarding the effects of a cancer diagnosis and treatment;
  - allowing a staggered return to work and full responsibilities – where this is needed and desired – which recognises the gradual recovery process.

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## Recommendations

1. Education programs for employers, people affected by cancer and their colleagues on:
  - a. The effects of a cancer diagnosis and treatment on an employee;
  - b. The legal frameworks, rights and responsibilities that apply when an employee or potential employee is affected by cancer, whether personally or as a carer, and practical solutions to common problems.
2. More research to accurately assess the extent and type of employment problems that people affected by cancer and their carers experience.

Furthermore, there is a case to be made for introducing more flexibility into the timeframes for making a complaint for an unfair, unlawful or general protections dismissal.

### Discrimination In Insurance

Access to insurance – particularly life and travel insurance – is an area of increasing concern for people affected by cancer, including those who may have a genetic predisposition to, or family history of, cancer.

### Key findings

- Feedback on our issues paper showed that many people find it difficult to obtain insurance following a cancer diagnosis and treatment. However, very few complaints about discrimination are made to the Australian Human Rights Commission (AHRC) or the Victorian Equal Opportunity and Human Rights Commission.
- There is anecdotal evidence of people being denied insurance based on inadequate data, or with no reasons given.
- Greater transparency in the collection and use of information may improve decision making processes and inspire greater confidence in people affected by cancer, who at the moment, perceive that they will not be treated fairly (whether or not this is actually the case).



The law has a significant impact on health outcomes for people with cancer, their experiences of cancer, and those of their families and health professionals. This project, *Making the law work better for people affected by cancer*, recognises that there are many opportunities to improve laws and policies, and their understanding and implementation, to enhance the health outcomes and experiences of people affected by cancer.

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## Recommendations

1. That the *Insurance Contracts Act* be amended to clarify the right to information from insurers for people who have received an adverse decision based on genetic information, including an entitlement to details of the actuarial, statistical or other data relied on by the insurance company. We support extending this right to others who receive an adverse decision, whether or not it is based on genetic information, and taking into account the sensitivities associated with this information.
2. Development of education programs and resources to support people affected by cancer to understand and use the protections in the *Disability Discrimination Act*, and to make a complaint where appropriate; and
3. More research on the uptake and use of genetic information for the purposes of insurance.

## End Of Life Decision-Making

Planning for the end of life can improve end of life care and increase the likelihood that a person's family, carer and healthcare team can make decisions that they feel confident are in accordance with the person's preferences and best interests. In Australia, laws relating to advance care planning mechanisms – appointing substitute decision-makers and recognition of advance care directives – can differ greatly between states and territories, which can lead to confusion and different outcomes for patients depending on which jurisdiction they are in.

## Key findings

- Feedback on our issues paper indicated low awareness of options for advance care planning.
- Many contributors acknowledged the importance of advance care planning but said that they had not made any arrangements “yet”.
- Others were more proactive, seeing advance care planning as an integral part of, or addendum to, making a will.
- It was also noted that conversations about end of life and advance care plans needed to happen a lot earlier than they ordinarily do, because often decisions were being made under pressure, or when a person had lost capacity.
- Stakeholder feedback suggested changing terms like ‘end of life’ – which may be too direct and confronting for some people – and ‘advance care planning’ which borders on being euphemistic.

## Recommendations

1. Implementation of the recommendations in the Victoria Law Reform Commission's (VLRC) Guardianship Final Report with regard to documenting wishes about the future, which in general state that there should be a broader statutory right to make an advance care directive, which encompasses future as well as current conditions, and the ability to provide consent and refusal to medical treatments in advance. Such legislation should also clarify the relationship between substitute decision-makers, and advance care directives; that is, which takes precedence if the substitute decision maker disagrees with the treatments proposed in the advance care directive. The VLRC recommends that new guardianship legislation should enable a person with capacity to document instructions about future decision-making by:
  - a. Appointing an enduring power of attorney with instructions; or
  - b. Appointing an enduring power of attorney with no instructions; or
  - c. Making a standalone advance care directive.

2. That there be a voluntary register of advance care directives and substitute decision makers, which can be easily accessed by health professionals, and which would be particularly useful in emergency situations.
3. That the way we talk about advance care planning in the community ensures the topic is raised sensitively so that people are willing to listen and engage. Part of this will involve developing education tools to improve how health professionals, and lawyers, talk about death and dying.



# Cancer in Victoria: A snapshot

## Cancer incidence is increasing

Cancer is a leading cause of disease in Victoria with 80 new diagnoses (excluding non-melanoma skin cancers) and 30 deaths from cancer every day.<sup>1</sup> A total of 29,387 Victorians were diagnosed and 10,780 died from cancer in 2012.<sup>2</sup> One in three Victorian women and one in two Victorian men will be diagnosed with some form of cancer before the age of 75.<sup>3</sup> It is estimated that by 2023-2027 the average annual incidence of cancer will reach more than 44,000, an increase of 53 per cent from 2008-2012.<sup>4</sup> During the same period, deaths from cancer are projected to increase to more than 13,000 per year.<sup>5</sup>

## Cancer survival rates are increasing

Survival rates for some cancers are increasing, meaning more people are living longer after a cancer diagnosis. Though

cancer incidence rates continue to increase (annual percentage increases of 0.8 per cent for men and 0.6 per cent for women), death rates have declined steadily since 1982 with average falls of 1.5 per cent per year for males and 1.2 per cent for females.<sup>6</sup> This reflects earlier detection through screening, falling tobacco-related cancer rates for males<sup>7</sup> and improvements in treatment and outcome.<sup>8</sup> During the period 1986-2010, five-year survival increased from 47 per cent to 65 per cent.<sup>9</sup>

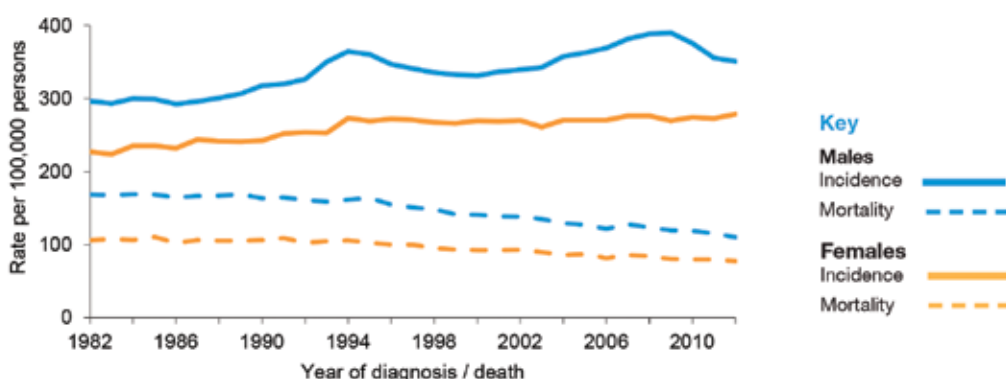
## Legal needs of people affected by cancer, their families and carers and health professionals

People affected by cancer are not always well served by the legal structures that impact on their treatment and support. Laws and policies can affect travel and accommodation entitlements for people affected by cancer, equitable access to insurance and superannuation, workplace

rights, and the quality of decision making at the end of life.

The challenge of navigating the legal and policy environments to address these issues can have a significant effect on treatment experiences and outcomes for people affected by cancer. For example, these challenges can lead to unnecessary uncertainty and stress and create barriers for people already under a range of pressures, including people diagnosed with cancer and their families and carers. For many health professionals there are complex legal and related financial issues that may affect how they provide treatment and support, and uncertainty about legal frameworks and protections regarding treatment decisions – particularly where substitute decision-makers are involved. This uncertainty can lead to a reluctance to raise or discuss legal issues with patients.

## Trends in cancer incidence and mortality rates by sex, Victoria 1982-2012.



Reproduced from Thursfield V. et al. Cancer in Victoria: Statistics and Trends 2012 Cancer Council Victoria, Melbourne 2013, p14.

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# The Project

In late 2012, the McCabe Centre for Law and Cancer (McCabe Centre) and CCV's Strategy and Support Division, supported by a major grant from the Legal Services Board of Victoria, began working on a project addressing legal issues for people affected by cancer.

The purpose of this project is to analyse the laws and policies that impact on Victorians affected by cancer, to encourage discussion about the impacts of these laws, and to formulate recommendations for law reform where appropriate. While the primary focus is on how law and policy in these areas impact on the experience of Victorians affected by cancer, many of the issues raised have national relevance with some of the laws focused on in this paper being Commonwealth rather than Victorian laws.

The project's initial key focus areas are:

- Access to treatment: access to support for travel and accommodation
- Employment: equal opportunity legislation and returning to work
- Discrimination: discrimination in insurance, and genetic testing in insurance
- Decision making at the end of life: advanced care planning, substitute decision making and the right to demand treatment.

In selecting the issues above, we relied on feedback and contributions from the project's steering committee and other stakeholders.

We were fortunate to be awarded a second major grant from the Legal Services Board of Victoria for a further two years, which will enable us to continue our work on the key legal issues already identified and to expand our focus to work on other legal and policy issues that impact on people affected by cancer, their carers and health professionals.

## The Issues Paper – Making the law work better for people affected by cancer

The first phase of this project (2012-2013) was a scoping exercise, to determine the level of concern in the community about legal issues for people affected by cancer. On 1 March 2013 we released the *Making the law work better for people affected by cancer* issues paper ('the issues paper') online for public consultation. The paper introduces the key focus areas, and discusses some of the practical legal issues arising under each area. The paper was distributed to our networks and promoted through social media. To facilitate responses, we included a list of questions at the end of each section of the issues paper to promote feedback, dialogue and ideas about how to make the law work better. We encouraged responses from people affected by cancer, carers and health professionals from a wide variety of backgrounds and experience, recognising that a broad perspective from all sectors is critical in understanding and reforming laws that affect people with cancer.

## Key stakeholder engagement

Throughout 2013 we ran a series of events and meetings to consult widely with key stakeholders about their experiences and recommendations with regard to the content of the issues paper. We spoke with key stakeholders from all over Melbourne, and also held a workshop in Gippsland. In late August 2013 we set a 30 September deadline for submissions on the paper, and circulated an online survey which included more direct questions about people's experiences and views to better enable people affected by cancer to contribute to the consultation.

## Events

Metropolitan workshop on draft issues paper

### Cancer Council Victoria, 20 February

At the start of the year we hosted a well-attended workshop on the draft issues paper with representatives from oncology, palliative care, cancer organisations, the legal sector and consumer advocacy groups. Attendees provided valuable feedback in a series of interactive sessions on the key legal issues. Presentations included:

- *Access to treatment – Informed decision making and complementary therapies*  
Beth Wilson, Former Health Services Commissioner
- *The insurance exemption in the Disability Discrimination Act and the rights of cancer patients*  
Sondra Davoren, Senior Legal Advisor, CCV
- *Palliative care and end-of-life decision making – Surrogate decision makers, and requests for futile care*  
Associate Professor Jenny Philip, Deputy Director Palliative Medicine & Centre for Palliative Care

Feedback was incorporated into the draft issues paper before it was publicly released on 1 March 2013.

### Regional workshop on the issues paper Latrobe Regional Hospital, 7 August 2013

We held a workshop at the Latrobe Regional Hospital in Traralgon in conjunction with the Gippsland Regional Integrated Cancer Services. We presented and consulted on the key legal areas with a diverse group of attendees, including lawyers, consumers, consumer advocates, cancer support services, occupational therapists, social workers, nurses and physiotherapists. In the evening we were fortunate to have local lawyer Belinda Wilson and local palliative care nurse practitioner mentor Irene Murphy participate in an engaging panel discussion on end-of-life decision-making.

### Key stakeholder meetings on the Victorian Patient Transport Assistance Scheme

On 8 August, we hosted a roundtable event in Melbourne, at which representatives from cancer, chronic disease and patient support agencies gathered to discuss ways in which the current patient transport and accommodation scheme can be improved for Victorians who have to travel for treatment. The key issues for attendees were:

- The cost of travel for specialist treatment is a significant burden to patients and their carers, causing financial and emotional stress; and is an area of concern for clinicians;
- Reimbursement rates for transport and accommodation in Victoria are significantly lower than reimbursement rates in most other states and territories;
- There is low awareness about the Victorian Patient Travel Assistance Scheme (VPTAS) and some patients experience difficulties in claiming reimbursements for which they are eligible; and
- No reimbursement is available for patients involved in clinical trials.

Roundtable attendees recognised the importance of improving the VPTAS to facilitate equitable access to treatment, by:

- Increasing current reimbursement rates to a reasonable proportion of actual travel costs, and securing a commitment to regular rate increases;
- Reforming eligibility requirements to take into account distance travelled at a lower threshold than the current 100kms each way/500kms over five consecutive weeks benchmarks, and to provide greater flexibility in choice of treatment provider; and
- Improving administration to allow for online processing and prepayment for accommodation costs.

Attendees also committed to taking steps to raise awareness of the availability of the scheme. See page 14 for more information about our VPTAS advocacy work.

### Victorian Patient Transport Assistance Scheme Alliance Launch

Following the roundtable event in August, we invited stakeholders from health and allied agencies to work together on ways to improve support for patients who need to travel for treatment, and people in financial distress. On 5 December 2013, CCV hosted a launch of the alliance, which will continue to work on these issues throughout 2014.

### Presentations

'Insurance, Discrimination and the Law – Protecting rights of Cancer Survivors'  
Sondra Davoren

Flinders Centre for Innovation in Cancer Survivorship Conference, Adelaide, 1-3 February 2013

'Making the law work better for people affected by cancer'

Deborah Lawson  
Victorian Integrated Cancer Services Inaugural Conference, Melbourne, 13-14 May 2013

Cancer Council Relay for Life Leadership Summit 2013  
Sondra Davoren  
Melbourne, 1 June 2013

'Making the law work better for people affected by cancer'

Sondra Davoren and Deborah Lawson  
Grand Round, Austin Hospital, Melbourne, 22 July 2013

'Making the law work better for people affected by cancer'

Deborah Lawson  
Cancer Social Work Victoria Annual General Meeting, Melbourne, 13 August 2013



The metropolitan workshop was held at CCV.



The GRICS co-hosted the regional workshop in Traralgon.



Victorian Patient Transport Assistance Scheme Alliance Launch.

CCV's Clinical Network sub-committee meetings

- Genetics
- Psych-Oncology
- Palliative Care

### Additional Stakeholder Input

We are grateful to the following people and organisations for taking the time to share their experiences of and recommendations in relation to the legal and policy areas under review.

#### The Alfred Hospital, Patient and Family Services

Anglicare Victoria

#### Austin Hospital

Australian College of Rural and Remote Medicine

#### Australian Medical Association Victoria

Baptcare Gippsland

#### Belinda Wilson, Solicitor, Tyler Tipping & Woods, Gippsland

Breast Cancer Network Australia

#### BreaCan

Cancer Action Victoria

#### Cancer Council Victoria's Clinical Network

Cancer Social Work Victoria

#### CanSpeak Australia

Centre for Palliative Care

#### Chronic Illness Alliance

Denise Horsey

#### Diabetes Australia (Vic)

Eileen Pica

#### Familial Cancer Genetics Service, the Royal Melbourne Hospital,

Gippsland Regional Integrated Cancer Services

#### Grampians Integrated Cancer Service

Health Issues Centre

#### Health Social Workers Directors Group

Hearts4Heart

#### Hume Regional Integrated Cancer Service

Insurance Council of Australia

#### Irene Murphy, Nurse Practitioner Mentor, Gippsland Palliative Care Consortium

Kidney Health Australia

#### Leukaemia Foundation

Lung Foundation Australia

#### McGrath Foundation

Mercy Health Lymphoedema Services

#### National Stroke Foundation

North Eastern Metropolitan Integrated Cancer Service

#### The Northern Hospital, oncology social workers

The Norwegian Cancer Society

#### Olivia Newton-John Cancer and Wellness Centre, Austin Health

Paediatric Integrated Cancer Service

#### Palliative Care Victoria

Peter MacCallum Cancer Centre

#### Professor Ingrid Winship, Melbourne Health

Public Interest Law Clearing House

#### Queensland University of Technology Health Law Research Centre

The Royal Children's Hospital

#### St Vincent's Hospital Melbourne

Sunraysia Cancer Resources

#### Victorian Council of Social Services

Western and Central Melbourne Integrated Cancer Service

#### Western District Health Service, Cancer Consulting and Education Suite

Think Pink Foundation

#### Travellers Aid Australia

Victorian Council of Social Service

### Online Survey

We developed an online survey (via SurveyMonkey) to enable people affected by cancer and their carers to easily and directly contribute to the consultation. The survey questions were loosely based on those posed in the issues paper, but sought to elicit evidence of people's actual concerns and experiences in relation to each key legal issue, in addition to their views on whether the law and legal processes are in need of change. Emma Sayers, Cancer Information and Community Engagement Lead at the Olivia Newton-John Cancer and Wellness Centre also provided valuable expert input into the survey questions.

The survey contained 70 open-ended and closed-ended questions, grouped under four headings relating to the key legal issues under review. Respondents could choose to skip any questions that were not relevant to their experiences, or that they did not wish to answer.

Breast Cancer Network Australia (BCNA) offered to disseminate the survey by email to more than two thousand members of their Review and Survey Group. A Victorian-specific survey was sent to all Victorian members of the group, and a

non-state specific survey was sent to non-Victorian group members. The questions differed only to the extent that the Victorian survey specifically mentioned the Victorian Patient Transport Assistance Scheme, and the Victorian legislative arrangements for making appointments for substitute decision-makers, whereas the non-Victorian survey referred more generically to the patient transport assistance scheme offered in the respondent's state/territory and the options available for advance planning in the respondent's state/territory.

The Victorian survey was also emailed to the McCabe Centre's networks. Results of the survey are included in this report.

### Publications and Media

Jill Stark 'Cancer survivors denied access to travel insurance' *The Age*, 17 March 2013

Grant McArthur 'Country cancer death rates are higher because of costs' *Herald Sun* 7 September 2013

Breast Cancer Network Australia 'Ask the expert – Sondra Davoren' *The Beacon magazine*, issue 64, Spring 2013, p 4

Deborah Lawson 'Access to Radiotherapy and the Victorian Patient Travel Assistance Scheme' *Cancer Action Victoria Newsletter*, issue 9, Spring 2013, pp 8-9

'Regional patients count cost of travelling for treatment' ABC 7.30 Report, Friday 25 October 2013

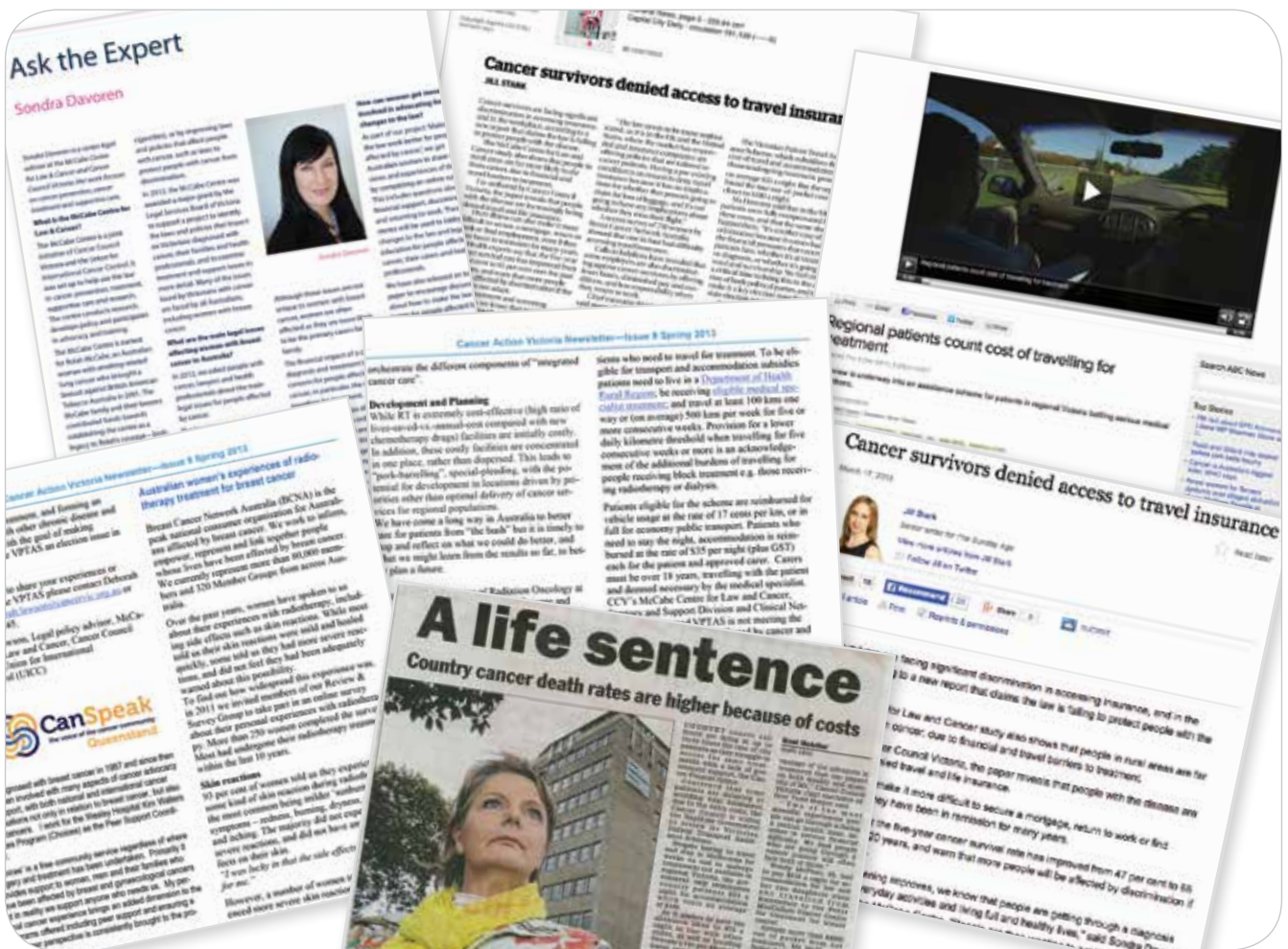
### Blogs

**Making the law work better for people affected by cancer: a McCabe Centre issues paper**

*'Whether we're consciously aware of it or not, the law influences how people make decisions about health care, treatment and support. This is no different for people affected by cancer...'*

**Read more at:** [http://www.mccabecentre.org/blog-main-page/issues\\_paper\\_making\\_law\\_work\\_cancer](http://www.mccabecentre.org/blog-main-page/issues_paper_making_law_work_cancer)

**Making the law work better for people affected by cancer: support for travel for treatment**



*'Across Australia, as geographical isolation increases, cancer care is less accessible. According to the Australian Institute of Health and Welfare, the further from a metropolitan centre a person with cancer lives, the more likely they are to die within five years of diagnosis. For some cancers, those who live remotely are up to 300% more likely to die within five years of diagnosis.'*

*In the second blog of our series, we outline some of the challenges for people who need to travel long distances for cancer treatment...'*

**Read more at:** <http://www.mccabecentre.org/issues-paper-blog-2>

**Making the law work better for people affected by cancer: employment**

*'While many employers are supportive when an employee is affected by cancer, retaining, returning to, or finding new employment can be difficult for some people who have or have had cancer. A diagnosis of cancer can have significant implications for a person's work, for example: long periods of leave for treatment; the physical and emotional toll of cancer treatments affecting a person's ability to work; and the potential for unfair treatment on the basis of their cancer diagnosis or history. Carers of people undergoing cancer treatment may also be affected, particularly if they need to take extended leave to look after a loved one or accompany them to treatment...'*

**Read more at:** <http://www.mccabecentre.org/blog-main-page/employment-paper-blog>

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# Access to treatment

*Cancer is a lot harder in the country (Female patient affected by cancer for 10 years, who moved from Melbourne to a regional Victorian town three years ago).*

In 2012, the estimated resident population in regional Victoria was 1.4 million, compared with 4.2 million living in metropolitan Victoria.<sup>10</sup> Victorians living in rural and regional areas generally experience poorer health than metropolitan residents.<sup>11</sup> While a complex set of factors contribute to this inequity, including higher levels of poverty and disadvantage in rural and regional areas and limited access to educational and economic opportunities,<sup>12</sup> a key barrier for rural and regional Victorians is distance to specialist medical services, most of which are concentrated in urban centres.<sup>13</sup> Lack of access to specialist treatment is especially telling in the health outcomes for people affected by cancer. As geographical isolation increases, cancer care is less accessible.<sup>14</sup> The further from a metropolitan centre a person with cancer lives, the more likely they are to die within five years of diagnosis.<sup>15</sup> For some cancers, those who live remotely are up to 300 percent more likely to die within five years of diagnosis.<sup>16</sup>

People from rural or remote areas will almost always need to travel for some elements of their cancer care due to the complexity of cancer treatment—including the way in which treatment is delivered, the requirement for input from more than one specialist, and the need for highly specialised medical equipment.<sup>17</sup> The costs of transport and accommodation for treatment represent a significant burden for people affected by cancer living in rural and remote areas, and contribute to the context in which decisions are made about treatment and recovery. People may defer treatment or seek alternative treatment options due to the financial burden that travel and accommodation can add to the process.

One in six (16 percent) of the 86 Victorians who responded to this online survey question indicated that transport and accommodation costs had an impact on their decisions about treatment.

*Too difficult to travel down to Melbourne for treatment as it was too expensive to stay in Melbourne. (Online response)*

*It impacted on my decision whether to have treatment in Melbourne on a clinical trial or stay in my local hospital and have generic chemo. (Online response)*

*As a result of our time spent with people in the chemo room and waiting rooms, we found that there were many people who couldn't bring family with them for support due to distance/cost factors and also that some people had opted to consider not to have further treatment purely due to the travelling involved. (Female carer of a male patient)*

## **Financial support for transport and accommodation costs**

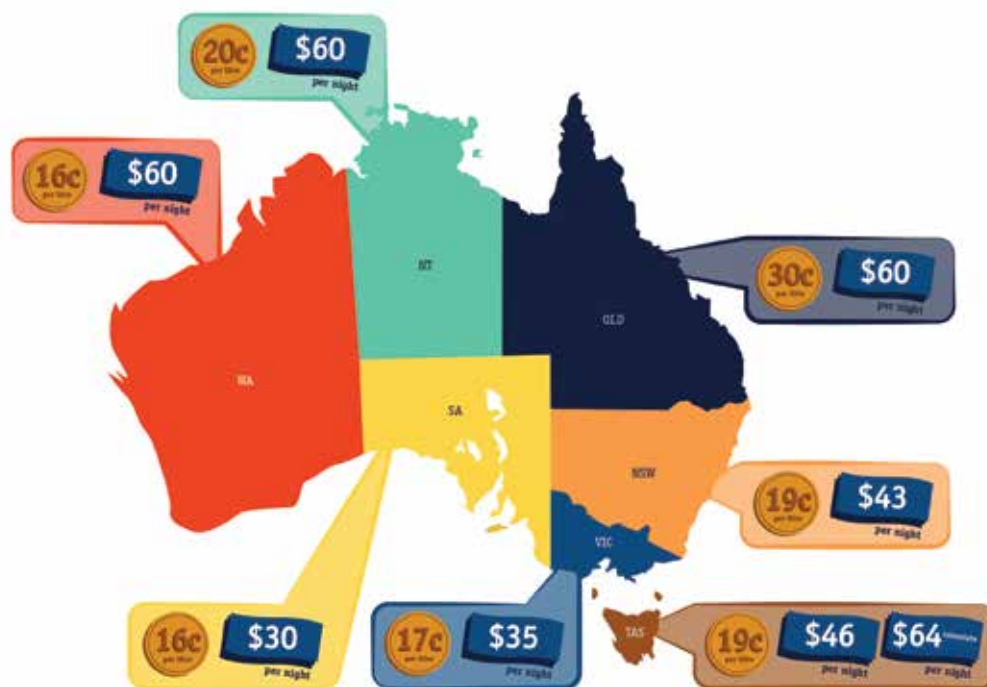
It would have been good to have something else, more support. With what happened to us, we couldn't afford to pay the mortgage, so we got threats from the bank. Because you're paying out so much money that you wouldn't normally be paying out – we got threatened with our house being taken. We nearly lost our house. I went without food some nights – you actually go without eating. And that's fine; I don't need to eat, as long as I've got some water. (Mother of a young male patient who required treatment in Melbourne for almost nine months)

CCV's Strategy and Support Division, and the Clinical Network, have previously highlighted their concerns that the VPTAS is not meeting the needs of many Victorians who need to travel for treatment. Our issues paper outlined the key concerns with the scheme:

- The low level of subsidies provided for travel and accommodation: just 17 cents per kilometre for private vehicles, and \$35 + GST per night for accommodation;
- The distance threshold for eligibility and the requirement that patients see the nearest specialist rather than the most appropriate specialist: only patients who travel at least 100 kilometres each way from their home to the nearest approved medical specialist, or travel an average of at least 500 kilometres per week for five consecutive weeks are eligible for the subsidies;
- Limited awareness of the VPTAS scheme and complexity of the paperwork and application process; and
- Lack of support for patients to attend clinical trials.

A recent article on the continuing trend of regional and remote disadvantage in cancer morbidity and mortality concluded that in the last two decades little progress has been made towards reducing the disparity.<sup>18</sup> Coory et al suggested that possible solutions include 'more support for regional and remote patients to travel to metropolitan centres (and more funding for associated accommodation)'.<sup>19</sup>

Some jurisdictions have recently taken steps to address the disparity. In the Northern Territory, where patient transport rebates had not been reviewed since 2008, the NT Department of Health noted that subsidy levels did 'not reflect the increased cost of travel since 2008 and have fallen behind the subsidy levels of other jurisdictions'<sup>19</sup> and took steps to improve accommodation and transport rebates, from \$35 per night for commercial accommodation to \$60 per night, and from 15 cents to 20 cents per kilometre petrol rebate. New South Wales also made improvements to their patient travel scheme in 2013 and South Australia is currently reviewing its scheme.



### Patient transport assistance scheme subsidies, by jurisdiction.

In Victoria, the VPTAS rebates have not increased since 2007, despite average petrol costs having risen by around 20 cents per litre since then<sup>20</sup> and standard accommodation rates in Melbourne now being upwards of \$100 per night.

#### Stakeholder feedback

##### What improvements could be made to the Victorian Patient Travel Assistance Scheme?

We asked stakeholders to give us their views about how the VPTAS could be improved.

##### Better promotion of the scheme

More than half (55 percent) of the 166 Victorians who responded to the online survey question had not heard of the VPTAS. Among the respondents who had personally been diagnosed with cancer, three quarters of those who live in regional Victoria were aware of the scheme, compared with just one in four of those who live in metropolitan areas.

*My breast care nurse informed me about the VPTAS. I didn't know about it for about two months into treatment (Online response)*

*My argument is "why aren't people told about this?" If it wasn't for the newspaper ad, I wouldn't have had a clue. (Patient who would have been eligible for the VPTAS, who travelled more than 1,000 kilometres return for treatment before hearing about the VPTAS via one of our newspaper advertisements)*

Many people with previous experience of travelling for medical treatment told us that they did not hear about the VPTAS until after they had already made several trips for treatment – or that the first time that they heard about it was through our consultation processes. For some it was too late to claim as they had lost receipts or missed the opportunity to have someone sign their forms, and others were out of time to claim (as completed VPTAS forms must be submitted within 12 months of the travel taking place).

Many of the people who contacted us recognised the lack of community awareness of the scheme, and so made a concerted effort to let others know about the VPTAS, often through conversations with other patients in treatment waiting rooms.

*A friend of mine in here at Alexandra said "have you claimed on your fuel going down"? I didn't know anything about it. She said "oh yes, I've got a form at home." (Elderly male patient who had made several trips to Melbourne for treatment before a friend told him about the scheme)*

*I tell a lot of people about it; a lot of people aren't aware it's available, that's the biggest problem – even just speaking to people in waiting rooms for X-Rays etc. – if you start talking to people, and they're from the country they always say "oh it's just so expensive to stay anywhere"... They used to have the forms sitting on their front counter; unless you're actually aware of them – that the scheme's available – then people don't know, and for country people the stress of that, the concern and worrying of wanting to be near the sick person... if they've got this it's just tremendous. (Female carer of male patient)*

*I can't remember who pointed me into the VPTAS direction, and I think that that is the problem. To find out about it. The medical, nursing, receptionist, allied health staff don't talk about it, don't point out that it is available. So making it public knowledge is*



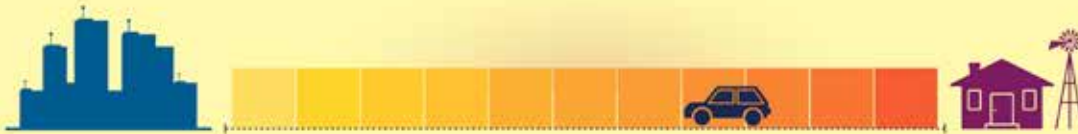
In 2012, the population in **regional Victoria** was **1.4 million**, compared with 4.2 million in metropolitan Victoria.



Due to our geography and population distribution, some cancer patients are required to travel for specialist treatment.



The cost of travel causes financial and emotional stress. Some people defer treatment or seek alternative treatment options, due to the financial burden of travel and accommodation.



The further from a metropolitan centre a person with cancer lives, the more likely they are to die within **five years of diagnosis**.



For some cancers, those who live remotely are up to **300% more likely** to die within five years of diagnosis.



Reimbursement for transport and accommodation in Victoria is **17 cents per kilometre**, and **\$35 per night + GST** for accommodation, which is around half the amount that patients are eligible for in Queensland.



No increase since 2007, despite average petrol costs having risen by around **20 cents per litre** since then and standard accommodation rates in Melbourne now being upwards of **\$100 per night**.



Some patients report waiting **up to 3 months** for reimbursement.



Many people are **unaware** financial support is available.

**The costs of travelling for treatment.**



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*very important, and at this point is lacking in my view. I certainly have informed people about it, as having cancer is a costly business, and travelling is a huge expense when one lives in the country... I have never seen brochures re VPTAS in waiting rooms or treatment areas.* (Female cancer patient)

Stakeholders' suggestions for better promotion of the scheme included placing ads in regional papers and other regional media, and posters and brochures at GP clinics and in regional hospitals.

[B]etter info for newcomers. Having to beg for a form from the [doctor's] is humiliating. Upon diagnosis maybe more info could be given by the [doctor's] rooms instead of finding out from word of mouth from other people who all have a different story and then having to go in and ask for a form that you know nothing about or never knew existed. I was so clueless at such a mind blowing time. (Online response)

#### **Change in the distance threshold eligibility criteria**

Patients who travel an average of at least 500 kilometres over five consecutive weeks are only eligible for the transport subsidy, not the accommodation subsidy, which is only paid to patients who live more than 100 kilometres from their treatment centre. We spoke with many stakeholders about their experiences of just missing out on eligibility for the VPTAS, by virtue of living a few kilometres short of the 100 kilometre distance threshold. Many of those who needed to travel regularly for cancer treatment were eligible for the private vehicle rebate of 17 cents per kilometre, by virtue of covering an average of 500 kilometres per week over five consecutive weeks, but were ineligible for the accommodation subsidy.

Ineligibility for accommodation support acutely impacts those having block treatment who are just short of the 100 kilometre threshold, as they must travel significant distances on a daily basis for several weeks, without the support of an accommodation subsidy should they need to stay overnight, rather than travel back and forth.

*The trips were absolutely shocking, when you're feeling so rough, and you're in the fifth and sixth weeks of treatment. I was just a bag of bones; I'd lost twenty percent of my body weight. We would have very much appreciated being able to stay in town, especially where we were too. At Peter Mac – the Sheraton was well within walking distance. Would have been much better than driving home in peak hour... I don't think that did me any good frankly. I genuinely think it was detrimental to the whole treatment program. It's not just a financial issue it's a health issue too. ... you have the knockout blow of a day's treatment and then having to travel home in peak period.* (Elderly patient who made a daily 184 kilometre round trip for treatment, for almost seven weeks, partly because they weren't eligible for accommodation assistance)

*When we're travelling we usually get up at 5.30 am, leave by 6.30 am – get down there about 8/8.15 am. We used to get home about 7 or 7.30 pm. Then [my husband] would have to run around and light the fire (because it was winter then) and make some food.* (Elderly patient who wasn't eligible for accommodation assistance because she lived 98 kilometres from her treatment centre)

*When [my husband] was a patient at Peter Mac at one stage, there was a guy from the Dandenongs, and he was having radiation twice a day; it was too far for him to go home and back between treatments but he wasn't eligible for accommodation assistance.* (Female carer of male patient)

*I live in Colac Victoria, 79 kilometres from Geelong. Under VPTAS we weren't able to claim any accommodation expenses even though it was 158 kilometres round trip. ... We have no alternative for cancer treatment. At a time where I was unable to work or get Centrelink payments it has proven to be a large financial stress. I had to go to the Salvos for fuel vouchers a couple of times, which was a completely demoralising and gut-wrenching experience – when you've formerly been independent and self-sufficient.* (Female patient)

We spoke with many people in south-west Victoria who were pleased about the development of a Warrnambool Cancer Centre, but at the same time, conscious of the fact that those who live in the neighbouring towns of Portland and Hamilton's south, would be ineligible for VPTAS support to travel to the new centre for cancer treatment, because Warrnambool is, respectively, 98 and 99 kilometres away.

*It just struck a chord with me that the new Cancer Centre will be just out of range for people in Portland. Our daughter is south, so she's fine; she's about four kilometres further than us – we're 99 kilometres from Warrnambool. I'm not eligible for hearing aid visits there because I fall about 200 metres short.* (Male patient)

*The reason I am writing is to say the new Cancer centre in Warrnambool is a great thing but it could bite the people that travel from Portland, as an example from our home it is 99 kilometres and the scheme won't pay under 100 kilometres, I realise 99 kilometres is not that far but if they had to do 40 trips as we did it could make it difficult for most people and I suggest that this could be looked at before it causes problems financially for patients but as I said the Warrnambool facility is a wonderful thing for the Western district.* (Male carer of female patient)

Some stakeholders raised a further limitation of the VPTAS eligibility criteria; which is that those who live in Department of Health designated Metropolitan areas are never eligible for the VPTAS even if they would meet the distance threshold otherwise.

*We had to travel from Toolangi to Peter Mac for six weeks of treatment after major surgery. In the end we had to stay in Melbourne as the travel was too much and we received NO assistance either for our travel (i.e. petrol) or accommodation because we were supposedly not in the designated rural zone. Do they know how far out Toolangi is? It is definitely rural. As you can tell it still makes me angry.* (VPTAS-ineligible female carer for male patient, travelling almost 750 kilometres per week for six weeks)

I live and work on a dairy farm approximately 90 kilometres out of Melbourne, which is situated about four kilometres inside the south west corner of the Cardinia Shire. I required six weeks of radiotherapy, five days per week. This was performed... 85 kilometres from my home. When I started treatment, I was told by the social worker I was eligible for financial assistance with the costs associated with travelling. At the end of my treatment, as I was filling out the form it became obvious that I was ineligible because the shire of Cardinia was considered "metropolitan". The trip was 85 kilometres one way, so each day I travelled 170 kilometres. This makes the 875 kilometres travelled well over the 500 km threshold needed to gain benefits. (Female cancer patient)

#### Increased subsidies

Many stakeholders informed us that the low subsidy levels were 'not making much of a dent' in their treatment travel costs and were unrealistic in light of how much petrol and accommodation actually costs. For some patients, the added costs of travelling for treatment influenced their treatment choices.

I live near Swan Hill in Victoria and my treatments and long stays with my husband are in Melbourne; about four hours' drive. We do get some reimbursement from VPTAS however the cost is now outweighing the benefit. I'm at a point where costs will stop me from continuing to see my oncologist at regular intervals... We have done this exercise for over a year now and we are at point of not attending appointments because we just don't have the \$500 at the time to fund the trip. Unfortunately that is just how it is for us now. More help from VPTAS financially and with accommodation would be extremely beneficial for my family and I to continue with my treatment. (Female cancer patient)

The other thing that still baffles me is why reimbursement is so low when you drive. The amount paid back does not even cover the petrol, let alone car running costs. The rate per km is way too low. \$35 a night is an absurdly low amount when accommodation in Melbourne is generally \$150 minimum. Several women who I know through a support group here in Mildura often complained about the low rebate which is a

burden, especially if you have to stay for a sustained time period. (Female cancer patient)

This scheme is better than nothing but it is a ridiculously low amount you can claim back... It's like a slap in the face; is my life worth that? I've paid all of my taxes; I can't get anything else? (Woman eligible for the VPTAS for breast cancer treatment)

We were paying 90 – 95 cents per litre then (in 2006); it'd be so much worse now at \$1.50 per litre. (Man who travelled 92 kilometres each way for seven weeks of treatment)

Average cost for a night was \$180 – reimbursed \$35. (Female cancer patient)

#### Faster processing of claims

Many stakeholders – particularly those whose professional roles include assisting people to apply for the VPTAS – said that the application forms had vastly improved in recent years and were much easier to complete than those in the adjoining states. However, there were still concerns over reimbursement delays. The requirement to make sometimes large upfront payments for petrol, flights<sup>21</sup> and accommodation was reported to be particularly difficult for those on benefits and low incomes.

There is a few weeks delay in VPTAS payments and with a young family is hard to budget for. With the Dr's bill, fuel, day of work, child care etc it cost me around \$500 for each appointment attended. And that's without staying overnight (too expensive)... (Female cancer patient)

Outlaying monies for travel expenses often can take two months to reimburse. I am currently waiting on reimbursement of \$1300 for flights and travel (it has been five weeks now). This is a burden when you consider the costs of medical and other expenses. (Female cancer patient)

Stakeholders suggested that subsidies could be more effectively administered if they were reimbursed similarly to Medicare rebates, so that rebates could be claimed promptly. Some respondents told us that receiving the subsidy a day or two after lodging their claims could be as helpful to some people as pre-payment.

Early on there used to be about a six week turnaround from submitting an application to being refunded. This seemed reasonable to me. More recently, the time it takes is closer to three months, which I believe is ridiculous. The airfare costs for two people to travel to Melbourne can easily be \$1000 and there have been times that it was financially difficult having to wait so long to be refunded. This was particularly so when we were a one income family. (Female cancer patient)

#### Additional feedback

##### Parking costs

The cost of parking was the single most independently raised problem for the stakeholders we spoke with. Many stakeholders also complained of limited parking options around hospitals, and the difficulty of avoiding parking fines while undergoing treatment.

You pay that much per day. We got a three day pass for about \$60. At Vizard House they used to give you a pass so if you're staying there you'd have a pass so you could park your car out the front. The Council took it away, so now you have to go there after 7 or 8 at night – you have to move it by 7 am in the morning. Then we'd go to the hospital and park it there. When the footy was on, I couldn't park at all. We had to leave the car at the hospital overnight, and pay for that parking. I'd hate to know the car park costs over that year. (Mother of young male patient who required treatment in Melbourne for almost nine months)

Parking was an issue in the first instance. [The hospital] provide parking ... for a nominal fee if you have an appointment card. You could rarely get in the car park unless you had an early morning appointment. Parking in the street was almost non-existent and involved moving your car every two hours. Once we tried [a commercial] car park and that was over \$100. (Female carer of a male patient, travelling one and half to two hours each way for weeks of chemotherapy)

##### More assistance for carers and families

The VPTAS provides no financial assistance for carers' transport and accommodation if they are not actually travelling or staying with the patient. In practice, this means that if a patient who has been staying overnight in a

Melbourne hotel suddenly needs to spend a night in hospital during their treatment, the carer's accommodation isn't reimbursed for the night/s that the patient isn't with them. If the carer needs to go home to work, to collect items for the patient, or to check on children, animals, or a farm, they receive no financial assistance to do so.

*After a couple of months I had to return to work or I would have lost my job. You need to travel with the patient – so I wasn't reimbursed for most of my train trips. They need to change it. City people don't have those costs. They've got their own house, kitchen, food. It's like nearly shifting home for a year. (Mother of young male patient who required treatment in Melbourne for almost nine months)*

*It was a very stressful time in so many ways as we were trying to keep two houses running. [My husband] was unable to claim for his trips to Traralgon to see me each weekend and I was not eligible to come home to see my family and friends... this is the information I received from a vague social worker. [My husband] was also unable to secure any time off during my radiotherapy as his place of employment were unable to release him for leave for this length of time and we did not have any funds left for [him] to take the leave without pay. At this time we felt like we just needed a fairy godmother to say here is a small token amount of cash to assist you so [my husband] could be with me to provide support, love and friendship. (Female cancer patient receiving radiotherapy 700 kilometres from her home town)*

*Rural patients don't have the luxury of going to work during the day and visiting inpatients at night. This becomes a huge burden on families and finances. (Manager, hospital family accommodation service)*

Many stakeholders also lamented the lack of additional accommodation assistance for dependent children, who need to travel with their parents when one parent is undergoing lengthy periods of treatment.

*Another group... would be parents with young children who travel for their child's treatment or parents who travel for their own treatment and have to leave children at*

*home which is traumatising for all – especially young children in single parent families. (Female patient with long history of travelling from Mildura to Melbourne for treatment)*

#### **Clinical trials**

Patients who are receiving treatment via a clinical trial are not eligible for the VPTAS. This particularly disadvantages patients who have no other treatment choices and are receiving very little or no financial assistance to be on a clinical trial.

#### **Subsidies for trips to a wider range of health care specialists**

Some stakeholders called for the VPTAS to be extended to subsidise travel costs for allied health services treatments. Many women with breast cancer-related lymphedema, for example, need to see physiotherapists, while many patients with head or neck cancers need to see dentists after treatment, due to the effects of radiation. The Stroke Foundation told us that country people who have had strokes need regular rehabilitation, for which travel and accommodation costs are currently not subsidised.

#### **Citylink**

A few stakeholders suggested that CityLink charges should also be covered under the scheme, particularly as the scheme requires applicants to take the shortest or most direct route to their treatment centre.

#### **More subsidised accommodation needed**

A large number of stakeholders told us of the need for more subsidised accommodation options, and emphasised the value of accommodation providers like Vizard House, Ryder-Cheshire Home and the Leukaemia Foundation accommodations. These not only subsidise accommodation – usually at the VPTAS rebate rate, so patients and carers are not out of pocket – but were also reported to be welcome respite from the hospital, with self-catering facilities and opportunities to interact with other people facing similar challenges. Stakeholders reported concerns about the often long waits to get in, and sometimes short stays due to high demand.

*It took a while to get in there – more than a month. They're fabulous there – everyone staying there is in the same boat. You realise how many people need this help to stay somewhere. I kind of missed it when I left. (Mother of young male patient who required treatment in Melbourne for almost nine months)*

#### **What level of transport and accommodation support is reasonable for those who need to travel for medical treatment?**

*I believe there needs to be a high level of support. People should not have to make decisions based on what they can afford but on what treatment is best for them. (Online response)*

The representatives from cancer, chronic disease and patient support agencies we met with at the roundtable events in August had a range of suggestions about the level of transport and accommodation support that is reasonable for people who need to travel for specialist medical treatment. It was generally agreed that the petrol rebate should be increased from 17 cents to 30 cents per kilometre (as it is in Queensland) and the accommodation subsidy should be increased from \$35 + GST per night, to \$75 + GST per night.

Regardless of the actual rate of the subsidies, many stakeholders suggested that the subsidies need to be more regularly increased to keep pace with inflation and other rising costs. Suggestions included tying annual increases to:

- the Consumer Price Index (CPI);
- a set percentage of RACV vehicle reimbursement rates increases (which are indicative of the cost to private motorists to own and operate their own vehicle for business use); or
- a set percentage of government employee travel reimbursement rates increases.

People affected by cancer who responded to our online survey had a range of suggestions for reasonable rates of transport and accommodation support, ranging from 20 cents per kilometre for private vehicle usage and \$50 per night for accommodation to 100 percent reimbursement of costs.

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### Should Australia have a national transport and accommodation support framework to ensure consistency and improved administration between states and territories?

Australia previously had a national patient transport and accommodation assistance scheme (the Isolated Patients' Travel and Accommodation Assistance Scheme), before this responsibility was devolved to the States in 1987, on the basis that it was thought the States would be better able to administer the scheme.<sup>22</sup>

Over the years it became apparent that the lack of uniformity between state schemes resulted in inequitable outcomes for patients from different regions, difficult border issues, and complexities for interstate travellers.<sup>23</sup> In 2007 the Senate Standing Committee on Community Affairs released a report, *Highway to health: better access for rural, regional and remote patients*, which recommended that:

*as a matter of urgency, the Australian Health Ministers' Advisory Council establish a taskforce comprised of government, consumer and practitioner representatives to develop a set of national standards for patient assisted travel schemes that ensure equity of access to medical services for people living in rural, regional and remote Australia.*<sup>24</sup>

It was recommended that the taskforce identify mechanisms to improve access for patients travelling between jurisdictions and identify, as a matter of priority, core, minimum standards that are relevant to all jurisdictions particularly in relation to eligibility criteria and subsidy levels.

In 2008 the National Health and Hospitals Reform Commission produced an Interim Report, which stated:

*There is a need for a patient travel and accommodation assistance scheme with nationally consistent guidelines and user-friendly submission processes. This scheme should be funded at a level that takes account of the 'real' costs to families, and have regard to a safety net for frequent users of specialist services.*<sup>25</sup>

Prior to the 2010 federal election Cancer Council Australia and the Clinical Oncological Society of Australia called on the next Australian government: 'to lead a national agreement with the states and territories to uniformly improve remote patient travel and accommodation assistance through increased funding, minimum standards and streamlined administration.'<sup>26</sup>

Most stakeholders – professionals and patients – who contributed to our consultations expressed the view that Australia should again have a national transport and accommodation scheme to ensure consistency and improved administration between states and territories. Those who work or live in border towns in particular emphasised the need for greater equity and consistency between the schemes. Of the 100 Victorians who responded to the online survey question, 90 (90 percent) were in favour of a national transport and accommodation scheme.

*Absolutely – justice/equity being the most obvious reason. There should also be equal access to services across the nation!* (Online response)

*The person would know "the rules and entitlements" no matter where in Australia they were.* (Online response)

*It would be a fairer system. I live in a border town; there are many examples of people living two kilometres from each other separated by a river and they are eligible for quite different benefits just because of where they live. The differences are very obvious and make no sense.* (Online response)

#### VPTAS Activities

We developed a cross-jurisdictional table to build a comprehensive picture of the patient transport assistance schemes in the other Australian states and territories (see Appendix A). An analysis of key elements, including eligibility criteria and private vehicle and accommodation rebates, revealed Victoria lags behind most other states and territories in the support offered to patients who need to travel for specialist medical treatment.

In August 2013, we convened two roundtable events with other cancer, chronic disease and patient support agencies to discuss shared experiences of, and concerns with, the VPTAS. Representatives from 25 agencies attended, and agreed to form an alliance to advocate for three key improvements to the VPTAS.

The key objectives of the VPTAS Alliance are:

- An increase in the VPTAS subsidies from:
  - 17 cents per kilometre to 30 cents per kilometre
  - \$35 (+ GST) per night to \$75 (+ GST) per night, plus annual increases to the subsidies indexed against the Consumer Price Index;
- A change in the VPTAS distance criteria from 100 kilometres each way/500 kilometres over five consecutive weeks to 200 kilometres per week; and
- Improved administration, to allow for online processing and prepayment for accommodation costs.

The group also agreed to promote awareness of the VPTAS through their own networks and through media and other public education campaigns.

Following the roundtable events we put out a call through our networks and regional newspapers for people to contact us with their stories of travelling for treatment; we received about 50 phone calls and emails in response. As mentioned above, some callers indicated that they had never heard of the VPTAS until they spoke with us. Some contacted us to express their gratitude for the scheme, while others reported their disappointment at being ineligible for their scheme, by virtue of living just short of the 100 km distance threshold for eligibility.

While being interviewed for the ABC's 7.30 Report 'Regional patients count cost of travelling for treatment' on Friday 25 October, the Minister for Health, the Hon. David Davis, said that the Department of Health was currently reviewing the VPTAS. In November, we wrote to the Minister on behalf of the VPTAS alliance to offer our collective assistance with this review.

On 5 December 2013 we formally launched the VPTAS Alliance.

# VPTAS Alliance Members



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## Reflections

- On a positive note, many of the patients and carers who contacted us and who had been eligible for the VPTAS were grateful that the scheme exists, and for the financial support it provided them at a difficult time.
- However, almost all stakeholders agreed that the VPTAS subsidy levels are too low and that the distance eligibility thresholds of 100 kilometres or 500 kilometres per week for five weeks seem arbitrary and are unfair, particularly for those who fall just outside the criteria despite having the same needs as eligible users of the scheme.
- Key challenges that came through strongly from regional patients and carers were a lack of awareness of the scheme, and the difficulties in finding and then paying for parking.
- Calling for personal stories and experiences of travelling for treatment through regional newspapers proved a highly effective method of engaging with rural and regional stakeholders. The large number of people who responded by phone or email emphasises the significance of the costs of travelling for treatment to country Victorians.
- There was a great deal of interest from a range of cancer, chronic disease, patient support and rural and regional organisations in partnering in an alliance to advocate for improvements to the VPTAS. The diversity and high profile of our partner organisations strengthens our message about the need for key improvements to the VPTAS.

## Recommendations

CCV will continue to support patients, carers and health professionals to access support for travel and accommodation for treatment. As part of this work, we will collaborate with other Victorian agencies to advocate for the following improvements to the VPTAS:

- Increase the VPTAS subsidies from:
  - 17 cents per kilometre to 30 cents per kilometre for private vehicle usage; and
  - \$35 (+ GST) per night to \$75 (+ GST) per night for accommodation
- With annual increases to the subsidies indexed against the Consumer Price Index;
- Change the VPTAS distance criteria from 100 kilometres each way/500 kilometres over five consecutive weeks to a single cumulative threshold of 200 kilometres per week; and
- Improve administration of the scheme, to allow for online processing and prepayment for accommodation costs.

In line with these priority areas, we will support the Victorian government's efforts to address some of the key concerns with the VPTAS.

Further, we recommend that GPs' offices, public and private hospitals and other cancer care treatment centres:

- Prominently display posters, brochures and VPTAS forms, to increase the likelihood that patients and carers who need to travel for treatment become aware of the VPTAS before they travel;
- Ask patients and carers about their likely need to travel for treatment as part of their initial patient information collection and needs screening, and then provide VPTAS information for those who require it.



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# Employment-related issues

While many employers are supportive when an employee is affected by cancer, retaining, returning to or finding new employment can be problematic for some people who have or have had cancer, and for people who care for someone affected by cancer. Undergoing time-consuming treatments, being physically or emotionally unable to work as a result of cancer or cancer treatment, a lack of understanding of cancer treatment on the part of employers and colleagues, and discrimination are among the range of factors that can impact on employment.

Our issues paper outlined the protections afforded to people affected by cancer and their carers by Commonwealth and Victorian anti-discrimination legislation. Cancer is considered to be a 'disability' pursuant to both the *Commonwealth Disability Discrimination Act 1992* (DDA) and the *Victorian Equal Opportunity Act 2010* (EOA). Both pieces of legislation protect people affected by cancer, (whether they have cancer now, have had cancer in the past or have an increased likelihood of developing cancer in the future due to family history or genetic predisposition) and their carers from direct and indirect discrimination (see Figure 1. for more detail).

Under the DDA or EOA, employers must take reasonable steps to accommodate the effects of a person's cancer, or caring responsibilities, whether a person continues to work during treatment, returns to work after taking leave for treatment, or is applying for a new role.

It is not unlawful for employers to discriminate against people affected by cancer, or their carers, if they're unable to 'carry out the inherent requirements of the particular work', even if 'reasonable adjustments' are made for them (section 21A(1) DDA). It is also not unlawful for employers to discriminate against a person on the ground of their being affected by cancer, if avoiding the discrimination would impose 'unjustifiable hardship' on the employer. See Figure 2. for more detail.<sup>27</sup>

The issues paper also discussed other legal issues that might impact on people affected by cancer in the workplace, including using leave entitlements and obtaining financial support when people are unable to work. Employees are entitled to use paid leave entitlements (personal and annual) or ask for unpaid time off if they're unable to work due to illness or treatment. Generally, it is unlawful to dismiss someone for taking leave due to illness, if they're off work for less

than three months over a 12-month period and they have provided medical certificates or statutory declarations for their absence within a reasonable period of time.

Further, people affected by cancer report difficulties accessing financial support if they're unable to return to work after diagnosis or treatment. Cancer treatments and outcomes can vary, and may be unpredictable. As such, it is difficult for some people to qualify for support. For example, eligibility for the Disability Support Pension is limited to people with a condition that renders them unable to work or to be retrained for work, for more than 15 hours per week within the next two years. Both the Disability Support Pension and the Sickness Allowance are means-tested, which can be problematic for people who are just over the income threshold and who are faced with significant treatment related costs. Anecdotally, people affected by cancer who do not return to work also experience difficulties in obtaining early access to superannuation funds or in accessing disability insurance, income protection and employer-provided retirement benefits.

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**Figure 1.** Types of discrimination.

## Direct discrimination

Treating a person with a disability *less favourably* than someone without a disability in the same or similar circumstances. For example, denying a person a job or promotion because of their cancer diagnosis or history.

## Indirect discrimination

Treating a person with a disability *the same* as a person without a disability, with the effect that the person with the disability is disadvantaged because they are not able to participate or comply with a condition. For example, requiring that employees in a manufacturing role stand all day, when an employee's cancer makes standing for long periods difficult, may constitute indirect discrimination.

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## Key challenge

One of the key challenges in exploring how cancer intersects with people's jobs and employment laws is getting an accurate picture of the scale of the problem. There is limited evidence of people affected by cancer making employment-related complaints to human rights commissions or pursuing court action.<sup>28</sup> However, a lack of evidence of formal complaints does not mean that problems do not exist.

Possible reasons why people do not make complaints include:

- Lack of knowledge or understanding of the law and employment rights among employees and employers;
- The usual need to maintain an ongoing relationship in employment contexts (which is not as frequently the case in other areas of discrimination e.g. insurance, the purchase of goods and services);
- Lack of confidence or energy to challenge an employer's decision;
- The challenges of proving a complaint, particularly in the context of direct discrimination, where it can be difficult for employees to prove that an employer's decision was related to the employee's cancer or caring responsibilities;
- Lack of knowledge of external avenues for recourse if the problem cannot be sorted out internally;

- Difficulty identifying which legislative scheme to complain under, and where and how to make a complaint – the specific circumstances in each case will dictate whether a person complains to the AHRC, the Victorian Equal Opportunity and Human Rights Commission, the Fair Work Commission (FWC), VCAT or the Federal Court;
- The tight deadlines for complaints – 21 days for unfair or unlawful dismissals and general protections dismissals;
- Not having the time, energy or money required to pursue a complaint.

We found that there is very little data on the effect of employment protections on people affected by cancer and their carers, including the level of discrimination, and reasons why people pursue a complaint or are dissuaded from pursuing a complaint. Accordingly, this part of the project was focused on canvassing the laws that may impact on employment experiences and outcomes for people affected by cancer, and seeking stakeholder feedback about employment experiences during and after cancer.

## Developments in employment law which may impact on people affected by cancer

### Legislative changes

The *Fair Work Amendment Act 2012* changed the time limit for lodging unfair

dismissal or general protections dismissal claims to 21 days (increased from 14 days for unfair dismissals and reduced from 60 days for general protections claims), from 1 January 2013.

From 1 January 2014 new anti-bullying provisions in the *Fair Work Act 2009* (FWA) will allow people who reasonably believe that they have been bullied at work to apply to the FWC for an order to stop the bullying. A person is bullied at work if a person or group repeatedly behaves unreasonably towards them, and the behaviour creates a health and safety risk.<sup>29</sup> This might involve spreading misinformation or malicious rumours about a colleague affected by cancer, for example, saying that they're not pulling their weight, or taking too much time off. The person bullied does not have to first make a complaint internally in the workplace. The FWC must respond within 14 days of the application, and may then hold a private conference, conciliate and/or have a hearing. Employees, volunteers, contractors, subcontractors, apprentices, trainees and students gaining experience will all be able to apply for an order to stop bullying. Employers who do not comply with anti-bullying orders may face penalties.

### Case – Fair Work Ombudsman v AJR Nominees Pty Ltd [2013] FCA 467

In 2012 the Fair Work Ombudsman

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Figure 2. Some definitions.

#### Inherent requirements

Not defined in the DDA. Determined in circumstances of the job, and may include the ability to:

- perform tasks or functions which are a necessary or essential part of the job;
- meet productivity and quality requirements;
- work effectively in a team or other type or work organisation; and
- work safely.

#### Reasonable adjustments

Depend on the circumstances, but may include adjustments to:

- workplaces, equipment or facilities, including provision of additional equipment or facilities;
- work methods;
- work arrangements, including in relation to hours or work and use of leave entitlement;
- work related rules; or
- access to training, transfer, acting, trial or higher duties positions, or traineeships.

The DDA does not require adjustments to *inherent requirements* of job.

#### Unjustifiable hardship

All relevant circumstances of the particular case are to be taken into account, including:

- the nature of the benefit or detriment likely to any persons concerned
- the effect of the disability
- the financial circumstances and estimated amount of expenditure required to be made by the person claiming unjustifiable hardship



commenced action against a Western Australian company for terminating a man's employment so that he couldn't take personal leave for cancer treatment. Upon learning of Mr Bill's cancer diagnosis, AJR Nominees coerced him to resign, and then, when that didn't work, fired him. In May 2013 the Federal Court found AJR Nominees Pty Ltd had contravened the FWA by terminating his employment in order to prevent him from exercising his workplace right to use accrued and accumulated paid personal leave for the purpose of his treatment. Gilmour, J ordered that AJR Nominees pay Mr Bill \$14,991 compensation for five weeks' pay in lieu of notice of termination and accumulated personal leave, plus interest.

### Stakeholder feedback

Much of the stakeholder feedback for this part of the report came via the online survey, most of the respondents to which are likely to be women who have been diagnosed with breast cancer, as the survey was distributed to Breast Cancer Network Australia's (BCNA) Survey and Review Group. Only the responses from Victorian participants are reported here because this project has a Victorian focus.

It is important to note at the outset that:

- The time since diagnosis for most respondents is unknown, which means that some of the policies and laws outlined in this section may not have applied at the time some respondents had their cancer diagnosis and treatment.
- Women with breast cancer generally receive better support than people with other types of cancer<sup>30</sup>, so their experiences, as reported via the online survey, may not be representative of the experiences of people with other types of cancer. In the context of exploring the extent of possible problems in employment and accessing insurance, it may be that people with other types of cancer, who are less supported, may have more negative experiences – although this is speculation.

We received additional feedback about employment experiences from other stakeholders at events and over the phone; some of their comments have been included below.

### Is discrimination in employment a significant issue for people affected by cancer?

The majority (72 percent) of Victorian respondents indicated that discrimination is a problem, even if they had never worried about being discriminated against or experienced discrimination themselves. The fact that there was not a 'don't know' option for this question could well have influenced people's responses in this regard. More than a quarter of respondents to the online survey question indicated that they did not think discrimination was a significant issue.

The framing of the question, and the absence of a 'don't know' response option, meant that it was difficult to know whether some of the comments given as to why discrimination is or isn't a significant problem for people affected by cancer were based on actual experiences, or concern or anxiety about how employers or future employers might react to a cancer diagnosis or history. However, a number of respondents commented about being treated unfairly based on assumed effects of a cancer diagnosis or history, as well as the actual effects.

*Even if you are in remission, future employers treat you as if you are still sick and maybe not wanting to employ you just in case you get sick again!*

*Many work areas are sympathetic in the short term, however, if the treatment is ongoing and multiple days are needed to cope with this, the sympathy dims very quickly.*

*I wasn't treated unfairly, but I still think it happens a lot. I think many miss promotions because of the lingering thought of "what if" in the employer's mind, re future absences etc.*

*My experience has shown me that once people find out I've had and again have cancer I'm definitely treated differently. Generally ignored and colleagues kept their distance. My last employer just stopped talking to me.*

*Extremely. I was in this position where my manager would not even speak to me. It was made quite clear that "I was employed to do that position". I was receiving treatment and still went to work. In the end I felt unsupported and I resigned.*

*Employers fear impending absences resulting from further diagnoses, fatigue, etc. When I apply for a job, I don't disclose my cancer history – it's all very well to say such discrimination is illegal but in practical terms it's impossible to 'police'.*

*I think this comes down to people not having a complete awareness of the long-term effects of cancer post-treatment, meaning that people who have not previously been exposed to what cancer entails may have preconceived notions of how survivors are affected post-treatment.*

One in three respondents indicated that they have worried about being treated unfairly because of cancer, while the majority (70 of the 110 respondents who answered this question) said they had not worried about this. The following concerns were articulated:

*Promotional opportunities or opportunities to travel or work harder are assumed to be out of reach for a person with cancer – unproven of course.*

*Once diagnosed with breast cancer, I took three weeks off work to have breast cancer surgery and recover. I felt if I was away any longer, I wouldn't have a job to go back to!*

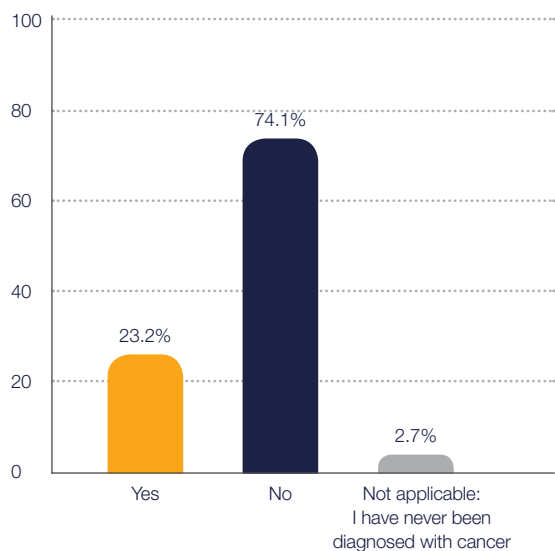
*Most people in my workplace are on short-term contracts, and we have been down-sizing so few people are offered new contracts when their current contract expires. Before my diagnosis I was confident of getting a new contract. I am not confident anymore. Why would they offer me a contract if there is a chance I will get sick and need time off again? And also because my energy levels have not returned to what they were so I feel I cannot produce the same amount of work as before.*

Of those respondents who had worried about being treated unfairly because of cancer, 70 percent (28 of 40) said that they had taken action to avoid being treated unfairly. Such actions often revolved around minimal disclosure of diagnosis and treatment, and taking minimal time off.

*Went back to work after surgery too soon.*

*Minimal time off, but struggled to get through some days.*

**Figure 3:** Have you ever felt or suspected that you were treated unfairly at work, or when applying for work, because of cancer?



*Went back to work early as. I was worried about my job.*

*I told as few people as possible about the diagnosis and continued to work as much as possible around my treatment.*

The majority of respondents indicated they had never suspected that they had been treated unfairly at work, or when applying for work, because of cancer. (Note that it is unclear whether all respondents were working at the time of the cancer diagnosis). However, almost a quarter (26 of 112) said they suspected they had been treated unfairly at work, or when applying for work, because of cancer. Four of the 111 people who responded to the question about discrimination as carers indicated they suspected that they had been treated unfairly at work, or when applying for work, because they were a carer of someone affected by cancer.<sup>31</sup>

Reasons given for having such suspicions included:

*A person in management made snide remarks to me and informed other staff I had cancer.*

*My manager would not speak to me. I was not given the opportunity of retraining to take another position within the organisation.*

*I was highly anxious when I returned to work as I felt the long hours were challenging and felt afraid to ask for consideration as the manager was a bit of a bully.*

*My thought process was really bad... I kept making small mistakes frequently (with a lot of eye rolling from other staff). My speech was affected and I could see my co-workers getting very frustrated with me, speaking to me like I was an idiot and on my return the relieving staff member made it very plain that she wanted to stay. Two staff members made my transition back to work very difficult for me. I knew I was struggling but they had little or no compassion and calls were going to management about me which resulted in a meeting with my boss. Unfortunately people see you back at work and think all is back to normal, which is not the case. At the meeting with my manager I had to explain my situation but I really didn't think anyone could understand. So I just laid low and tried my best. I spoke with the HR person about what was going on she was very supportive but I didn't take things further; I still don't have the energy but I am playing the game.*

Carers' experiences of unfair treatment included:

*Husband was demoted (role not salary) as he couldn't put in his normal hours as he was either caring for me or running household or doing school runs for about*

*18 months of treatment. It affected his career but not necessarily finances.*

*My husband at the time was treated harshly by his employers when he asked for reduced hours during the months that I had active treatment. Asking for time off being so hard, that he felt he had no choice but to stop working and become my full time carer. He has since found it hard to find work, as he had been honest in his interviews that he may require time off occasionally as he was my carer.*

*When I had my breast cancer surgery, my husband took three days off work to care for our three young children, he was not paid for those three days, so when I started chemo I felt he could not help me as financially our life would become extremely more difficult. He had worked for this company for 10 years and hardly taken a sick day, they claimed they didn't have to pay sick leave as my husband wasn't sick.*

### Experiences of other employment problems

One in five respondents (21 percent or 23 of 110) told us that they had experienced other (not necessarily discrimination-related) problems at work due to a cancer diagnosis or history.

Other employment problems people reported experiencing included:

- feeling isolated or bullied;
- being overlooked for opportunities;
- a lack of understanding of the effects of cancer and its treatment among colleagues and employers;
- struggling to get through the day; and
- having no sick leave available, for example, because of being self-employed.

### How could the law respond better for people affected by cancer?

Respondents to the online consultation were asked what would make things better for people affected by cancer in a variety of different employment scenarios, for example, continuing to work during treatment or seeking a new job after treatment. Not all of the participants' suggestions related to legal issues or support, but are of interest nonetheless in terms of additional employment supports that may improve experiences and outcomes for people affected by cancer.

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### For people who continue in their employment while undergoing treatment

Respondents emphasised flexibility when asked what would make things easier for people affected by cancer who continue to work during treatment. Almost all of the 80 respondents who responded to this question mentioned the need for greater flexibility. For many this meant the option to work reduced or different hours, and to sometimes work from home.

*If employers could be as flexible as possible to allow cancer patients to work when and how they could during treatment if they were well enough. Work and normality can help some patients [get] well.*

*Flexible working hours and ability to work from home or job share - it helped me enormously to keep in touch with work during treatment. During chemo, I worked whenever I felt able - some days, not at all, some days a full day.*

Several respondents indicated that more knowledge, understanding and sympathy on the part of employers would be very helpful, and recommended practical support for employers, such as an education kit explaining the different challenges for their employees. Two respondents recommended employers make greater effort to reduce stigma and bullying. One respondent suggested the option to get treatment outside of normal business hours.

### For people who take leave for treatment and return to work

Many of the 66 respondents to this question gave the same or similar responses as they did for the question about supporting people to continue work while undergoing treatment. Respondents emphasised the need for flexibility and for more understanding and support from employers and colleagues.

*A general understanding that once you have finished treatment that there can be very long term or permanent effects.*

Several respondents placed particular emphasis on the need for a slow or staggered return to work and full responsibilities, to take into account the person's gradual recovery.

*Starting back on reduced hours and increasing over the next few weeks as person's health improves.*

*A transition period when returning, meaning that survivors slowly come back and then do more and more work as they feel capable.*

### For people who seek new employment after treatment

*Being considered as the same as any illness or injury. A life experience that can add to a person's life experience and not an ongoing disability.*

Fifty seven respondents commented on the online survey question as to what might make things easier for people affected by cancer who seek new employment after completing cancer treatment. Some respondents felt that a history of cancer was irrelevant to new employers:

*Again, why should it be an issue? Is there a form somewhere that asks if you have had cancer? I certainly hope not!*

*I don't understand why having had cancer should define you. It doesn't define me.*

There clearly exists some concern among people with a cancer history that they will be discriminated against or treated differently by employers or colleagues if they seek new employment:

*Employers to look at our experience not our illness. We have all thought long and hard about when we return back to work.*

*That future employers can look past the fact that they are/were cancer patients, and give us a chance to feel worthy of having employment again.*

*Guidance on how to explain an absence from the workforce due to medical reasons and how much you should disclose to a potential employer without fear of being treated unfairly.*

A person who has or has had cancer in the past, or someone who cares for someone with cancer, is under no obligation to disclose this fact to their employer, or a prospective employer. However, a person affected by cancer, or a carer, may find that they are unable to keep the situation private, depending on the impact of the illness and



treatment type. Additionally, it may become necessary to disclose their situation if it will affect their performance or if they need to take leave, as some employers require medical certificates for personal leave (although they need not disclose cancer in particular).<sup>32</sup> Many of the respondents to the online survey cautioned against disclosing a history of cancer for fear of not being offered a role or being treated differently:

*Don't disclose the cancer history.*

*Keep it a secret, quite frankly. Never reveal a personal weakness of any kind to a potential employer. You won't be considered.*

*Whether we agree or not the industry I was in would not agree to grant an interview unless you fully disclosed full medical history. It would be hard to prove that you missed out on employment in that circumstance, due to cancer.*

Other respondents advocated honesty, and suggested getting supporting documentation from a health professional about work-readiness, capabilities and limitations.

To be honest about limitations if still not back mentally and physically to 100 percent.

For their specialist to advise the employer that the person is fit to be a part of the workforce.

#### **For people who choose not to, or are unable to, return to employment after treatment**

Of the 69 respondents who made comments in response to the question of what might make things better for people who choose not to, or are unable to, to return to employment after cancer treatment, 42 explicitly called for more financial assistance. For some this meant easier access to their superannuation, while others called for more accessible government-funded financial assistance for people who cannot work because of cancer.

Many respondents reiterated that more understanding and support is needed for people affected by cancer, whether they're able to go back to work or not.

*There is life after cancer. This should be conveyed.*

*An understanding that once treatment has been completed there still may be problems even if there is no sign of the cancer. Five year survival rates give a very incomplete picture of cancer.*

A few respondents recommended counselling in particular while others indicated that more support to go back to work or remain in other meaningful activities would be beneficial for people affected by cancer.

Along similar lines, a small number of respondents suggested that volunteering might be beneficial for people affected by cancer who are unable to go back to work.

#### **Are changes required to current employment and discrimination laws and processes to better enable and support people affected by cancer to pursue complaints? For example, more advocacy support, or longer timeframes within which to lodge complaints? Are existing legal remedies for discrimination sufficient to redress the needs of people affected by cancer?**

In response to the question as to whether respondents had ever made a formal complaint about being treated unfairly at work, three quarters of respondents (84/110) indicated that they had never been treated unfairly at work because of a cancer diagnosis or history. None of the respondents had ever made a formal complaint about unfair treatment at work based upon a cancer diagnosis, including the 26 respondents (23 percent) who said that they had been treated unfairly at work due to cancer, and all of those who said that they had been treated unfairly at work because of being a carer for someone affected by cancer.

Reasons given for not making a complaint included: not knowing that they could complain; not wanting to make things worse; wanting to keep their jobs; it not being worth the effort or cost to complain; not trusting that the truth would come out; and not having the energy to complain.

*I wanted to keep my job.*

*Was too unwell and exhausted to do anything about it.*

*I didn't know I could at the time and just put up with it.*

*You have to be joking; do you think I wanted to make things worse?*

*I do not want to leave with a sour note since I have been with the company for a very long time.*

*COST and when you are having treatment it is difficult to find the strength and courage to do so.*

*Since my cancer diagnosis I am less ambitious and haven't got the energy or desire to take my complaint to a higher power.*

A male stakeholder we spoke with over the phone told us that in his experience most people who feel discriminated against just want an apology, rather than compensation, and that people don't want to be labelled as victims for making complaints. Further, he emphasised the emotional costs of making a complaint, the fact that you might not succeed, and that even if you did, you were unlikely to be adequately compensated for what you'd been through.

Almost half (48 percent) of the respondents thought that there needed to be changes to the laws and complaints processes relating to unfair treatment at work, to make it easier for people to make complaints. It is perhaps unsurprising that 42 percent (46 of 110) said that they did not know whether changes to the law were required, given that many people had not experienced employment problems, and among those who had many indicated that they did not know their rights and had not made a complaint.

Many of those who considered that changes to the law were required emphasised that longer timeframes within which to make complaints were needed:

*Time frame extended as it can often be months before a person can deal with the issue. Often a person does not complain because they need the job.*

*Funds available for people in hardship and a longer timeframe in which to complain. When one has cancer they don't have the confidence to complain as they are too unwell.*

*I see no reason why timeframes for any complaint should be very tight, it seems unfair. When people are not well, it's even harder to cope. Why should cancer discrimination laws be so, well, discriminatory?*

*Maybe extended time frame in which to complain. Difficult to make a complaint and cover all aspects of the issues when unwell...most of your energy is spent just trying to get better and resume your normal/usual lifestyle*

Others supported the idea of having an advocate available to assist people with complaints.

*An advocate for the patient.*

*Counsellors, social workers to support and assist those who want to make a complaint.*

*Most people affected thus are sometimes not well equipped emotionally to deal with the issues. There needs to be a "cancer aware" advocate for such people, someone with the sensitivity to pursue the case.*

*Support for the cancer patient in preparing for the process and necessary document. (Chemo Brain is a problem) Longer timeframe MAY be necessary and should be an option particularly if treatment is long.*

Some respondents emphasised the need for more readily available information about employment rights and laws:

*Let patient be aware of different avenues available for support about unfair treatment while being treated at hospitals.*

*I really don't know, but the early days of my treatment required many letters to request extended leave. I think an information checklist for Victoria might have been helpful then.*

*Not knowing all the laws and processes it is every difficult to comment. Managers, Payroll Officers and HR Departments need to have more training. They need to explain the process and where they receive their information from.*

Other comments included:

*Financial support for legal advice or representation.*

*The current process you described in previous questions is cumbersome, bureaucratic, stressful and sometimes costly. If people have to lodge complaints themselves, it needs to be a simple, cost effective process.*

## Reflections

The key challenge identified in our issues paper – assessing the extent of employment problems for people affected by cancer remains – although we are now better informed about some of the challenges and priority issues for people affected by cancer in the workplace. The responses to the online survey revealed mixed results in terms of whether discrimination and other employment problems were common for people affected by cancer and their carers. The responses are not necessarily representative of the experiences of other Victorians, given almost all responses are from women affected by breast cancer, but they do provide further anecdotal evidence about the types of concerns and experiences people affected by cancer can encounter.

Cancer-related problems are clearly not a problem for everyone; many respondents told us that their employers were very supportive when they were diagnosed and having treatment.

However, others expressed concern about unfair treatment at work, which seemed particularly acute in relation to taking time off, losing opportunities and the possibility of losing one's job. The actions respondents reported taking to avoid unfair treatment may have been suboptimal for their productivity, safety and health. Respondents reported not disclosing their cancer to employers or colleagues and taking less time off for treatment than they felt was needed. Among those respondents who reported being treated unfairly, many referred to relationship and communication problems with employers and colleagues, which were often related to taking time off.

These concerns were not limited to patient experience, and it appears that some carers also experience difficulties at work.



Not one of the stakeholders we spoke with, or who responded to our survey, had made a formal complaint about being treated unfairly at work. In our issues paper we speculated about the reasons people might not make complaints, including not knowing one's rights or the avenues for complaint, the need to maintain an ongoing relationship, fear of losing one's job, and it not being worth the time, money or energy to complain. These barriers were also identified by respondents to the survey, who made suggestions for better supporting people affected by cancer by: allowing longer timeframes for complaints, because people with cancer are unwell; having advocates available to assist people with cancer to make complaints; and increasing availability of information about employment rights and complaints processes so people know their options.

While the FWC can extend the time period for lodging an unfair dismissal application if it is satisfied that there are exceptional circumstances, 'mere ignorance of the statutory time limit' for lodgement is not an exceptional circumstance.<sup>33</sup> In determining whether there were exceptional circumstances the FWC considers:

- The reasons for the delay;
- Any action taken by the former employee to dispute the dismissal;
- Prejudice to the employer (including prejudice caused by the delay);
- The merits of the application; and
- Fairness between the employee and other persons in similar situations.<sup>34</sup>

People affected by cancer or other illnesses have sometimes been granted extensions when they have been able to convince the FWC that their medical condition, appointments, treatment and mental state comprise exceptional circumstances that prevented them from lodging an application on time.<sup>35</sup> However, the FWC does not grant automatic extensions of the time to all applicants affected by cancer. Previous cases have emphasised that: the person needs to have been too ill in the 21 day timeframe immediately following the dismissal to lodge the claim<sup>36</sup>; that medical conditions cannot be used indefinitely to justify out of time applications<sup>37</sup>; and that the exceptional circumstances should cover the duration of the period by which the application is late, not just part of the period.<sup>38</sup>

Survey respondents also reported additional employment problems such as: feeling isolated or bullied; being overlooked for opportunities; a lack of understanding of the effects of cancer and its treatment among colleagues and employers; struggling to get through the day; and having no sick leave available.

Clearly, some people affected by cancer fear they will face discrimination in the future if they look for new employment. Many respondents suggested they would not disclose their cancer diagnosis or history to a new employer for fear of not being offered a role or of being treated differently, despite the discrimination protections in place.

The difficulties of obtaining financial relief either through early access to superannuation or government assistance programs were emphasised by several people in their responses to the questions about what could make things easier for people who are unable to return to work. We included a question about whether a new category of income support was required for people affected by cancer. The majority of respondents indicated that income support needs to be more readily available to people affected by cancer and pointed to the unique aspects of cancer and other long-term chronic diseases of uncertain prognoses. We recognise that there is a need for improvements to income support benefits and processes for people affected by cancer and other chronic diseases and will continue to explore this challenge in the next phase of the project.

The context of these issues is important. Fifty percent of Australian men and a third of Australian women will be diagnosed with cancer by the age of 85.<sup>39</sup> Although cancer remains a leading cause of death in Australia (around three in 10 deaths) the survival rate for many common cancers has increased by 30 percent in the past two decades; as screening services and treatment options improve, it is likely that people will be living longer with a cancer diagnosis.<sup>40</sup> As indicated by our survey results, many people choose to return to work after a cancer diagnosis, and/or treatment, but current approaches to facilitate a return to employment after cancer may not be sufficiently sensitive to cancer patients', survivors' or carers' needs. Employment



laws and policies will need to adapt to these needs to ensure equitable treatment for people affected by cancer.

Equally, as our survey indicated, some people will choose not to return to work, and therefore support and social services must be equipped to properly respond to the needs of this group.

### What measures are needed to reduce discrimination and other employment problems for people affected by cancer?

Regardless of whether people continued to work during treatment, returned to work after treatment, sought new employment, or chose not to or were unable to return to work, similar suggestions were offered as to how the law could respond better for people affected by cancer. While not all of the suggestions for what would make things better necessarily related to legal responses, there were some complementary common themes, including:

- the need for greater flexibility, including reduced or flexible hours or the ability to work from home;
- the need for more knowledge, understanding and sympathy regarding the effects of a cancer diagnosis and treatment among employers and colleagues;
- allowing a staggered return to work and full responsibilities—where this is needed and desired—which recognises the gradual recovery process.

It seems that tailored education and information for employers, people affected by cancer and their colleagues, could go some way towards reducing the problems that people face at work when diagnosed or being treated for cancer. It appears that in some workplaces there is either a lack of understanding of or compliance with anti-discrimination laws and the FWA. Employers, people affected by cancer and their colleagues need to know about the protections in place for people who need to take time off for treatment, and who may need reasonable adjustments made on their return to work. It would also be beneficial for employers and colleagues to understand more about the potential short and long-term effects of a cancer diagnosis and treatment on a colleague or employee. More understanding of employment law

frameworks and what to expect when a colleague or employee is affected by cancer may help to reduce stigma, bullying, the fear of disclosure, and discrimination, and has the potential to make workplaces more supportive.

In terms of the emphasis stakeholders placed on the need for more flexibility in the workplace, the existing protections in the anti-discrimination legislation at both the Victorian and Commonwealth levels should provide some support, if properly utilised. Employers must make reasonable adjustments to support people affected by cancer, unless this would cause unjustifiable hardship. Reasonable adjustments may well include allowing more flexible work hours and the opportunity to work from home, so long as the employee is still fulfilling the inherent requirements of the job. As outlined above, more understanding of the effects of cancer treatment, and education on the anti-discrimination protections and how they should apply in practice could assist employers and employees to reach mutually agreeable solutions.

Similarly, carers who have worked for their employer continuously for more than 12 months and who meet the definition of a carer in the *Carer Recognition Act 2010*<sup>41</sup> currently have the right to request a flexible working arrangement under the National Employment Standards (section 65 FWA). Results from our survey suggest that this option may not be known to many carers. Perhaps if more carers were aware of this right and employers were more aware of caring responsibilities, more flexible working arrangements could be established.

It is apparent from the responses to our survey—and perhaps implied from the small number of employment law cases related to cancer—that there are multiple reasons why people do not make formal complaints when they think that they have been treated unfairly at work. Respondents indicated that more support and more time is needed to encourage people with cancer to pursue employment complaints. Regardless of the ease and efficacy of complaints processes, many people may never complain about employment problems because of the need to maintain an ongoing relationship with an employer.

While the increased protections in respect of bullying, as of 1 January 2014, are encouraging, it is questionable how many people affected by cancer will avail themselves of the complaints mechanism, given the apparent reluctance to make formal complaints with respect to other employment problems (as demonstrated by the anecdotal evidence from our stakeholders, and the lack of evidence regarding formal complaints being made to human rights commissions, the FWC and the courts).

### Recommendations

Responses to the issues above will require a combination of law and policy reform, but mostly, research and evidence collection to more clearly define the problem, and an extension of support services for people affected by cancer. It is clear that there is still a limited understanding of the extent of the problem and a lack of support for people who do have a problem. Accordingly, our recommendations are for:

- Education programs for employers, people affected by cancer and their colleagues on:
  - The effects of a cancer diagnosis and treatment on an employee;
  - The experience of living with cancer;
  - The legal frameworks, rights and responsibilities that apply when an employee or potential employee is affected by cancer, whether personally or as a carer, and practical solutions to common problems.
- More research to accurately assess the extent and type of employment problems that people affected by cancer and their carers experience.

Furthermore, there is a case to be made for introducing more flexibility into the timeframes for making a complaint for an unfair, unlawful or general protections dismissal.

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# Insurance

In Australia, health insurance is provided universally under Medicare and supplemented by private insurance providers. Many people also elect to take out other policies such as life, travel, home and contents and income protection insurance. Medicare is the national health insurance scheme that provides free or subsidised health care services for people living in Australia.<sup>42</sup> Medicare funds most primary medical health care treatment, including by GPs or specialists, and treatment in public hospitals and also part-funds some private health services.<sup>43</sup> Medicare is funded by the Commonwealth Government.<sup>44</sup>

Private health insurance cover is also available and provides cover for services not covered by Medicare.<sup>45</sup> While private health insurance is not compulsory, people in Australia are encouraged to take out insurance through an income tested tax rebate for those people who take out cover. Additionally, people who earn above a threshold amount, and do not have approved hospital cover with a registered health fund, have to pay a Medicare levy surcharge.<sup>46</sup> Private health insurance is 'community rated', which means that an individual's risk is shared and equalised in a large pool of insured people. This means that everyone is entitled to the same insurance product at the same price, and insurers are not permitted to refuse insurance on the basis of a person's health or likelihood of claiming.<sup>47</sup>

Other forms of insurance, such as life and travel insurance are 'risk-rated' through the insurance underwriting process. Underwriting takes into account an individual's risk profile to ensure that the premiums paid by each policyholder reflect their risk relative to the whole pool. Cover is offered and premiums are set by making differentiations based on risk. In at least some cases, the presence of an illness or disability (or risk of illness or disability) including cancer, will increase an individual's risk, and the probability

that they will make a claim against their insurance policy. Many people elect to take out other forms of insurance and the inability to obtain cover can have important, broader implications for people.

Access to insurance (particularly life and travel insurance) was identified by CCV's Strategy and Support division, and colleagues from the McCabe Centre's European network, as an area of increasing concern for people who have finished active treatment for cancer.

Internationally, fears about people affected by cancer being denied insurance – in particular, being denied health insurance – have resulted in legislative responses in the US and UK. In 2008, the USA enacted the *Genetic Non-Discrimination Act*, which prohibits health insurance plans from requesting or requiring that a covered member or family member undergo genetic testing. In the UK, there is an agreement between the Association of British Insurers and the UK Government setting out broad principles for the use of genetic testing in insurance, and a moratorium on the use of genetic testing in specific circumstances.<sup>48</sup> According to the moratorium, individuals are not obliged to disclose the results of predictive genetic tests when applying for life insurance up to £500,000, critical illness insurance up to £300,000 or for income protection insurance of more than £30,000 per annum. Above these threshold amounts, insurers may ask, and customers must disclose, the results of a predictive genetic test, but only where the test is one that has been specifically approved by the UK Government.

In Australia, the availability of Medicare and of community-rated private health insurance policies means that people affected by cancer have broad access to public and private health insurance. However, access is more complicated in relation to risk-rated insurance policies, such as travel and life insurance policies, where a person's cancer diagnosis or history of cancer can affect their ability to obtain cover.

The *Disability Discrimination Act 1992* (Cth) (DDA) makes it unlawful to discriminate against a person on the grounds of disability by refusing to provide goods or services, including financial services and insurance. Because cancer comes under the definition of disability, and the DDA prohibits discrimination on the basis of a past, present, future or imputed disability, discrimination on the basis of a family history of cancer or genetic predisposition to cancer is prohibited. However, there is an exemption in the DDA in relation to risk-rated insurance policies and superannuation. This exemption allows insurers discretion to make reasonable distinctions when offering insurance policies; and for such distinctions to not be discrimination in accordance with the DDA.

In our issues paper, we outlined how the insurance exemption in section 46 of the DDA operates. This includes the requirement for insurers who refuse to cover, or modify an insurance policy for, a person affected by cancer to show that the decision:

- is based upon 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; or
- in a case where no such actuarial or statistical data is available and cannot reasonably be obtained – the discrimination is reasonable having regard to any other relevant factors.

In order to measure the effectiveness of the DDA's protection for people affected by cancer trying to obtain insurance cover, it is essential to find out if people are being denied insurance, and if so, on what basis. However, measuring the overall effectiveness of disability discrimination laws in protecting cancer survivors attempting to access insurance is difficult.

The case study in Box 1 is indicative of some of the anecdotal reports we have received in



the course of our work on this topic. In our issues paper, we noted that there have been few complaints under anti-discrimination law about discrimination in insurance on the basis of cancer. However, there have been only limited investigations carried out to determine if Australians affected by cancer are facing refusals of insurance cover; thus the key question for us was whether people with cancer, or with a genetic predisposition to cancer, are being unreasonably denied insurance cover.

We looked at two aspects of this topic: general issues about discrimination; and the implications of genetic testing for insurance. These will be dealt with separately below. Initially, this section of the issues paper examined issues relating to insurance and superannuation, however given there were few reported problems with people affected by cancer obtaining superannuation policies, and many more questions and feedback in relation to insurance issues, this section was reframed for the purposes of this report.

As with the stakeholder feedback for the employment section, feedback for this part of the report came via the online survey, and so the caveats identified in relation to the employment section feedback also apply here. Most of the respondents are likely to be women who have been diagnosed with breast cancer, as the survey was distributed to Breast Cancer Network Australia's (BCNA) Survey and Review Group. Again, as the time since diagnosis for most respondents is unknown, some of the policies and laws outlined in this section may not have applied, or may have changed in the time since respondents were diagnosed with cancer, or had their experience with obtaining insurance. We received additional feedback from other stakeholders about difficulties obtaining insurance; some of these comments have been included below.

“Life insurance and genetic test results: a mutation carrier’s fight to achieve full cover’ *Medical Journal of Australia* 2013

In September 2013 the *Medical Journal of Australia* published an article that described the experience of an Australian man who was refused insurance on three separate occasions on the basis of genetic information that he disclosed.<sup>49</sup> The man, in his early 20s and with a family history of cancer – which he had previously disclosed – was denied extended cover for cancer under an existing life insurance policy, after he revealed that he had discussed genetic testing with a genetic counsellor.<sup>50</sup> It was suggested that there was no actuarial or statistical data to justify this decision, and at most, should have only postponed the decision of the insurer until after the results of the genetic test.<sup>51</sup> The man was later tested and found to have an increased risk of Lynch syndrome (hereditary non-polyposis colorectal cancer).<sup>52</sup> Following this test, he applied to two different insurers for life insurance cover and was offered restricted cover that excluded cancer in both instances.<sup>53</sup> The man challenged the decision of the third insurer.

As noted above, the DDA requires insurers to use actuarial or statistical data in order to justify a decision to discriminate, or where such data is unavailable, to make a reasonable decision having regard to other relevant factors. Additionally, insurers are to take into account the benefits of special medical surveillance (as the man was willing to undertake) in accordance with the Financial Services Council's (FSC) Standards, which are compulsory for all FSC members.<sup>54</sup>

The man provided information to the insurers to show that, with regular health checks, he presented no greater risk than the risk in the average population.<sup>55</sup> He also asked for the actuarial evidence relied upon to justify the decision, but was never supplied with this evidence.<sup>56</sup> He complained to the AHRC and advised the third insurer of the same; following which, he was offered full cover by the third insurer. The authors noted that this response from the insurance company suggested that the company did not have actuarial data to justify its decision.<sup>57</sup> They highlighted the case study as an example of the ‘high level of initiative and proactivity required for a consumer to achieve a fair result.’<sup>58</sup>

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## Stakeholder feedback: Discrimination in insurance

### How significant is the problem of discrimination in insurance and superannuation for people affected by cancer?

Eighty-seven per cent (81 of the 93 people who responded to this question) thought that obtaining insurance cover is a problem for people affected by cancer. Around half of those who responded had personally experienced problems getting insurance because of a personal or family history of, or genetic predisposition to, cancer.

*I believe travel insurance has improved. I was demoralised when I was told that I was 'uninsurable' in terms of income insurance etc in the early days late 1990s, to the extent that I haven't followed it up.*

*Could be but I have chosen not to disclose this when applying for insurance. I have life insurance but took out this policy prior to diagnosis and too scared to change now to another provider in case my family lose the benefits.*

*Premiums go up and up, it's not fair, we don't know if the cancer will come back.*

*We have to declare our illness and are judged on this even though we are in remission. This adds to our stress of the cancer returning.*

*I travelled overseas recently and wanted medical insurance for when I was away. I couldn't get any because of my previous diagnosis. I want it to be that you can exclude certain illnesses from insurance, not just not get any at all. I would have loved to have general medical insurance that excludes any cancer related illness.*

*Difficulty getting travel insurance because of past breast cancer even when there was a small chance of re-occurrence and not something that would require immediate treatment while away.*

### Have you ever made a complaint about discrimination in insurance on the basis of current, past or an increased risk for cancer?

None of the respondents had made a complaint about discrimination in insurance. Sixty-four per cent indicated they have not

been treated unfairly as a result of being affected by cancer, while 36 per cent said they had been treated unfairly, but had never made a complaint. Although the majority of respondents indicated they had not been treated unfairly, it is not clear whether this means that discrimination is rare; this result may also indicate a level of acceptance by people affected by cancer of the status quo, or lower expectations of protection.

It may also be possible that people lack access to, or knowledge of, the relevant complaints mechanism. We asked people if they had ever made a complaint about discrimination in insurance on the basis of current, past or an increased risk of cancer, and if not, why not. Most people did not want the 'hassle'; others believed that they should not get cover.

*Because I would never win against a big multinational insurer. If they gave me a policy it would probably include so many restrictions that it was worthless anyway. So, decided against making a complaint because I do not trust the system.*

*To waste time and money making a complaint, didn't think me against the insurance company was going to work out to my advantage (or anyone else's). Plus with cancer you don't have the energy to fight those sort of battles...likely to spend whatever energy on things that add to wellbeing not subtract!*

*I do not believe I will get anywhere. I do not want to go through another stressful situation. It will be very costly exercise financially and emotionally. It is acceptable norm to reject cancer survivors.*

### Do you think the law about unfair treatment in insurance, and the exception that lets insurance companies treat people differently according to their health risks, needs to be changed?

As noted above, the law allows for the differentiation between someone with cancer and someone without for the purposes of risk rated insurance policies, but stresses that if such a distinction is drawn, then it should be evidenced through statistics, and not anecdote. However, many respondents felt that insurance providers had limited understanding of the implications of living with cancer.

*With advances in medical treatment, cancer is not necessarily a death sentence. So, insurance companies should review their policy regarding cancer survivor applicants.*

*People who have had cancer, or are of an increased risk don't necessarily get cancer. One can pass from many things in life, with or without cancer/and or risks. Because you cycle to work, should you have to be insured or excluded from insurance?*

*A family history does not mean that member will get that disease. Insurance companies have too much leeway to opt out of payments.*

Some people suggested that they understood the challenges that insurers face when considering cover for someone with a history of cancer:

*I can understand the insurance company's point of view. They are in a business but cancer is often not caused by decisions a person makes, so it is hard to be penalised for something I have no control over. How relevant are the health risks? Do smokers or illegal drug users suffer the same as cancer sufferers? It is assumed a cancer sufferer will die early, I guess, but with current survival rates is this relevant.*

*Usually the little person against insurance companies isn't a fair match and in so many legal situations trying to get fairness from the law is a very demanding task and not for someone who is unwell or lacking in resources- however, there has to be some protection of the company and other policy holders if someone is an enormous risk. Maybe a small increase in premium and limits to payouts might be a reasonable course of action.*

### Do you think that changes are required to complaints processes to help people affected by cancer to make complaints about unfair treatment in insurance?

Most respondents (80 per cent) thought that changes were needed to the complaints process to help people affected by cancer make complaints about unfair treatment in insurance.

When asked what sorts of changes were required, respondents asked for the correction of perceived power imbalances, to 'stop making people feel intimidated'.

Other respondents suggested:

*As for other discrimination complaints, a 'cancer sensitive' and aware advocate.*

*Insurance companies can't just take your money for policies when you are healthy. There needs to be a fairer system to allow those who have had cancer in the past, (say cancer free for at least five years), to be able to take out standard insurance, and if they can't there needs to be an ombudsman to complain to.*

*Risk assessments of cancer patients seeking insurance should be conducted by an independent and informed third party.*

A number of respondents also wanted more information about where to complain.

### Genetic testing and insurance

A component of the discussion on access to insurance focused on the implications of genetic testing and the prospect of genetic discrimination. The key concerns in relation to genetic testing are that:

- Very few current genetic tests are actually predictive and guarantee a specific outcome, for example, disease. Most genetic tests can only indicate, at best, increased susceptibility for particular conditions.
- People may be discriminated against purely on the basis of a family member having a heritable genetic condition.

As noted in the issues paper, Australians are protected from discrimination in the DDA on the basis of a past, present, possible future or imputed disability. The exemption which allows for reasonable distinctions (discussed above) also applies in relation to applicants who have had a genetic test, or a family history of cancer, which may indicate an increased risk of cancer. Therefore, where a genetic test indicates a higher risk of cancer, insurers may charge a higher premium or change the terms under which they provide cover (in the same way as if insuring someone with a history of cancer), but only if there is sound actuarial and other relevant statistical data to underpin the decision.

Predictive genetic testing is currently available for a limited, but increasing number of inherited conditions including some cancers, for example, hereditary breast cancer, ovarian cancer and

Lynch syndrome.<sup>59</sup> In time, advances in technology and genomics may lead to more – and increasingly sophisticated genetic tests. However, there are limitations to genetic test results. Sometimes results can provide guidance only; results may be unclear; or give false impressions. A genetic test result can only give an indication of increased risk, and can't predict what will happen to a person.<sup>60</sup>

### 'Essentially Yours': Australian Law Reform Commission Report

In 2003, the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee of the NHMRC examined an extensive range of activities in which genetic information plays an important role, including in relation to insurance.<sup>61</sup>

The report, 'Essentially Yours', tabled in May 2003, made 144 recommendations about how Australia should deal with the ethical, legal and social implications of genetic information and testing. Four of the recommendations related to an insurer's duty to disclose reasons for unfavourable decisions made on the basis of genetic information (although the ALRC noted that the rationale for providing reasons applied also to other cases of unfavourable decisions, and not just those using genetic information).<sup>62</sup>

Submissions to the ALRC highlighted a lack of transparency and accountability to the public in relation to risk assessments using genetic information.<sup>63</sup> As noted above, a decision to refuse or modify the terms of insurance may be discriminatory if an insurer cannot point to relevant actuarial or statistical data supporting the decision. However, although individuals can request written reasons for an unfavourable decision, including where genetic information has been disclosed, it is not clear from the legislation whether an insurer is obliged to provide the actuarial or statistical data relied upon in making the decision.<sup>64</sup> Often, an applicant is able to gain access to this information only after lodging a complaint with a human rights commission, but not before – a position which diminishes an individual's capacity to assess a decision before determining whether to challenge it under anti-discrimination legislation.<sup>65</sup> It was submitted

that consumers should have the right to access sufficient information about the basis for an insurer's decision, including actuarial or statistical evidence, without having to first lodge a complaint with the AHRC.<sup>66</sup> The Inquiry accepted that some of this actuarial and statistical evidence was likely to be commercially sensitive; but also, and more importantly, this evidence would be personally sensitive to some people because of the inclusion of data about expected morbidity and mortality.<sup>67</sup>

These sensitivities notwithstanding, the ALRC recommended the following improvements to disclosure requirements:

- Amending the *Insurance Contracts Act 1984* (Cth) (ICA) to include disclosure requirements for decisions based on genetic information, that include clear and meaningful reasons and that explain the actuarial, statistical or other basis for the decision.
- The Financial Services Council and Insurance Council of Australia to develop policy guidelines for members that outline how applicants are to be informed of unfavourable decisions, including informing applicants of their statutory entitlement to reasons for an adverse underwriting decision.

The Government responded to the report in December 2005.<sup>68</sup> In its response the Government agreed that clear and meaningful reasons should be provided to those denied insurance.<sup>69</sup> However, it was proposed that the best way to facilitate this was through appropriate industry body policies, rather than an amendment to the ICA.

### Stakeholder feedback

The issues paper sought input from stakeholders with regard to their concerns about, and experiences of problems getting insurance due to a genetic test or a family history of cancer, and how that affected their views of genetic testing.

We asked if people had ever considered genetic testing to learn if they have an increased risk for cancer, and (separately) if people had undergone a genetic test for cancer predisposition. Fifty-four per cent of respondents (56 of the 103 respondents to this question) had considered genetic testing to find out if they have an increased

risk of cancer. Forty-six per cent had not considered genetic testing for cancer; of this group, 30 per cent didn't have a strong family history for cancer while 16 per cent did have a strong family history.

Thirty-nine per cent (29 of the 75 respondents who answered this question) had actually had a genetic test for cancer.

### **How did the possibility of having problems getting insurance affect your decision whether or not to have genetic testing for increased risk to cancer?**

The majority of respondents (82 percent or 59 of the 72 respondents to this question) said that the possibility of having problems getting insurance did not affect their decision whether or not to have genetic testing for increased risk of cancer. For some respondents, the primary concerns around genetic testing and insurance related to the impacts on their families, including their children, in the future. Others were concerned that a positive test would mean that they could never be insured.

*If the genetic testing shows I have an increased risk of cancer then this may influence decisions insurers may make about my children. I worry about the flow on effect. My children are aware and take care of themselves with regular checks but the flow on effect does concern me.*

*I was worried a positive test would make cover impossible to get.*

### **Why did the possibility of having problems getting insurance not affect your decision whether or not to have genetic testing for increased risk to cancer?**

Most people did not think that the possibility of having problems obtaining insurance had affected their decision whether or not to have genetic testing.

*Have strong family history for the cancer I have. Felt it was more important to know, and have the possibility of some treatment to affect the outcome of a familial cancer. Didn't see having genetic testing, and then difficulties with insurance as an impediment to the testing.*

*The potential information it can provide me and other family members is important to me.*

*Because I wanted to do the test for my children's future.*

*More important to me to see if there were going to be any family issues, not bothered about the insurance side.*

### **Meetings with the Insurance Council of Australia**

We met with a representative from the Insurance Council of Australia and were invited to present the insurance section of our issues paper during a teleconference with the Insurance Council and leading insurers.

We discussed the approach taken by insurers when assessing risk in relation to people affected by cancer. Attendees confirmed that they look at a range of factors including actuarial data, but also take into account direct previous claims experiences. Insurers we spoke to confirmed that they differentiate between different cancer streams, and apply separate guidelines depending on the type of cancer, due to different risk profiles. Insurers also confirmed they take a case by case approach to each person affected by cancer, including taking into account how long ago the person was diagnosed, whether they're receiving treatment, and whether they're in remission.

### **New disclosure rules for some insurance contracts**

In June 2013, the ICA was amended and new duty of disclosure requirements for 'eligible contracts of insurance' were introduced, to come into effect in 2015. Eligible contracts of insurance include travel, motor vehicle, home contents, consumer credit, and accident and sickness insurance. Life insurance is not an eligible contract of insurance, within the definition in the *Insurance Contracts Regulations 1985*.<sup>70</sup>

Pursuant to the ICA, insurers are required to ask insurance applicants specific questions that are relevant to the insurer's decision to offer insurance protection, and on what terms.<sup>71</sup> Prior to the June law change (which comes into effect in 2015) insurers

were also permitted to ask 'catch all' questions, designed to capture any other items relevant to their decision whether to enter the contract of insurance.<sup>72</sup> Applicants were obliged to disclose 'exceptional circumstances':

- a. that a reasonable person could be expected to know what would be relevant to the insurer's decision whether to accept the risk; and
- b. which would be unreasonable for the insurer to ask a specific question about.<sup>73</sup>

A review of the ICA recommended this 'catch all' provision be removed because it imposed an unreasonable burden on applicants to know what the insurer regarded as relevant.<sup>74</sup> Furthermore, it was argued that insurers are in a better position to decide what matters are relevant to their decision to provide insurance, and to formulate specific questions accordingly.<sup>75</sup>

As a result of the law change, an insurer will no longer be able to ask 'catch all' questions when assessing cover under an eligible contract of insurance, and must ask specific questions relevant to the decision whether to accept risk, and if so, on what terms.<sup>76</sup> In practice, this will mean that insurers are no longer allowed to ask non-specific questions – an example of which might be a question about 'any other disorder or impairment'. The new law also applies to renewals, where insurers can either ask a policy holder, before renewal, to answer specific questions; or insurers can ask the policy holder to confirm or update previous information disclosed. There will be no duty to disclose beyond these two options on renewal.<sup>77</sup>

Life insurance policies are still subject to the general provisions regarding the duty of disclosure in section 21 of the ICA, which is to say that an insurance applicant is required to disclose matters that are known or should be known to the insurer.<sup>78</sup>

The effect of these changes is likely to be seen in more detailed application processes for eligible insurance contracts. There is a further question about the relationship between the new duty of disclosure requirements for eligible contracts, and the overarching good faith principle for all insurance contracts, which may not be answered until tested in court.

## Reflections

It was clear from the responses to our survey questions that many people find it difficult to obtain insurance following a cancer diagnosis and treatment. As survival rates improve, and people live longer after a cancer diagnosis, more people will be affected by cancer; as such, we would expect that more people will be affected by laws and policies which govern access to insurance.

However, the level of concern expressed about insurance discrimination in the literature and from the stakeholders who participated in our survey, is not reflected in the number of complaints to the AHRC or the Victorian Equal Opportunity and Human Rights Commission. This is not to say that insurance discrimination is not an issue; many of the survey respondents indicated that for some people it is a challenge simply to muster the energy or motivation to complain, or for people to understand how to make a complaint and where.

Some of the later stakeholder feedback indicated that some people may have decided not to disclose a history of cancer when approaching another insurance provider, for fear of being refused again.

It is also possible that insurers differ in terms of their approach to insuring people affected by cancer. Large insurers are likely to be in a better position to absorb the risk-related costs. The Bassanelli case (see Box 2.) may have had a positive impact on availability of travel insurance for cancer patients. This case also established that it is not lawful for smaller insurers to refuse cover purely on the basis of financial hardship.

In our survey, respondents highlighted some of the challenges to making a complaint:

*How do we navigate all the different mechanisms for making complaints now? Unless you know the system it does not happen. Complaints relating to health – whether work, insurance, home loans or anything else ought to have one central point e.g. the ombudsman. This needs to be part of the information provided during treatment - someone to go through all the 'stuff' that is handed out and highlight what might apply individually would make this information more useful to people who are sick or caring for someone who is sick.*

### Denise Bassanelli: *QBE Travel Insurance v Bassanelli*

In one of the leading cases on this topic, *QBE Travel Insurance v Bassanelli* (2004), the Federal Court upheld the protection from discrimination in insurance in the DDA. Ms Bassanelli was declined all travel insurance cover by an insurer on the basis of pre-existing metastatic breast cancer. The Court found that the insurer had not acted reasonably in coming to the decision to decline cover, and further held that a person cannot be discriminated against for having a pre-existing condition – in this case, cancer – when the insurance sought did not relate to the condition, and where the insurer had not based its decision to discriminate on relevant factors.

This case featured in a presentation we delivered on this topic at the Flinders Centre for Innovation in Cancer Survivorship Conference in Adelaide in February 2013, and in our issues paper. Later, we were contacted by Denise Bassanelli, who had brought the action. She emailed us after her oncologist attended the presentation in Adelaide, and said:

*I am glad that my legal precedent is still being kept alive in the public arena through presentations like yours. I continue to get emails from other women with breast cancer about troubles they have in obtaining travel insurance.*

We were able to discuss the effect of the court case on Denise and her family, and share with her some of the work we are doing in this area to assist other people affected by cancer, who are unable to get insurance. Sadly, Denise passed away from cancer on Thursday, 30 May, 2013.

How do we navigate all the different mechanisms for making complaints now? Unless you know the system it does not happen. Complaints relating to health – whether work, insurance, home loans or anything else ought to have one central point e.g. the ombudsman. This needs to be part of the information provided during treatment – someone to go through all the ‘stuff’ that is handed out and highlight what might apply individually would make this information more useful to people who are sick or caring for someone who is sick.

(stakeholder feedback)

Respondents requested help to make the process easier for people affected by cancer:

Anything that makes life easier for the patient/carer to deal with. The news of a life threatening condition is enough to test the best of people, let alone those who are coping with something like cancer. Like most patients, upon learning of my diagnoses of cancer, I was more intent on daily survival rather than how I was going to be treated with regards to any insurance issues.

The availability of robust actuarial and statistical data to assist insurers making decisions about people affected by cancer has been raised on more than one occasion – in the ‘Essentially Yours’ recommendations, in case law, and in published commentary. In relation to genetic testing, the paucity of data is compounded by low awareness of the usefulness of genetic tests for insurers and lack of policy guidance about how genetic tests are to be used in underwriting insurance.<sup>79</sup>

Of concern is that we are still hearing stories of people being denied insurance based on inadequate data, or with no reasons given whatsoever. Otowski’s 2013 paper documents one such occurrence of this, and responses to our issues paper suggest others have been similarly affected.

In this respect, we support the recommendations of the ‘Essentially Yours’ report, to clarify the right to information from insurers for people who have received an adverse decision based on genetic information. Under section 75 of the ICA individuals may request, in writing, written reasons for an adverse decision; however it is unclear whether this right to information includes an entitlement to details of the actuarial, statistical or other data relied on by the insurance company. Currently, the only guaranteed way for a person to access this data is to lodge a complaint with the AHRC; this triggers the operation of section 107 of the DDA under which the

AHRC can require an insurer to disclose to the Commission the source of the actuarial or statistical data on which a decision was based. In ‘Essentially Yours’ it was noted that this is an unduly onerous and impractical approach – particularly when the availability of this information may be influential for a person deciding whether or not to bring proceedings under the DDA (or equivalent state or territory legislation).<sup>80</sup>

We support the ALRC’s recommendation to clarify the right to information, and support extending this right to others who receive an adverse decision, whether or not it is based on genetic information, and taking into account the sensitivities associated with this information. Greater transparency in information would hopefully encourage the collation of relevant information to inform decisions, but also inspire greater confidence in cancer patients affected, who at the moment, perceive they will not be treated fairly (whether or not this is in fact the case). Access to reasons without having to lodge a discrimination complaint would also assist to educate consumers about what is permissible differentiation, and what is unlawful discrimination; and to better facilitate the ability for people to obtain reasons for an unfavourable decision.

Genetic testing for cancer susceptibility is a relatively new phenomenon, which is likely to increase as technology improves. Currently, discrimination on the basis of genetic information seems to be limited; and very few respondents to our survey said that they would not get a genetic test for fear of how this information might be used for insurance purposes. However as noted in the Australian Medical Association’s (AMA) position statement on genetic testing, ‘[i]n order for the community to accept and embrace genetic testing, it’s important to minimise the real and perceived risk of genetic discrimination; otherwise, individuals might forego beneficial genetic testing due to fear of discrimination.’<sup>81</sup>

## Recommendations

The issues identified above will require responses based on stakeholder engagement, education and information to drive law reform where required, as well as support for policy and attitudinal changes. The path forward includes reform of insurance contract laws to allow better access to information about individual decisions, and education and information to assist people to understand the implications of these decisions, and their right to complain.

Future work will be undertaken on this topic to:

- support specific areas of law reform in relation to insurance contracts to require insurers to give detailed reasons, including where appropriate, details of actuarial or statistical data relied on in adverse decisions;
- educate people affected by cancer to understand and use the protections in 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.

The issues paper looked at the potential impact of the Human Rights and Anti-Discrimination Bill 2012 for people affected by cancer – specifically in relation to current protections against genetic discrimination. While the Draft Bill retained the protection from discrimination on the basis of having had, or possibly having in the future one of the attributes protected by the Bill (including disability)<sup>82</sup>, an explicit reference to past or possible future (included because of a genetic predisposition) disability was removed from the scope of the disability definition. Progress on the draft bill has stalled, and it is unclear whether it will be introduced in the new Parliament.

# End of life decision-making

I think people often have difficulty accepting the reality when cancer is rapidly progressing towards death. To talk about it and write it down well before this happens is in a way preparing everyone for the end. Sort of summarising the completion of life on the basis of how the life has been lived. (Respondent to the online survey)

## Background

Planning for the end of life can be valuable for all members of the community, whether or not a person has cancer. Clearly expressing and recording wishes and directions – in addition to appointing a substitute decision-maker for when a person loses capacity to make his or her own decisions – can improve end of life care and increase the likelihood that a person’s family, carer and healthcare team can make decisions that they feel confident are in accordance with the person’s preferences and best interests.<sup>83</sup>

Advance care planning is the general term for the process of planning for a person’s future health and personal care to guide decisions if they become unable to communicate or to make their own decisions. The law facilitates advance care planning in two ways, through:

- **Substitute decision-making**, which provides the means for a substitute to make decisions in relation to healthcare and other matters when a person is no longer competent to make their own decisions; and
- **Advance care directives**, which document the decisions about medical care a patient would or would not choose in the future, if they become unable to make their own decisions. While directives usually record decisions about refusing life-sustaining treatments, they are not restricted to end of life decision-making.<sup>84</sup>

Ideally the development of advance care directives and the appointment of substitute decision-makers occur together, through exploration and discussion of values and

desired outcomes, between the person affected by cancer, their family and relevant health professionals. As well as being a beneficial process generally, this increases the likelihood that patients’ recorded wishes will be understood and adhered to.

In Australia, laws relating to advance care planning mechanisms can differ greatly between states and territories, which can lead to confusion and drastically different outcomes for patients depending on which jurisdiction they are in.<sup>85</sup> In particular, the legal regulation of advance care directives differs vastly from state to state, and there is uncertainty about the recognition of common law advance care directives in Victoria and Queensland.<sup>86</sup>

The legal framework around substitute decision-making – for situations when a patient is unable to make a treatment decision for themselves – differs significantly from state to state, and indeed, within states. In Victoria for example, two decision-makers may be appointed by a competent adult (enduring guardian and an agent), and the powers of each are governed by different but overlapping pieces of legislation.<sup>87</sup>

Advance care planning and end of life decision-making can be confusing processes, even within Victoria alone, due to the range of possible substitute decision-makers (with varying levels of authority) as well as the unclear legal status of advance care directives.

This part of the project aimed to explore the impact of the divergent legal frameworks and the range of advance care planning options on the knowledge and experiences of Victorians affected by cancer, their carers and health professionals; and make appropriately informed recommendations for law reform.

## Advance care directives in Victoria

The issues paper discussed the equivocal legal status of advance care directives in Victoria. The *Medical Treatment Act 1988* (Vic) (‘MTA’) provides a statutory right for a



### Substitute decision makers for medical decisions in Victoria

- **Enduring power of attorney (medical treatment)** appointed by the person concerned, pursuant to section 5A and Schedule 2 MTA:
  - Authority to consent to and refuse treatment on behalf of the patient.
  - Can refuse treatment if the medical treatment would cause unreasonable distress to the patient or there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and well-being, would consider the treatment unwarranted.
- **Enduring guardian** appointed by the person concerned, pursuant to section 35A *Guardianship and Administration Act 1986* (the GAA):
  - Authority depends on the nature of the appointment and the capacity of the concerned person but can include powers in relation to health care, and power to consent to medical treatment.
  - If the instrument does not specify powers, an enduring guardian has all the powers of a plenary (section 35B GAA) (see below) – but enduring guardians are not authorised to refuse medical treatment under the MTA.<sup>89</sup>
  - If an enduring guardian withholds consent to medical treatment the health professional can accept the decision or notify the guardian and the Office of the Public Advocate (the OPA), within three days of consent being withheld, of the intention to treat and advise the guardian that they can apply to the Victorian Civil and Administrative Tribunal (VCAT) if they want to prevent the treatment (sections 42L and 42M GAA). The enduring guardian and other interested parties may apply to VCAT for an order as to whether the treatment should go ahead (section 42N GAA).
- **Plenary guardian** appointed by VCAT, pursuant to sections 22(1) and 24(1) GAA:
  - Only appointed if not sufficient to appoint guardian with more limited powers;
  - Has all the powers and duties which they would have if they were a parent and the represented person was a child, which means they are able to refuse treatment on the person concerned's behalf (as plenary guardians are under an appropriate order for the purpose of section 5A of the MTA).<sup>90</sup>
- **Limited guardian with power to make decisions about medical treatment**, appointed by VCAT pursuant to section 25 GAA:
  - Such orders may be broad enough to empower a limited guardian to refuse treatment under the MTA.<sup>91</sup>
- **Limited guardian with power to consent to health care**, appointed by VCAT pursuant to section 25 GAA:
  - More limited authority than a guardian who has authority to 'make' decisions about medical treatment;
  - Cannot refuse medical treatment pursuant to the MTA;<sup>92</sup>
  - If a limited guardian withholds consent to medical treatment the health professional can accept the decision or notify the guardian and the OPA, within three days of consent being withheld, of the intention to treat and advise the guardian that they can apply to VCAT if they want to prevent the treatment (sections 42L and 42M GAA). The limited guardian and other interested parties may apply to VCAT for an order as to whether the treatment should go ahead (section 42N GAA).
- **Person responsible**, pursuant to section 37 GAA, includes all of the appointees above. When there are no appointees, and the patient lacks capacity, the person responsible is the first of the following who is reasonably available, willing and able to make the relevant decisions: spouse or domestic partner; primary carer; or nearest relative.
  - Can consent to medical treatment, but not refuse medical treatment.
  - If a person responsible withholds consent the health professional can accept the decision or notify the guardian and the OPA, within three days of consent being withheld, of the intention to treat and advise the guardian that they can apply to VCAT if they want to prevent the treatment (sections 42L and 42M GAA). The person responsible and other interested parties may apply to VCAT for an order as to whether the treatment should go ahead (section 42N GAA).



patient or their agent to make a refusal of treatment certificate in respect of medical treatment generally or treatment of a particular kind, for a current condition only (sections 5 and 5A).

Similar legislation in other Australian jurisdictions provides for *advance refusal* and *consent* to medical treatment and allows directions about treatment for future conditions, and not just a current condition.

It is unclear whether a broader advance care directive (for example a directive which encompassed treatments a person would or would not want in respect of potential future conditions or circumstances) would be recognised at common law in Victoria. Tending towards recognition, such a right has been recognised in NSW and the MTA appears to preserve common law rights generally (section 4). The current uncertainty can leave carers and health professionals in difficult circumstances when a patient is unable to communicate or make their own decisions.

Another complexity in the Victorian scheme for refusing treatment is that the MTA excludes palliative care from the definition of 'medical treatment' for the purposes of the Act. Palliative care is defined as the provision of reasonable medical procedures for the relief of pain, suffering and discomfort or the reasonable provision of food and water. The exclusion has the effect that agents cannot refuse palliative care or food or water on behalf of a patient. Notably however, the Supreme Court of Victoria has ruled that *artificial* feeding does not fall within the definition of palliative care, and constitutes medical treatment which can be refused under the Act.<sup>88</sup>

The variability in name, form, scope and legislative prescription of advance care directives across Australia makes it difficult for jurisdictions to recognise directives made in other states and territories, which may result in further distress at an already distressing time.

### Substitute decision-makers in Victoria

There is a wide range of possible substitute decision-makers in Victoria who may be appointed to make decisions on behalf of people who have lost capacity to communicate or make their own decisions. Some substitute decision-makers have the authority to refuse medical treatment on behalf of a patient, while some can only provide consent to treatment. Carers, guardians, people with powers of attorney and health professionals need to be aware of the authority that each substitute decision-maker has, in order to ensure that treatment decisions are made with lawful and appropriate consents or refusals.

Uncertainty about who has the power to make which decisions in respect of a patient when they lack capacity can result in delay when life and death decisions need to be made and anguish for carers and health professionals. Arguably, the right to refuse treatment – including feeding – needs to be more clearly defined in Victoria, particularly in respect of patients who are not competent to make decisions for themselves. A lack of clarity around the right to limit or refuse treatment in end of life situations may result in patients being given aggressive therapies instead of palliative care.

### The Victorian Law Reform Commission recommendations

To deal with the uncertainties in the scope and application of advance care directives and the authority of various substitute decision-makers, the Victorian Law Reform Commission (the VLRC) has recommended areas for law reform (see Box 3. for more detail).<sup>93</sup>

In line with the Respecting Patient Choices Program advice, the VLRC also recommended that people be encouraged to: write instructional directives in outcome-based terms, recording their personal values, ethics, religious and cultural beliefs, wishes and life goals, where relevant; and to discuss their instructions, wishes and values with their family and treatment team.<sup>94</sup>

### VLRC recommendations

Permitting competent people to plan for future decision-making in three ways, through:

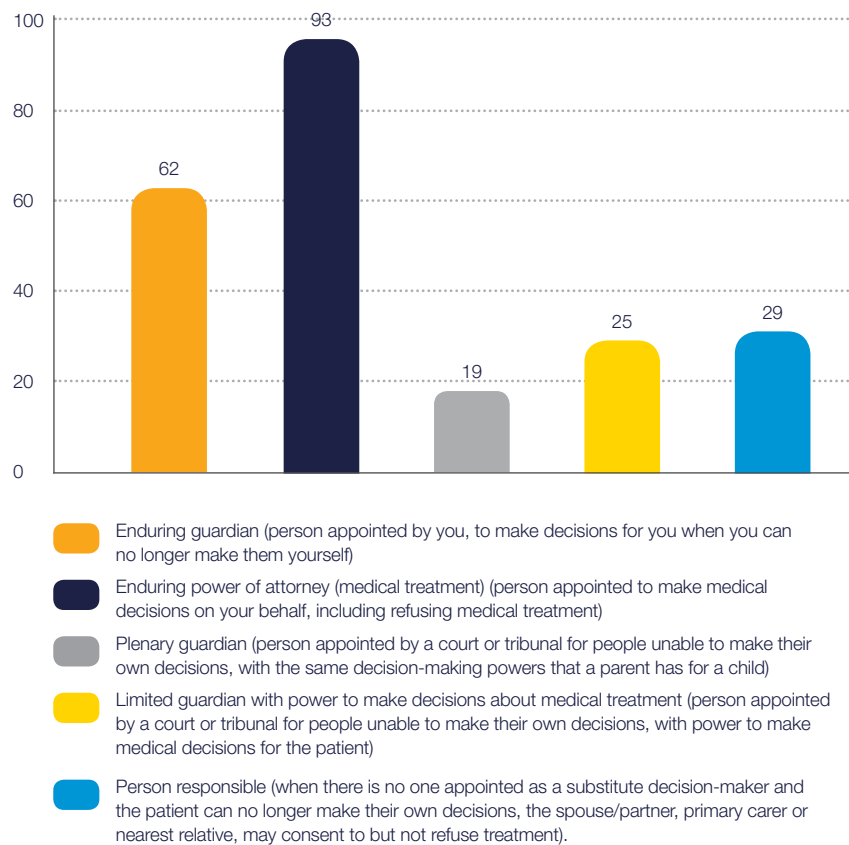
- Appointing an enduring personal guardian with no instructions about the exercise of their decision-making powers;
- Appointing an enduring personal guardian with instructions about how to exercise their decision-making power;
- Making a stand-alone 'instructional directive'.

Replacing 'refusal of treatment certificates' with a statutory scheme that provides for binding 'instructional health care directives' (in prescribed form) to be made in a broader range of circumstances, including directives about future as well as current conditions, and the provision of advance consent (in addition to advance refusal).

Instructional directives should be able to provide binding or advisory instructions about health matters (and advisory instructions about personal and lifestyle matters, which should be followed where reasonably possible but should not be legally binding).

An instructional directive should be binding on healthcare providers and substitute decision-makers if it is valid and the direction operates in the circumstances that have arisen. Circumstances in which a direction may not operate relate to advances in medical science, uncertainty in the directive, and persuasive evidence that the direction is based on incorrect information or assumptions. Where there is a question about whether the instructional directive is valid or applicable, a healthcare provider, substitute decision-makers or any person with a special interest in the patient's affairs could apply to VCAT to make a determination about the effect of the directive.

**Figure 4:** Which of the following types of substitute decision-makers are you aware of?



### Should there be a right to demand treatment?

Health professionals report that patients, their family members or medical colleagues requesting ‘futile’ treatment on behalf of a patient, can give rise to one of the most common disputes in palliative care and end of life treatment. By law, health professionals are not obligated to provide treatment to a competent patient where the health professional deems that treatment would be futile. They are also not obligated to provide futile treatment to a patient who has lost capacity to communicate or make their own decisions, even when such treatment is demanded by a substitute decision-maker.<sup>95</sup> In *Slaveski v Austin Health*<sup>96</sup> the Supreme Court of Victoria stated:

*there is undoubted jurisdiction in this Court to act to protect the right of an unconscious person ... to receive ordinary, reasonable and appropriate as opposed*

*to extraordinary, excessively burdensome, intrusive or futile medical treatment, sustenance and support. What constitutes appropriate medical treatment in a given case is a medical matter in the first instance. Where there is doubt or serious dispute in this regard the Court has power to act to protect the life and the welfare of the unconscious person.*<sup>97</sup>

The issues paper asked stakeholders if there is sufficient clarity in practice around whether there is a legal right to demand treatment that health professionals deem futile, and whether there should be a right for people affected by cancer (or their substitute decision-makers) to demand such treatment.

### Stakeholder feedback

Before providing details about the specific types of advance care directives and substitute decision-making appointments available in Victoria, we asked survey

respondents whether they were aware of the advance care planning options available in Victoria. Many respondents indicated that they weren’t aware of the available options, and some indicated that they would like to know more.

When asked about awareness of refusal of treatment certificates and advance care directives, roughly even numbers of respondents indicated that they were aware of each (37 and 35 respectively).<sup>98</sup> Several respondents indicated that they were not aware of either of these options.

When asked specifically about which of the five types of substitute decision-makers respondents were aware of, the highest number (93) were aware of enduring powers of attorney (medical treatment).

More respondents (40) indicated that they had appointed an enduring power of attorney (medical treatment) than the number (18) who indicated that they had appointed an enduring guardian to make their medical decisions should they lose competence.<sup>99</sup> For some these appointments were seen as a natural addendum to making a will. Several respondents indicated that they hadn’t gotten around to appointing a substitute decision-maker ‘yet’.

Other comments included:

*I have always thought I was still too young for this!!!*

*Husband and I did one for each other about two weeks before he had a major stroke. They are very worthwhile and should get more publicity e.g. radio and TV campaigns.*

*Am not sure of the specifics of this application in Vic, as I am originally from Sth Aust, but am aware of the type of guardianships/powers etc that usually apply to those in a position of deciding what is best for a cancer or similar patient.*

### Are there limitations to the refusal of treatment certificate process in practice?

Just four respondents indicated that they had completed a refusal of treatment certificate, and just nine had completed an advance care directive.<sup>100</sup> It is unsurprising that a higher number had completed an advance care directive, given refusal of treatment certificates can only be made in

the limited circumstances outlined above (to refuse treatment for a current condition). Five respondents commented that they had not recorded their advance care wishes in writing 'yet'. A further four respondents said that they had had discussions with family or the person whom they've appointed as a substitute decision-maker, but had not formalised these discussions in writing.

### Do health professionals require further education about legal issues in end-of-life decision-making?

The majority (76 of 104) of respondents to our survey question thought that health professionals need more information and education about rights and responsibilities at the end of life. Some respondents commented that they did not know the current state of knowledge of health professionals in this area. Many of those who commented as to why health professionals need more information and education on rights and responsibilities at the end of life suggested that this would result in more informed patients.

*Because it's not something that's routinely offered.*

*To be able to offer assistance to people who find themselves in this position, or so that at least have enough information to be able to direct people in the right direction for assistance for these matters.*

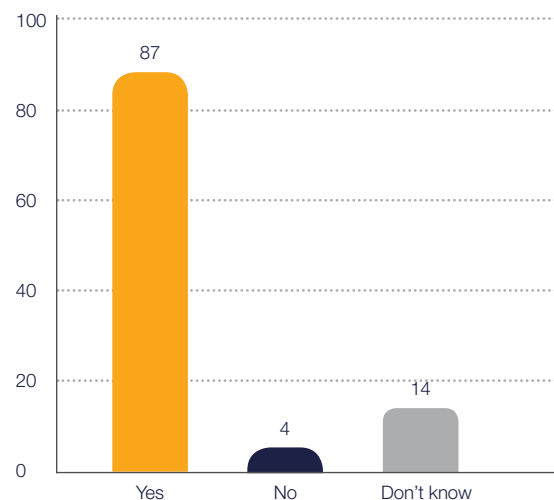
### How can people affected by cancer, their families and health professionals be better informed about rights and responsibilities at end-of-life?

The majority (87 of 105) of respondents to our survey question indicated that people affected by cancer and their carers also need more information and education about rights and responsibilities at the end of life.

Many respondents said that more information and education was needed because they personally had not heard about these advance care planning options before completing the survey, and they surmised that many others hadn't either. Some respondents saw information as power and as key to being able to plan and prepare for the future.

*Information gives back some of the control that cancer and the medical system takes away.*

**Figure 5:** Do people affected by cancer and their carers need more information and education about advance care planning?



*Cancer is not something you plan for getting so when it happens it is all a surprise and you know nothing and are in an unbalanced state to find out.*

Two respondents indicated that they felt that this type of information was just as important, if not more so, for the public generally, as it is for people affected by cancer.

*Everyone does, not only cancer patients.*

*A cancer diagnosis medically is unlikely to lead to a prolonged cause of life support in my understanding, even with distraught family. However we are no more immune to a nasty car accident and head injury than others, so it's probably good to do.*

Some respondents cautioned that end of life decision-making is not something that people affected by cancer necessarily want to think about and therefore information and education needs to be provided sensitively.

*It's something most people prefer not to think about.*

*We try to focus on the positive and beating the cancer. I try to move forward rather than concentrating on the fact that I might die.*

*Yes, but it needs to be done in a sensitive way – some people may take it as a sign they are dying, rather than sensible financial and medical advice.*

*I think it could be terribly wearing an item of information. There are so many other things to think about. ... I do think it's more troubling for people with cancer, however the right support would probably help.*

### What are the key issues for people affected by cancer in relation to the VLRC's recommendations on reforms to guardianship laws?

We outlined the VLRC's recommendations with regard to advance care planning (as included above in this report) in the online survey. We asked respondents for their thoughts on the recommendations, and in particular, whether they thought they would be helpful for patients, their families and health professionals. Almost all of the 65 respondents who commented expressed support for the recommendations. Comments indicated that respondents thought the proposed new arrangements for advance care planning would reduce uncertainty for substitute decision-makers and health professionals and increase patient confidence that their wishes would be adhered to should they lose capacity to communicate and make their own decisions.

*Required urgently so that people can make their own decisions.*

*It would be helpful and help to avoid conflict at a crucial time when relatives disagree.*

*Advance care directive is a decisive clear cut direction that the patient wishes to take and should be followed to the letter. No guardian or family member should be able to change or override the patient's care plan.*

*I think they look good. There is an option for those who want control and those who don't. I assume it isn't compulsory to have anything in place!*

*Spelling it out has to be helpful as waiting until it is too late for the patient to make decisions and being the decision maker would be a hard task except where you truly know the wishes of the patient.*

*Yes the decision makers – health care professionals and family members – need a holistic view of the patient's needs, views and beliefs which may not be able to be communicated at the time a decision needs to be made.*

*Yes, I think advance care planning is a fantastic idea, as the individual has the potential opportunity to have their own wishes etc granted and followed, without doubt or argument from outside sources. It is stressful to think of your family arguing over your care should you not be in the position to express your own wishes, or to know what they were never given a choice in such matters if the situation was suitable for their involvement in deciding.*

One respondent commented that they thought that implementation of the proposed arrangements would make situations more confusing, and two respondents expressed general approval with a couple of caveats:

*I think they would be helpful but I think that the family's views should also be considered. I believe they should also be reviewed occasionally as your beliefs sometimes change with experience.*

*Yes, however they are documented. Will past documents be accepted? The biggest impediment is health professions have no universally recognised way to find a person's legally appointed representative however that is titled.*

### **Are there other issues that need addressing in terms of end-of-life decision making?**

Respondents were asked whether there were other issues that needed addressing for people affected by cancer and their carers in the context of planning for and making decisions at the end of life.

Some respondents mentioned the need to consider the impact of limited healthcare resources in advance care planning and end of life decision-making:

*All comes at a cost. Who pays?*

*I know that health professionals will be faced with meeting budgets in treatment costs at some stage. I suspect as a society we may need to have a conversation about expense of resources and whether we can afford to offer short term life sustaining treatments. Doctors may need legal protection should this occur.*

Others suggested that conversations about the end of life should happen earlier than they do currently.

*The importance of opening the discussion early enough which may need to be led by a health care professional. All too often these decisions are reached in haste as illness progresses.*

One respondent emphasised that effective processes need to be in place so that people's advance care plans and substitute decision-maker appointments can be readily accessed when needed.

*Access to the advance care plan. Where are they kept, how does everyone know it exists for this particular patient? Who is responsible to document the advance care plan, the patient, GP, specialist, nurse, other health professional etc?*

Six respondents suggested that euthanasia should be legalised in Australia, and that people be able to incorporate the possibility of euthanasia into advance care plans.

## **Activities**

### **Advance care planning strategy for Victorian health services**

In 2013, we participated in a consultation held by the Victorian Department of Health for the development of an advance care planning strategy for Victoria. The rationale for the strategy development is to provide a framework to embed advance care planning into the usual care provided by health services. The strategy will develop actions to:

- Support advance care planning with patients
- Increase the capability of health services to provide advance care planning; and
- Establish systems to support advance care planning across services.

### **Australian Medical Association Victoria Roundtables**

In August and September we participated in AMA Victoria's End of Life Care Roundtables, which brought together a range of key participants with an interest and expertise in end of life decision-making to discuss a preferred model for advance care directives and its implementation in the healthcare system. Hearing from a range of experts with first-hand experiences of the distressing consequences of non-existent, misunderstood, or ignored advance care directions reinforced our view that law reform is required to ensure that a person's own wishes relating to their care will be understood, respected and acted upon should they lose capacity to communicate or make decisions.

## **Reflections**

Many respondents to our survey acknowledged the importance of advance care planning; while at the same time admitting to 'not yet' having any arrangements. Others seemed to delay thinking about it, and then acting on it. There are clear reasons for this reticence, as also indicated in the survey responses – people are generally uncomfortable talking about death and dying, and for some, planning for end of life was an uncomfortable acceptance that they were not going to be cured.

## Futile Treatment

Defining futility in a medical treatment setting is complicated, and often, a subjective evaluation.<sup>101</sup> Stewart identifies the problem with the concept of futility, which is that it is a 'subjective notion masquerading as a form of professional objective and scientific assessment'.<sup>102</sup> Although there are many approaches to defining futility, none have been universally accepted as an objective test.<sup>103</sup>

The AMA defines 'futile treatment' as follows: 'treatment is futile when it is no longer providing a benefit to a patient, or the burdens of providing the treatment outweigh the benefits'.<sup>104</sup>

Futile treatment is not defined in Victorian legislation. In theGAA, the process for determining whether medical treatment would be in the best interests of the patient, sets out the following matters that must be taken into account:

- a. the wishes of the patient, so far as they can be ascertained; and
- b. the wishes of any nearest relative or any other family members of the patient; and
- c. the consequences to the patient if the treatment is not carried out; and
- d. any alternative treatment available; and
- e. the nature and degree of any significant risks associated with the treatment or any alternative treatment; and
- f. whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient; and
- g. any other matters prescribed by the regulations.<sup>105</sup>

This process is consistent with the common law test of 'best interests' which also includes a checklist of factors. These are essentially the same as the statutory test above.

Stewart suggests that a good way to deal with a determination of futility is to adopt a procedural approach based on clinical consensus and the input of substitute decision-makers.<sup>106</sup> Both the statutory and common law requirements for the consideration of 'best interests' encourage the seeking of consent (whether from the patient or a substitute decision maker), emphasise the importance of consultation, and do not rest solely on a clinical assessment of futility.

As part of the online survey, we asked stakeholders if there should be a right for people affected by cancer to demand treatment that is not clinically indicated. There was majority support (55 of 89) among respondents for patients to have this right, and respondents who commented on this question emphasised the importance of patient autonomy. Respondents were not given a 'don't know' option, which may have influenced the responses, as a small number of respondents indicated by their comments that they were unsure or that a case-by-case approach needed to be taken.

Some of the comments from those who did not support a right to demand treatment that is not clinically indicated mentioned the scarcity of resources in the health system, and the need to avoid wasting money. Others emphasised the greater medical knowledge of health professionals and were concerned that some patients would be worse off if they were given the right to demand treatment.

Respondents were more equivocal about whether there should be a right for substitute decision-makers to demand medical treatment that is not clinically indicated on behalf of a person they represent. Many respondents gave the same or similar reasons for why they did or did not support such a right for substitute decision-makers, as they gave for the preceding question. The main additional point emphasised by some respondents was that substitute decision-makers should only have the right to demand treatment, which is not clinically indicated, where there is evidence that this is what the represented person would have wanted.

The complexity of the legal issues in relation to futile treatment, and some of the sensitivities related to this topic, were evident in the responses we received through our online questionnaire. Better understanding the views of patients, their carers and families, and health professionals, will be a key focus of the next phase of this project.

In contrast, some people wanted more information about advance care planning, and the survey responses indicated a general lack of awareness of options for advance care planning. Others were more proactive, seeing advance care planning as an integral part of, or addendum to making a will.

Tying the advance care planning process to the making of a will was suggested by a number of practitioners in this area as a good mechanism through which to introduce the topic to patients, on the basis that people make wills quite readily. This was proposed as a way to ensure people regularly revisit their plans and wishes for future treatment, and to change the perception of advance care planning as being morbid.

It was also noted that conversations about end of life and advance care plans needed to happen a lot earlier, because often decisions were being made under pressure, or when a person had lost capacity.

Much of the feedback, and discussion arising from the various stakeholder meetings, suggested that it might be necessary to change some of the terminology when talking about the end of life. Many people were put off by terms like 'end of life' – which may be too direct and confronting for some people – and 'advance care planning' which borders on being euphemistic. The difficulty around language may compound the general reluctance to discuss end of life decision making – this point came through strongly in the AMA Victoria roundtables. It was suggested that talking about a 'good death' might be more constructive.

## Recommendations

There is a need for law reform in Victoria to improve specific areas in relation to end of life law and advance care planning, as well as a move towards greater harmony across all Australian jurisdictions. Equally important is tailored education for people affected by cancer, their carers, substitute decision-makers and health professionals, in relation to advance care planning options and legal frameworks. Part of this will need to involve reframing the way we talk about advance care planning in the community to ensure the topic is raised sensitively so that people are willing to listen and engage. Another part of it will involve developing education tools to improve how health professionals, and lawyers, talk about death and dying.

In relation to law reform, we support the Victoria Law Reform Commission's (the VLRC) recommendations outlined above, which in general states that there should be a broader statutory right to make an advance care directive, which encompasses future as well as current conditions, and the ability to provide consent and refusal to medical treatments in advance. Such legislation should also clarify the relationship between substitute decision-makers, and advance care directives; that is, which takes precedence if the substitute decision maker disagrees with the treatment choices in the advance care directive. In this respect, the VLRC recommends three options:

1. Appointing an enduring power of attorney with instructions; or
2. Appointing an enduring power of attorney with no instructions; or
3. Making a standalone advance care directive.

Many of the respondents to the online survey supported these recommendations. It has also been suggested that there be a voluntary register of advance care directives and substitute decision makers, which can

be easily accessed by health professionals, and which would be particularly useful in emergency situations. This is consistent with recommendations made by the VLRC and in other stakeholder consultations.

One thing that needs to be considered in relation to these recommendations is an issue that has been highlighted by the OPA, as well as a contributor to the online survey, which is the potential for unintended consequences in adopting too formulaic an approach to instructional health care directives as proposed in recommendation 139 of the VLRC report. The OPA has some concerns about the automatic operation of advance refusals of medical treatment that relate to future medical conditions:

*'There is evidence to suggest that such directives, made long in advance of the onset of any particular condition, are not always accurate reflections of a person's later state of mind should the person one day experience that condition. In other words, sometimes people react differently to a condition than they thought they might. (This, of course, is only a problem in terms of written directives where the person also loses the ability to make their own decisions.)'*<sup>107</sup>

Recommendation 151 of the VLRC's report includes proposed exceptions where a directive would not be operational (including, for example, where advances in medical science would likely have changed the view of the maker of the directive). However, there is a challenge to build into a law exceptions that operate on the basis of a predicted future state of mind – and the OPA is concerned that the VLRC's proposed exceptions might not be extensive enough to ensure the protection of the personal and social wellbeing of the people in question. It is likely that further discussion of possible safeguards to that might be needed if Recommendation 139 is adopted.<sup>108</sup>

# About us

The McCabe Centre for Law and Cancer is a joint initiative of CCV and the Union for International Cancer Control. Its mission is to contribute to the effective use of the law for cancer prevention, treatment, supportive care and research.

The McCabe Centre conducts research, policy development, capacity building and advocacy. It employs lawyers, and hosts international interns and fellows, law student interns and pro bono secondees in a multidisciplinary environment that includes expertise across cancer control generally, including epidemiology and behavioural science. It brings together lawyers, legal academics and cancer control experts and advocates. It collaborates with other non-governmental organizations, law schools and legal practitioners, and works, as appropriate, with governments and intergovernmental organizations.

CCV's Strategy and Support Division includes the Cancer Information and Support Service (CISS) which provides support and evidence-based information to those affected by cancer, their families and friends; and the Clinical Network office, which supports the work of our Clinical Network (formerly the Victorian Cooperative Oncology Group or VCOG). Established in 1976, the Clinical Network consists of a state-wide representative committee, an executive committee and 16 cancer-site or task-specific advisory sub-committees, involving over 650 specialists. It is the peak multi-specialty representative oncology forum in Victoria, and its aim is to advise the Cancer Council on all clinical aspects of cancer and in particular, on research, prevention, screening, diagnosis, treatment, palliative medicine and professional education.



**Appendix A:** Comparison of patient transport assistance schemes across Australia

Eligibility criteria	Patient contribution	Clinical trials	Private vehicle	Public transport	Air travel	Taxi travel	Parking	Accommodation
<b>Victoria</b>								
Vic. resident receiving medical treatment under designated Medicare codes. Need to travel > <b>100 kms</b> one way or on average <b>500 kms per week</b> for minimum of <b>five consecutive weeks</b> .	<b>\$100 every 12 months</b> , except for pensioners and Health Care Card Holders.	No.	17 cents p/km.	Full reimbursement.	If travelling 350 km +, economy fare on commercial flight only.	To nearest public transport only.	No.	<b>Commercial</b> <b>\$35 (+GST)</b> p/n each for commercial accommodation for patient plus approved escort <b>Private</b> <b>No subsidy.</b>
<b>Queensland</b>								
Qld resident accessing essential specialist medical service unavailable <b>within 50 kms</b> of nearest public hospital, which is closest service of its type.	<b>First four nights of accommodation per financial year</b> , unless qualify for reduction (Health Care, Seniors Health and Concession Card holders; pensioners; dependent children under 17 years.)	No.	30 cents p/km.	Full reimbursement at lowest rate.	Full reimbursement at lowest rate.	Potentially, limited circumstance.	No.	<b>Commercial</b> <b>\$60 p/n each</b> for patient and approved carer <b>Private</b> <b>\$10 p/n.</b>



Eligibility criteria	Patient contribution	Clinical trials	Private vehicle	Public transport	Air travel	Taxi travel	Parking	Accommodation
<b>New South Wales IPTASS</b>								
NSW or Lord Howe Island residents, who need to travel <b>&gt; 100 kms one way</b> or <b>&gt; 200 kms in one week</b> , for specialist treatment claimable under Medicare.	Mandatory personal contribution of <b>\$40 per claim up to \$1,000 threshold</b> p.a. except for pensioners and Health Care Card Holders.	No.	19 cents p/km.	Full reimbursement, economy rates (- GST).	Prior approval sought by medical practitioner/specialist, that there is a 'valid medical reason' for air travel.	1 visit: \$20 Short term (2 – 7 day) visit: \$40 Medium term (8 – 14 day) visit: \$80 Long term (15 + day) visit: \$160.	No.	<b>Single room \$43 p/n each</b> if approved carer in separate room <b>Double room \$60 p/n</b> (patient and approved carer in same room) <b>Private \$20 p/n.</b>
<b>Western Australia PATS</b>								
Permanent residents of WA Country Health Service regions who <b>need to travel &gt; 100 km</b> to nearest eligible specialist services (including Telehealth enabled service) People who need to travel between 70 – 100 kms for cancer or dialysis treatment may be eligible for limited assistance.	None.	No.	16 cents p/km 25 cents p/km when travelling in minibus or similar group vehicle, owned by community or org (payment to org).	Full reimbursement of economy or discounted fare (coach or rail).	Economy fare – cheapest on the day.	Limited circumstance.	No.	<b>Commercial Patient or escort: \$60 p/n</b> Patient and escort: <b>\$75 p/n</b> <b>Private</b> Patient: <b>\$20</b> Patient & Escort: <b>\$40 p/n</b> <b>Hospital</b> Patient: <b>\$34.50 p/n</b> Escort: <b>\$69 p/n</b> Escorts are entitled to accommodation assistance or return journey home and back, whichever is cheapest, except for <b>escorts for cancer patients, who are entitled to accommodation assistance for length of patient's treatment.</b>

Eligibility criteria	Patient contribution	Clinical trials	Private vehicle	Public transport	Air travel	Taxi travel	Parking	Accommodation
<b>South Australia Pats – UNDER REVIEW</b>								
Permanent citizens/residents residing in SA who live > 100 km from nearest treating specialist, for Medicare claimable treatment, on local doctor's referral.	\$30 patient contribution for each return journey (unless hardship application accepted).	No.	16 cents p/km.	Reimbursement of economy or discounted fare minus the \$30 patient contribution.	Pre-approval required, and deemed essential by local doctor.	Special arrangement.	No.	<b>Commercial</b> \$30 + GST p/n each for patient and approved escort.
<b>ACT IPTAS</b>								
Permanent residents of WA Country Health Service regions who <b>need to travel &gt; 100 km</b> to nearest eligible specialist services (including Telehealth enabled service)	None.	No.	<p>Rebate up to amount below:</p> <p>Syd \$101,48 Melb \$225.50 Adel \$420.25 Bris \$462.28</p> <p>Escorts required to remain with patient interstate for extended periods may be eligible for assistance to attend to pers. /household needs. Max. 2 return journeys (road/rail) per month, assessed on an individual basis.</p>	<p>Return economy fare</p> <p>Coach Syd \$75.85 Melb \$135.30 Adel \$244.98 Bris \$324.93</p> <p>Rail Syd \$103.53 Melb \$194.75 Adel \$217.30 Bris \$217.30</p>	Pre-approval required, on certification by referring medical practitioner or treating specialist that the patient has a specific medical condition that requires them to travel by air.	No.	No.	<p><b>Commercial</b> \$36.90 p/h each patient and/or escort.</p> <p><b>Private</b> \$11.28 p/h each patient and/or escort.</p>
People who need to travel between 70 – 100 kms for cancer or dialysis treatment may be eligible for limited assistance.								

Eligibility criteria	Patient contribution	Clinical trials	Private vehicle	Public transport	Air travel	Taxi travel	Parking	Accommodation
<b>Northern Territory PATS</b>								
Permanent NT residents who need to travel > <b>200 kms</b> one way for specialist services or <b>more than 400 kms</b> cumulatively in one week. <b>Wherever possible, the PATS Patient Travel Clerks</b> make all travel and accommodation bookings for patients and approved escorts.	No.	No.	20 cents p/km.	Full reimbursement of lowest available discount fare. Reimbursement of up to \$50 for ground travel at destination.	Full reimbursement of lowest available discount fare.	Reimbursement of up to \$50 for ground travel at destination.	No.	<b>Commercial</b> <b>\$60 p/n</b> for patients and approved escorts <b>Private</b> <b>\$20 p/n</b> Escorts can be automatically approved for patients travelling interstate for surgery or intensive treatment such as radiation therapies, non-surgical cancer treatments, cardiology or neurosurgery.
<b>Tasmania</b>								
Tasmanian residents who need to travel: - - more than 50 km (one way) to the nearest <b>oncology or dialysis treatment centre;</b> <b>or</b> more than 75 km (one way) to the nearest appropriate specialist medical service or for lymphoedema treatment.	Health Care or Pensioner Concession card-holders pay \$15 towards each return journey to a max. of \$120 p.a. Non-cardholders pay \$75 towards each return journey to a max. of \$300 p.a.		19 cents p/km.	Return economy bus tickets. King and Furneaux Islands residents can claim return economy airfare (Island Resident rates), plus most appropriate transport from airport to and from medical facility.	King and Furneaux Islands residents can claim return economy airfare (Island Resident rates), plus most appropriate transport from airport to and from medical facility.	King and Furneaux Islands residents can claim return economy airfare (Island Resident rates), plus most appropriate transport from airport to and from medical facility.	No.	<b>Intrastate</b> <b>\$46 each</b> p/n for patient and carer (when subsidised accommodation is not available or appropriate at Tas. medical facilities). Non-cardholders and their escorts must pay first two nights' accommodation for each stay. <b>Interstate</b> <b>\$64 each</b> p/n for patient and carer.

# References

- <sup>1</sup> Thursfield V. et al. *Cancer in Victoria: Statistics and Trends 2012* Cancer Council Victoria, Melbourne 2013, 9 and 12.
- <sup>2</sup> Ibid.
- <sup>3</sup> Thursfield V., Farrugia H. and Giles, G. *Cancer in Victoria: Social Context 2010* Cancer Council Victoria, Melbourne 2011, 1.
- <sup>4</sup> Thursfield, above, n 1.
- <sup>5</sup> Ibid.
- <sup>6</sup> Ibid.
- <sup>7</sup> Lung cancer has one of the poorest survival rates of all cancers (see above, n 1.).
- <sup>8</sup> Thursfield and Farrugia, above, n 1.
- <sup>9</sup> Ibid.
- <sup>10</sup> Spatial Analysis and Research branch of the Planning Building Systems and Strategy Division 'Victorian Population Bulletin 2013' (Department of Transport, Planning and Local Infrastructure (Vic), 2013) < [http://www.dpcc.vic.gov.au/\\_\\_data/assets/pdf\\_file/0011/158492/Victorian-Population-Bulletin-2013\\_18062013\\_email\\_spread.pdf](http://www.dpcc.vic.gov.au/__data/assets/pdf_file/0011/158492/Victorian-Population-Bulletin-2013_18062013_email_spread.pdf)>
- <sup>11</sup> Victorian Council of Social Service, 'Submission to the Victorian Rural and Regional Committees' Inquiry into the Extent and Nature of Disadvantage and Inequity in Rural and Regional Victoria' (2010) 6 < [http://vcoss.org.au/documents/VCOSS%20docs/Submissions/2010/SUB\\_100430\\_VCOSS\\_Rural%20and%20Regional%20Submission.pdf](http://vcoss.org.au/documents/VCOSS%20docs/Submissions/2010/SUB_100430_VCOSS_Rural%20and%20Regional%20Submission.pdf)>
- <sup>12</sup> Ibid.
- <sup>13</sup> Senate Standing Committee on Community Affairs, 'Inquiry into the operation and effectiveness of Patient Assisted Travel Schemes' (20 September 2007) < [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Completed\\_inquiries/2004-07/pats/report/c01](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2004-07/pats/report/c01)>
- <sup>14</sup> Cancer Council Australia 'Closing the loop: bringing patients to the new regional centres' (31 March 2011) <http://www.cancer.org.au/policy/electionpriorities2010/remotepatienttravel.htm>
- <sup>15</sup> Australian Institute of Health and Welfare and Australasian Association of Cancer Registries *Cancer survival in Australia 1992–1997: geographic categories and socioeconomic status* Cancer Series no. 22. Cat. no. CAN 17, Canberra: AIHW, 2003; Jong KE, Vale PJ, Armstrong BK 'Rural inequalities in cancer care and outcome' *Med J Aust* 2005, 182(1), 13-14; Australian Institute of Health and Welfare Health in rural and remote Australia Canberra: AIHW, 1998 (AIHW Cat. No. PHE 6).
- <sup>16</sup> Jong K.E., Smith D.P., and Yu X.Q., et al 'Remoteness of residence and survival from cancer in New South Wales' *Med J Aust* 2004; 180: 618-622).
- <sup>17</sup> National Health Priority Action Council, National Service Improvement Framework for Cancer (2006, Australian Government Department of Health and Ageing) 42; [http://www.health.gov.au/internet/main/publishing.nsf/content/96C9CD63196A62ACCA25714100045165/\\$File/cancall.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/96C9CD63196A62ACCA25714100045165/$File/cancall.pdf)
- <sup>18</sup> Michael D Coory, Tsun Ho, Susan J Jordan 'Australia is continuing to make progress against cancer, but the regional and remote disadvantage remains' 2013, 199(9), MJA, 605
- <sup>19</sup> Department of Health (2013) Review of the Patient Assistance Travel Scheme, Northern Territory Government, p 6.
- <sup>20</sup> <http://www.ratesmate.com.au/OtherTaxMatters/Cars/AverageRetailPriceofPetrol/tabid/279/Default.aspx> viewed 16/10/13.
- <sup>21</sup> Patients who live 350 kilometres or more from their approved specialist medical treatment centre are eligible for reimbursement of economy airfares.
- <sup>22</sup> National Rural Health Alliance Inc. (2009) 'Fact Sheet 10 – Patient Assisted Travel Schemes' May 2009.
- <sup>23</sup> Ibid.
- <sup>24</sup> Senate Standing Committee on Community Affairs (2007) Highway to health: better access for rural, regional and remote patients Commonwealth of Australia, p ix.
- <sup>25</sup> National Health and Hospitals Reform Commission (2009) *A Healthier Future For All Australians: Interim Report* December 2008, Commonwealth of Australia p 233.
- <sup>26</sup> Cancer Council Australia and Clinical Oncological Society of Australia (2010) 'Election Priorities Backgrounder'.
- <sup>27</sup> Reference for information in Figure 2.: Australian Human Rights Commission "Employment and the Disability Discrimination Act: Guidance from the Australian Human Rights Commission" <https://www.humanrights.gov.au/employment-and-disability-discrimination-act-part-1#hardship>, viewed 6 December 2013.
- <sup>28</sup> The Australian Human Rights Commission Complaint Statistics from 2010/2011 show that of the 1097 complaints received about disability discrimination, pursuant to the DDA, just 104 related to discrimination on the grounds of "presence in the body of organisms causing disease (excluding HIV/AIDS)" (16) and "medical condition" (88). It is not clear whether the complaints were related to people affected by cancer. A search of the Australasian Legal Information Institute case law databases also revealed few cases relating to discrimination or other workplace related complaints on the grounds of cancer.
- <sup>29</sup> New section 789FD Fair Work Act 2009 (Cth).
- <sup>30</sup> The Social Research Centre (2011) 'Cancer Council Victoria Cancer Information Support Service: Report of qualitative research', The Social Research Centre, Melbourne, 21 December 2011.
- <sup>31</sup> Note that 57 of the 11 respondents said that the question was not applicable, as they weren't carers, and 50 said they hadn't been treated unfairly at work as carers – although it's possible that many of them were also not carers, and simply ticked no, rather than not applicable.
- <sup>32</sup> Wuellner, L. (2011) *Cancer, Work and You: Information for employed people affected by cancer*, Cancer Council NSW, Sydney.
- <sup>33</sup> *Nulty v Blue Star Group Pty Ltd* [2011] FWAFFB 975 (16 February 2011).

- <sup>34</sup> Section 366 Fair Work Act 2009.
- <sup>35</sup> *Chillmaid v Patrick B. McInerney T/A Patrick B. McInerney Transport* [2012] FWA 9572, 16 November 2012.
- <sup>36</sup> *Muir McMeeken v Action Industrial Catering Pty Ltd* [2012] FWAFB 5933.
- <sup>37</sup> *Raza v Eureka Operations Pty Ltd T/A Coles Express* [2012] FWA 5919 (20 July 2012).
- <sup>38</sup> *Cheval Properties Pty Ltd (t/as Penrith Hotel Motel) v Smithers* (2010) 197 IR 403.
- <sup>39</sup> Cancer Council Australia 'Cancer in Australia' <<http://www.cancer.org.au/about-cancer/what-is-cancer/facts-and-figures.html>>
- <sup>40</sup> *Ibid.*
- <sup>41</sup> For the purposes of the Act, a carer includes: a person who provides personal care, support and assistance to another person who needs it because they have a medical condition, including a terminal or chronic illness, (except where the carer is providing care through a contract, volunteer work, or for education or training purposes).
- <sup>42</sup> Amanda Biggs 'Medicare Background Brief' (E-Brief. Parliament of Australia. Issued 9 May 2003 update 29 October 2004) <[http://www.aph.gov.au/About\\_Parliament/Parliamentary\\_Departments/Parliamentary\\_Library/Publications\\_Archive/archive/medicare](http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/Publications_Archive/archive/medicare)>
- <sup>43</sup> Department of Human Services Medicare services (8 January 2014) <<http://www.humanservices.gov.au/customer/subjects/medicare-services>>
- <sup>44</sup> Australian Tax Office Medicare levy (28 June 2013) <<http://www.ato.gov.au/Individuals/Medicare-levy/>>
- <sup>45</sup> Department of Health Private health insurance – frequently asked questions (4 October 2013) <<http://www.health.gov.au/internet/main/publishing.nsf/Content/Frequently+Asked+Questions-1>>
- <sup>46</sup> Australian Tax Office, above note 3
- <sup>47</sup> Private Health Insurance Ombudsman How health funds work <<http://www.privatehealth.gov.au/healthfunds/howhealthfundswork/>>
- <sup>48</sup> HM Government (UK) and Association of British Insurers 'Concordat and Moratorium on Genetics and Insurance' (2011) Clause 24 <[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216821/Concordat-and-Moratorium-on-Genetics-and-Insurance-20111.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216821/Concordat-and-Moratorium-on-Genetics-and-Insurance-20111.pdf)>
- <sup>49</sup> Louise Keogh and Margaret Otlowski 'Life insurance and genetic test results: a mutation carrier's fight to achieve full cover' (2013) 199 (5) *Medical Journal of Australia* 363
- <sup>50</sup> *Ibid.* 364
- <sup>51</sup> *Ibid.*
- <sup>52</sup> *Ibid.*
- <sup>53</sup> *Ibid.*
- <sup>54</sup> Financial Services Council 'Financial Services Council Standards' <<http://www.fsc.org.au/standards-guidance/financial-services-council-standards.aspx>>
- <sup>55</sup> Keogh above note 8, 365
- <sup>56</sup> *Ibid.*
- <sup>57</sup> *Ibid.*
- <sup>58</sup> *Ibid.*
- <sup>59</sup> Human Genetics Society of Australasia 'Position statement: Genetic Testing and Life Insurance in Australia' (19 March 2013) <<http://www.hgsa.org.au/documents/item/20>>
- <sup>60</sup> National Health and Medical Research Council 'Genetic testing and screening' (Genetics in Family Medicine, The Australian Handbook for General Practitioners 2007) <[http://www.nhmrc.gov.au/\\_files\\_nhmrc/file/your\\_health/egenetics/practioners/gems/fact\\_sheets/17\\_genetic\\_testing\\_screening.pdf](http://www.nhmrc.gov.au/_files_nhmrc/file/your_health/egenetics/practioners/gems/fact_sheets/17_genetic_testing_screening.pdf)>
- <sup>61</sup> Essentially Yours: The Protection of Human Genetic Information in Australia (ALRC Report 96, May 2003) <<http://www.alrc.gov.au/publications/report-96>>
- <sup>62</sup> *Ibid.* 27.93
- <sup>63</sup> *Ibid.* 27.93
- <sup>64</sup> *Ibid.* 27.71
- <sup>65</sup> *Ibid.* 27.71
- <sup>66</sup> *Ibid.* 27.76
- <sup>67</sup> *Ibid.* 27.90
- <sup>68</sup> Full Australian Government Response to Australian Law Reform Commission, Australian Health Ethics Committee report 96, Essentially Yours: The Protection of Human Genetic Information in Australia (9 December 2005) <<http://www.alrc.gov.au/inquiries/health-and-genetics/full-australian-government-response-alrc-report-96>>
- <sup>69</sup> *Ibid.*
- <sup>70</sup> Insurance Contracts Regulations 1985
- <sup>71</sup> Paula Pyburne, Insurance Contracts Amendment Bill 2013, No132 of 2012-2013, 11 June 2013, 16
- <sup>72</sup> *Ibid.*
- <sup>73</sup> *Ibid.*
- <sup>74</sup> *Ibid.* 17
- <sup>75</sup> *Ibid.*
- <sup>76</sup> Explanatory Memorandum, Insurance Contracts Amendment Bill 2013 4
- <sup>77</sup> *Ibid.*
- <sup>78</sup> This provision has also been amended to better articulate how the duty of disclosure test is applied. In the new law, section 21(1)(b) has been amended so that disclosure is required about relevant matters, having regard to: (i) the nature and extent of the insurance cover to be provided under the relevant contract of insurance; and (ii) the class of persons who would ordinarily be expected to apply for insurance cover of that kind. Section 21(1)(b) (i) and (ii) will assist the courts to determine whether a person could be expected to know whether a matter was relevant to decision of an insurer when entering a contract of insurance.
- <sup>79</sup> Professor Margaret Otlowski, Submission to the Productivity Commission, Review of the Disability Discrimination Act 1992, 4.
- <sup>80</sup> Essentially yours, above note 20, 27.76
- <sup>81</sup> Australian Medical Association 'Position Statement: Genetic Testing' (2012) <<https://ama.com.au/position-statement/genetic-testing-2012>>
- <sup>82</sup> Human Rights and Anti-Discrimination Bill 2012 Clause 19(4)

- <sup>83</sup> Detering, Karen M., Hancock, Andrew D., Reade, Michael C., and Silvester, William (2010) 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial' *BMJ* 340: c1345.
- <sup>84</sup> Stewart, C. (2011) 'Law and cancer at the end of life: The problem of nomoigenic harms and the five desiderata of death law' *Public Health* 125, 915.
- <sup>85</sup> *Ibid.*
- <sup>86</sup> Willmott, L. et al. 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria) (2011) 18 *Journal of Law and Medicine* 773, 790
- <sup>87</sup> *Ibid.*
- <sup>88</sup> Gardner; re BWV [2003] VSC 173.
- <sup>89</sup> Enduring guardians can also not consent to "special procedures", which are defined by the GAA as being: procedures intended, or reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out; pregnancy termination; removal of tissue for the purposes of transplantation to another person; or any other medical or dental treatment prescribed by the regulations (section 3 GAA).
- <sup>90</sup> Willmott, L., White, B. and Then, S-N., 'Withholding and Withdrawing Life-sustaining Medical Treatment' in White, B., McDonald, F. and Willmott, L. (eds.) *Health Law in Australia* (Thomson Reuters, Sydney, 2010) at 13.210.
- <sup>91</sup> Willmott, L. et al. refer to EK (Guardianship) [2005] VCAT 2520; BK (Guardianship) [2007] VCAT 332; BWV [2003] VCAT 121; and Korp (Guardianship) [2005] VCAT 779 - Willmott, L. et al. 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria) (2011) 18 *Journal of Law and Medicine* 773, 790.
- <sup>92</sup> Willmott, L. et al. refer to EK (Guardianship) [2005] VCAT 2520 and AV (Guardianship) [2005] VCAT 2519 - Willmott, L. et al. 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria) (2011) 18 *Journal of Law and Medicine* 773, 790.
- <sup>93</sup> Victorian Law Reform Commission (2011) *Guardianship: Final Report*, Tabled 18 April 2012, Chapter 11.
- <sup>94</sup> *Ibid.*
- <sup>95</sup> Stewart, C. (2011) 'Law and cancer at the end of life: The problem of nomoigenic harms and the five desiderata of death law' *Public Health* 125, 905, at 914.
- <sup>96</sup> [2010] VSC 493
- <sup>97</sup> [2010] VSC 493, at para. 35.
- <sup>98</sup> These responses cannot be tallied as a proportion of all responses. A total of 169 Victorians started the survey, however, as respondents were free to skip questions, it cannot be ascertained how many respondents considered this question and didn't tick one of the two boxes, because they weren't aware of either option, and how many simply skipped the question or entire section.
- <sup>99</sup> These responses cannot be tallied as a proportion of all responses. As respondents were free to skip questions, it cannot be ascertained how many respondents considered this question and didn't tick one of the two boxes, because they hadn't made either appointment, and how many simply skipped the question or entire section.
- <sup>100</sup> These responses cannot be tallied as a proportion of all responses. As respondents were free to skip questions, it cannot be ascertained how many respondents considered this question and didn't tick one of the two boxes, because they weren't aware of either option, and how many simply skipped the question or entire section.
- <sup>101</sup> Cameron Stewart, 'A defence of the requirement to seek consent to withhold and withdraw futile treatments' (2012) 196 (6) *Medical Journal of Australia* 406, 406
- <sup>102</sup> *Ibid.*
- <sup>103</sup> *Ibid.*
- <sup>104</sup> Australian Medical Association 'The Role of the Medical Practitioner in End of Life Care' (Position statement 20 August 2007)
- <sup>105</sup> *Guardianship and Administration Act 1986* s 38
- <sup>106</sup> Stewart, above note 14.
- <sup>107</sup> Office of the Public Advocate (2012) *Response to the Victorian Law Reform Commission's Final Report on Guardianship*, Office of the Public Advocate, Victoria, viewed 17 December 2103 at <http://www.publicadvocate.vic.gov.au/file/file/Research/Submissions/2012/OPA%20response%20to%20VLR%20Final%20Guardianship%20Report%202012.pdf>
- <sup>108</sup> *Ibid.*

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### **The steering committee members are:**

Lauren Adamson, Senior Rights Legal Clinic, Public Interest Law Clearing House

Nicola Bruce, Cancer Action Victoria

David Hill, CCV

Michael Jefford, Peter MacCallum Cancer Centre and CCV

Carolyn Lethborg, Social Work Department, St Vincent's Hospital

Louise Milne-Roch, Victorian Mental Illness Awareness Council

Paul Mitchell, Austin Health Cancer Services

Peter Noble, Loddon Campaspe Community Legal Centre

Jennifer Philip, Centre for Palliative Care, St Vincent's Hospital

Emma Sayers, Senior Policy Officer, Consumer Program, Cancer Australia

Loane Skene, Melbourne University Law School

Cameron Stewart, Sydney University Law School

Pamela Williams, Cancer Action Victoria

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615 St Kilda Road  
Melbourne Vic 3004 Australia

**T** +61 3 9514 6100

**F** +61 3 9635 6800

**W** [www.cancervic.org.au](http://www.cancervic.org.au)

Cancer Council Helpline 13 11 20