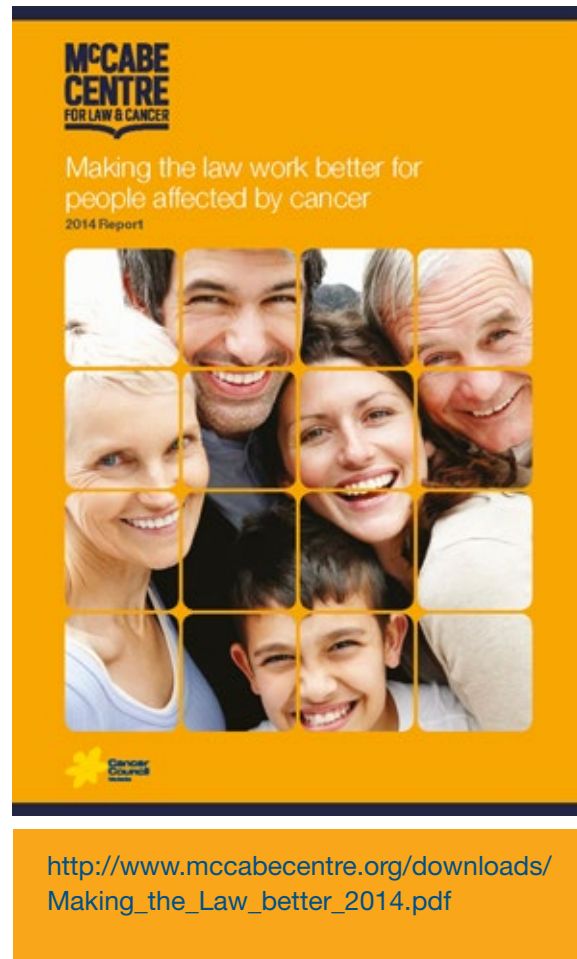
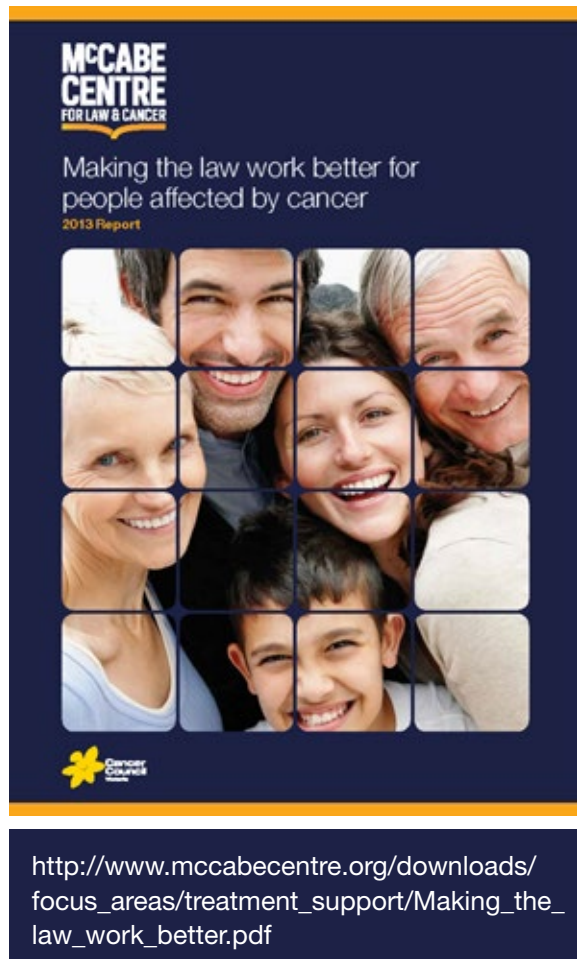


Making the law work better for people affected by cancer

2015 Report



Previous reports available for download



Author Deborah Lawson, McCabe Centre for Law and Cancer

This report is the third in a series of three funded by the Victorian Legal Services Board's Major Grants program

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615 St Kilda Road
Melbourne Vic 3004 Australia

T +61 3 9514 6100

W www.cancervic.org.au

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About the project

In late 2012, the McCabe Centre for Law and Cancer and Cancer Council Victoria's Strategy and Support Division, supported by a major grant from the Victorian Legal Services Board, commenced the *Making the law work better for people affected by cancer project*.

The Victorian Legal Services Board supported the continuation of the project with a second major grant for 2014-15.

Project aims

The project aimed to improve experiences and outcomes for Victorians affected by cancer, their carers and health professionals by:

- Mapping and analysing the ways in which law impacts on experiences and outcomes for people affected by cancer, their carers and health professionals.
- Improving understanding of legal rights and responsibilities for people affected by cancer, their families and health professionals.
- Educating policy-makers about ways in which the law (and related policies) can be clarified and reformed to better support people affected by cancer, their families and health professionals.

- Improving access and equity in treatment and support options during and after cancer treatment.

While the project focused primarily on improving experiences and outcomes for Victorians affected by cancer, many of the key focus areas have national and international relevance, and are also relevant to people with other chronic disease or terminal illness.

Project partners

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

It conducts research, policy development and capacity building, and connects lawyers, legal academics and law students with cancer control researchers and advocates.

Cancer Council Victoria (CCV) is a non-profit cancer charity organisation involved in cancer research, patient support, cancer prevention and advocacy.

CCV's Strategy and Support Division programs strive to reduce the impact of cancer by providing reliable information and compassionate support to people living with cancer, their family and friends.

The **Victorian Legal Services Board** is an independent statutory authority, responsible for regulation of the legal profession in Victoria.

The Victorian Legal Services Board Grants Program distributes funding to projects that aim to improve the administration of laws, increase access to justice, improve legal services and inform and educate the wider community about legal services.

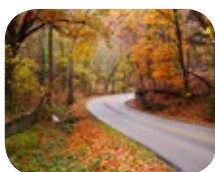


Victorian Legal Services
BOARD + COMMISSIONER
Funded through the Grants Program

Key focus areas

The project primarily focused on six areas of law and policy that have key roles in experiences and outcomes for people affected by cancer, their carers and health professionals.

These areas were identified through existing CCV priorities, stakeholder consultation and literature reviews.



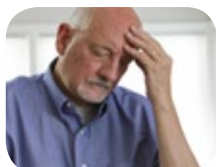
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Regional patient access to treatment: the Victorian Patient Transport Assistance Scheme

Victorians living in rural and regional areas generally experience poorer health than metropolitan residents.¹ While a complex set of factors contribute to this, a key barrier for rural and regional Victorians is the distance to specialist medical services, most of which are concentrated in urban centres.²

Lack of access to specialist treatment can impact on health outcomes, and this is especially telling for people affected by cancer.

The further from a metropolitan centre a person with cancer lives, the more likely they are to die within five years of diagnosis.³ For some types of cancer, those who live in remote areas are up to three times more likely to die within five years of diagnosis.⁴

People from rural or remote areas will almost always need to travel for some elements of their cancer care.⁵

The costs of transport and accommodation associated with accessing treatment can be a significant burden for people affected by cancer living in rural and remote areas. This can impact decisions that 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.

While some assistance is provided for transport and accommodation costs by the Victorian Patient Travel Assistance Scheme (VPTAS), the current level of reimbursement is insufficient (although there have been recent increases, as discussed further below). VPTAS subsidies are among the lowest in Australia (Figure 1).

At the commencement of the project, there were four main concerns about VPTAS:

- VPTAS subsidies did not provide adequate cover for costs
- The distance eligibility criteria were too restrictive, causing many patients in need to miss out on subsidies
- There was limited awareness in the community about the support that VPTAS provides
- The application process was cumbersome and people could wait several weeks to receive their rebates.

Advocacy activity

To address these concerns, in 2013 CCV established and coordinated the VPTAS Alliance, a multi-organisational collaboration to advocate for improvements to the scheme. The VPTAS Alliance comprises more than 30 agencies concerned with cancer, chronic disease, and regional and rural patient support.

In 2014, we coordinated pre-budget advocacy work on behalf of the VPTAS Alliance and welcomed the announcement of an additional \$13.8 million in the State Budget to expand the VPTAS.

The VPTAS Alliance continued its advocacy to the State government in 2015, with an additional focus on greater promotion and community awareness of the VPTAS.

Improvements to policy

The advocacy efforts of the VPTAS Alliance have contributed to significant identifiable improvements in policy and funding:

- Ministerial announcement of a review of the VPTAS in 2013
- Increases to the subsidies in 2014 for the first time since 2007, from \$35 per night for accommodation to \$41 per night, and from 17 cents per km for private vehicle use to 19 cents per km
- Streamlining of internal processes to reduce waiting times for payments
- Reduction of the cumulative distance threshold for VPTAS eligibility (from an average of 500 kms per week over 5 consecutive weeks to an average of 500 kms over just one or more weeks) resulting in more patients becoming eligible for subsidies

VPTAS Alliance members



- A commitment to regular reviews of VPTAS, incorporating consultation with the VPTAS Alliance as part of those reviews.

The voices of regional Victorians affected by cancer and other chronic disease, and those who work with them, will now be regularly heard by the government department responsible for recommending and implementing improvements to the VPTAS (the Department of Health and Human Services).

The benefits resulting from improvements to the VPTAS extend beyond people affected by cancer to all Victorian patients and carers who are eligible for VPTAS subsidies when they travel for specialist medical treatment.

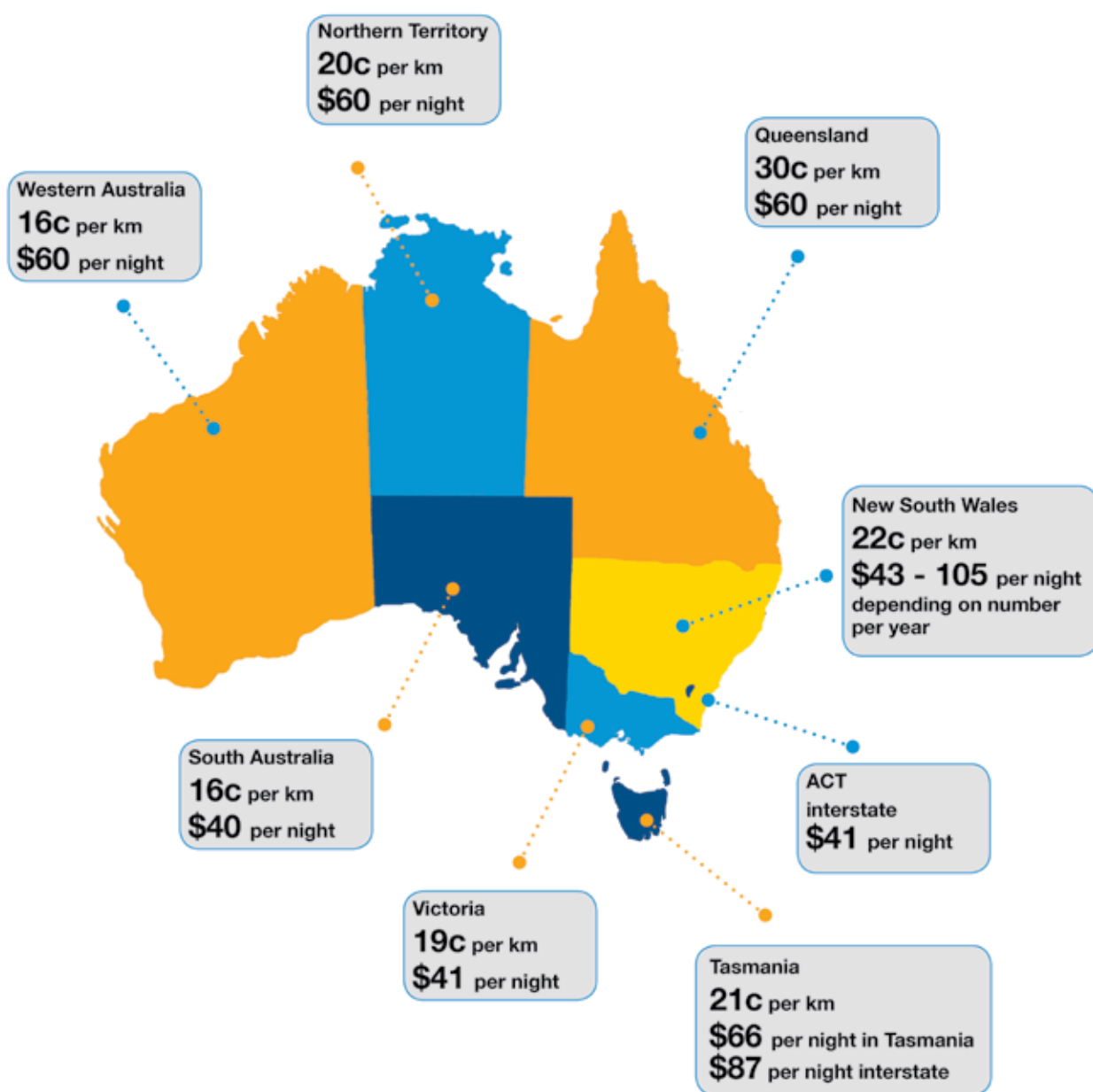
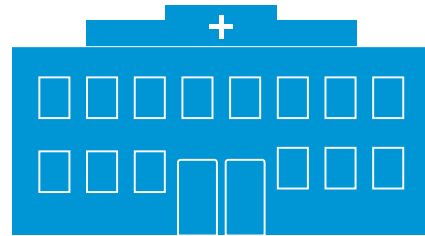


Figure 1 Patient transport assistance scheme travel and accommodation subsidies by jurisdiction



1.4 million Victorians live in a rural or regional location



Rural or regional cancer patients may need to travel to the city or to regional centres for specialist cancer treatment



The cost of travel and accommodation can be too great a burden

Costs 'deter' rural patients

HEALTH organisations fear country Victorians miss out on financial help when travelling for treatment. Patients in country areas delay and avoid treatment because of travel expenses involved, Cancer Council Victoria support services director Nicola Quin says. An alliance of health organisations, including the Cancer Council and Kidney Health Australia, want eligibility criteria reduced and travel rebates increased to improve financial help for patients who have to travel to Melbourne for medical treatment and specialist care.

Some patients defer treatment or seek alternative treatments



The further from a metropolitan centre a cancer patient lives, the more likely they are to die within 5 years of diagnosis



For some cancers, those who live remotely are up to 3 times more likely to die within 5 years of diagnosis



Victorian Patient Transport Assistance Scheme

VPTAS

Current reimbursement rates fail to provide adequate cover for costs

Many eligible people unaware of the scheme

Some patients report waiting up to 3 months for reimbursement

Melbourne accommodation costs

\$100+ per night

Queensland rates

30 cents per km
\$60 per night

VPTAS rates

19 cents per km
\$41 per night

Awareness of VPTAS

There was concern that limited awareness of VPTAS among patients and health professionals was resulting in some patients and carers missing out on the support it offered.

To address this, we developed a poster for display in agencies across Victoria. The poster was publicly launched at the Bendigo Eaglehawk Community Health Centre, in August 2015, attracting significant regional media attention.

It was subsequently distributed to thousands of patients, health centres and health professionals through VPTAS Alliance networks.

It is anticipated that improved awareness of VPTAS among patients and health professionals will result in increased use of the scheme by patients and their carers, reducing the financial burden of travelling for specialist medical treatment for many regional Victorians.

Do you need to travel a long way to receive specialist medical treatment?

The Victorian Patient Transport Assistance Scheme (VPTAS) can help lessen the financial burden

Victorians who travel 100+ kms each way or 500 kms in a single week

for specialist medical treatment may be eligible for subsidies:

- for petrol or public transport fare reimbursement
- for accommodation to stay near your treatment centre.

For information and support please contact **Cancer Council Victoria**:

- Call: 13 11 20
- Visit: www.cancervic.org.au/patient-transport

For more information:

- Call: 1300 737 073
- Email: vptas@health.vic.gov.au
- Visit: www.health.vic.gov.au/hurshealth/patient-transport-assistance.htm

Cancer Council Victoria

Local backs calls to increase patient travel rebates

A LOCAL cancer survivor who forked out thousands of dollars travelling to Melbourne for cancer treatment has called for greater travel rebates for regional patients. Last Friday an alliance of more than 30 leading community and health organisations appealed for increased petrol and accommodation rebates under the Victorian Patient Transport Assistance Scheme (VPTAS), a State Government program for patients travelling more than 500km per week for medical treatment.

After a breast cancer diagnosis in 2012 Rebecca Herman travelled to Melbourne every three weeks for treatment but has since switched to an oncologist in Bendigo because it was financially unsustainable to travel from her Woorinen South home to Melbourne so frequently. The VPTAS alliance, which

includes the Cancer Council Victoria, the Country Women's Association and the Victorian Farmers Federation, want to increase the petrol rebate from 20 cents to 30 cents and the overnight accommodation rebate from \$41 to \$60, but Ms Herman says she would like to see at least 50 percent of costs refunded.

"We have to travel to see an oncologist, it's not something we have a choice in," she said. She labelled the VPTAS a "logistical nightmare". "A lot of the trips just got missed because I'd forgotten the forms, and they aren't something the specialists have on hand," she said.

Ms Herman said she would like to see the scheme improved in the hopes other Swan Hill cancer patients could seek medical treatment anywhere, regardless of travel costs.



HARD WORK: Local cancer survivor Rebecca Herman says the State Government doesn't offer enough financial support to patients forced to travel for medical appointments.

Access to insurance and superannuation

Access to insurance

In Australia, health insurance is provided universally under Medicare and supplemented by private insurance providers.

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.⁶

Many people also elect to take out other policies such as life, travel, home and contents and income protection insurance. These forms of 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 policy holder reflect their risk relative to the whole pool. Cover is offered and premiums are set by making differentiations based on risk.

The Commonwealth *Disability Discrimination Act 1992* prohibits discrimination against people because they have cancer, have had cancer or may have cancer in the future (whether because of a genetic predisposition to, or family history of, cancer). This means that a person affected by cancer should be able to access the same goods and services

as a person who has never had cancer, and at the same price.

However, an exemption under the Act allows insurers, (excluding health insurers, see section 55.5 *Private Health Insurance Act 2007* (Cth)) to refuse insurance cover or change the terms of an insurance policy for a person affected by cancer so long as this decision is supported by statistical or actuarial data or other reasonable evidence (section 46, *Disability Discrimination Act 1992* (Cth)).

Decisions are made on a case by case basis, but in general, insurers will consider information about factors that may increase or reduce risk, including whether the applicant is having treatment or is in remission.

The Australian Human Rights Commission's guidelines for insurers recommend that insurers consider whether risks can be managed by restricting cover or increasing premiums, rather than refusing outright to insure a person with cancer.⁷

Key concerns

Access to risk-rated insurance coverage, 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.

Many stakeholders report difficulties in obtaining insurance following a cancer diagnosis and treatment. We are aware of people being denied insurance based on inadequate data, or with no reasons given.

However, very few formal complaints are made, which makes it difficult to gauge the magnitude and nature of the problem.

Stakeholder feedback

In 2013, we conducted a consultation with stakeholders regarding the key legal issues for people affected by cancer. As part of this, to enable people to easily and directly contribute to the consultation, we developed an online survey. Survey participants were recruited through Breast Cancer Network Australia's Review and Survey Group and primarily were women with an experience of breast cancer.

Survey findings

There were 93 respondents to the survey. Obtaining insurance cover was thought to be a problem by most respondents (87%). Approximately half had personally experienced problems with getting insurance because of a personal or family history of cancer, or a genetic predisposition to cancer.

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.

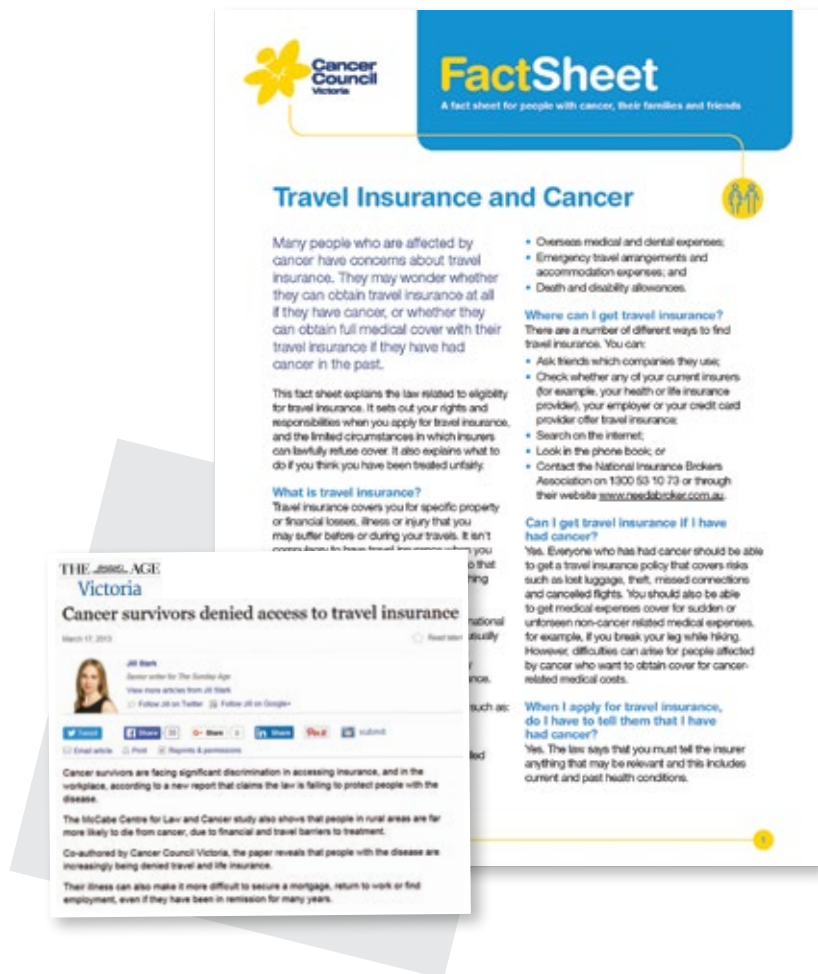
None of the respondents had ever made a complaint about discrimination in insurance, even though over a third of people said they had been treated unfairly. When asked why complaints had not been made, most indicated they did not want the 'hassle'; others believed that they should not get cover.

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.

While the majority of respondents indicated they had not been treated unfairly, it is possible that this may reflect a level of acceptance by people affected by cancer of the status quo, or lower expectations of protection.

It may also be that people lack access to, or knowledge of, the relevant complaints mechanism.



Recommendations

The following recommendations were made:

1. That the *Insurance Contracts Act 1984* (Cth) be amended to clarify the right to information from insurers for people who have received an adverse decision, including an entitlement to details of the actuarial, statistical or other data relied on by the insurance company.
2. Development of education programs and resources to support people affected by cancer to understand and use the protections in the *Disability Discrimination Act 1992* (Cth), and to make a complaint where appropriate.

3. More research on the uptake and use of genetic information in insurers' decisions about providing cover.

Greater transparency in the collection and use of health 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).

Information resources

We developed a factsheet for people affected by cancer and their carers to inform them of their rights and responsibilities in relation to obtaining travel insurance after a cancer diagnosis.

Early access to superannuation

Key concern

Many people with cancer experience financial difficulty near the end of their lives, due to an inability to work and additional costs associated with treatment.

While early access to superannuation assists people at this stage, cancer patients have reported experiencing difficulty obtaining access to the funds.

Early access to superannuation is available for people with terminal illness, but previously this required the provision of a certificate, signed by two medical practitioners (including a specialist), stating that the person suffered from an illness that was likely to result in death within 12 months.

Anecdotally, cancer patients experienced difficulties in obtaining this, as doctors appeared reluctant to sign a form stating that the patient was likely to die within this period.

Additionally, the 12-month life expectancy requirement restricted the length of time in which terminal cancer patients were able to use their superannuation for their medical and other costs, and to spend valuable time with their families.

Advocacy

We supported Breast Cancer Network Australia in its advocacy to the Commonwealth Government to amend the legislation governing early access to superannuation for people with a terminal illness.



The advocacy effort was aimed at having the 12-month life-expectancy requirement extended to 24 months, to allow more people with terminal illnesses to access their superannuation early.

Legislative change

On 7 May 2015, the Minister for Superannuation announced that the government would amend the provision for early access to superannuation for people with terminal illness from one to two years, following “representations from Breast Cancer Network Australia and other organisations”.

Impact

This legislative change means that people with terminal cancer (and other terminal illnesses) will be able to access their superannuation more easily and earlier than previously, which will ease their financial burdens and distress.

“Changing the provision from 12 months to two years will mean that I can access funds to allow me to spend time with my three young children, take a holiday together and do things with them that I won’t always be well enough to do.”⁸

Working through and after cancer: employment law

While many employers are supportive of employees affected by cancer, for some people with cancer or their carers, retaining employment, returning to work or finding new employment can be a problem.

There are a range of factors that can impact on work including undergoing time-consuming treatments, being physically or emotionally unable to work as a result of cancer or treatment, a lack of understanding of cancer treatment on the part of employers and colleagues, and discrimination.

The survival rate for many common cancers has increased by 20% in the past three decades⁹ as screening services and treatment options improve.

If people are living longer with a cancer diagnosis, there may be more people choosing to return to work following their cancer diagnosis. It is important that measures to facilitate a return to employment after cancer are sufficiently sensitive to cancer patients', survivors' or carers' needs.

The *Disability Discrimination Act* protections against discrimination for people affected by cancer, their carers and family members also apply in the context of employment, including in recruitment processes, job offers, terms and conditions, and promotions,



training and other benefits. As with insurance, there are limited exceptions, such as where a person would not be able to perform the inherent requirements of the job even if reasonable adjustments were made.

The Commonwealth *Fair Work Act 2009* contains protections against unfair dismissals, unlawful terminations and provides other general protections, including leave entitlements, which offer additional safeguards for people affected by cancer and their carers in the employment setting.

Key concerns

There is little evidence about the nature and extent of employment-related problems for Victorians diagnosed with cancer. This is partly due to there being only limited evidence of people affected by cancer making employment-related complaints to human rights commissions or pursuing court action.

Stakeholder feedback

To explore this issue further, questions about employment experiences were included in the 2013 online survey with stakeholders regarding the key legal issues for people affected by cancer.

Survey participants were recruited through Breast Cancer Network Australia's Review and Survey Group and primarily were women with an experience of breast cancer.

Survey findings

The majority (72%) of respondents thought that discrimination in employment is a problem for people affected by cancer, even if they had never worried about being discriminated against or experienced discrimination themselves.

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.

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.

A third of respondents indicated that they were worried about being treated unfairly because of cancer.

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 who had worried about being treated unfairly, 70% said that they had taken action to avoid being treated unfairly. Such actions commonly involved minimal disclosure of diagnosis and treatment, and taking minimal time off.

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

Almost a quarter (23%) said they suspected that they had been treated unfairly at work, or when

applying for work. (It is unknown how many of the respondents were working at the time of the cancer diagnosis.)

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

None of the respondents had ever made a formal complaint, including the respondents who said that they had been treated unfairly at work due to 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.

Almost half (48%) 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. Many of those who considered that changes to the law were required emphasised that longer timeframes within which to make complaints were needed:

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.

Respondents were asked what would make things easier for people who continue to work or return to work after cancer. 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. 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.

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. Some respondents also emphasised the need for more readily available information about employment rights and laws for employees.

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.

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.

Recommendations

Responses to the issues above will require a combination of law and policy reform and an extension of support services for people affected by cancer.

There is also a need for research to more clearly define the problem.

The findings of the survey were based on a limited sample of Victorians affected by cancer, primarily women with a diagnosis of breast cancer. There is the need to expand the research to include a broader range of people and cancers.

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.
- Additional research to accurately assess the extent and nature of employment problems facing people affected by cancer and their carers.
- More flexibility in the timeframes for making complaints about dismissal or termination.

Information resources

As part of our education strategy, we developed a factsheet for people affected by cancer and their carers to inform them of their rights in relation to employment and cancer.

We also contributed to an international resource to help employers from all over the world to better support employees living with cancer to return to work.



End of life decision-making: advance care planning and substitute decision-making

Planning for the end of life can be valuable for all members of the community, whether or not a person has cancer.

Advance care planning (ACP) 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.
- 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.¹⁰

Expressing and recording clear wishes and directions, in addition to appointing a substitute decision maker, can improve end of life care and increase the likelihood that a person's family, carers

and healthcare team can make decisions that they feel confident are in accordance with the person's preferences and best interests.¹¹ 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.

Key concerns

Laws relating to advance care planning differ greatly across the states and territories. This can lead to confusion and different outcomes for patients depending on which jurisdiction they are in.¹⁰

Advance care planning and end of life decision-making can be confusing processes, 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.

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, or withhold, 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.

Victoria's *Medical Treatment Act 1988 (Vic)* (sections 5 and 5A) provides a statutory right for a patient, or their agent, to make a refusal of treatment certificate in respect of medical treatment generally or treatment of a particular kind, but for a current condition only.

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.

Uncertainty about whether advance care directives must be followed and who has the power to make which decisions, in respect of a patient who lacks capacity, can result in delay when life and death decisions need to be made. This lack of clarity can result in anguish for carers and health professionals.

Stakeholder feedback

To determine community opinions, questions concerning end of life decisions were included in the online survey (see page 7), which was distributed primarily through Breast Cancer Network Australia.

Survey findings

Many respondents acknowledged the importance of advance care planning; while at the same time admitting to 'not yet' having any arrangements.

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

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.

Others seemed to delay thinking about, or acting on, advance care planning. There are clear reasons for this reticence, as 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.

The majority (83%) of survey respondents indicated that people affected by cancer and their carers need more information, and education, about rights and responsibilities at the end of life.

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.



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 that they were never given a choice in such matters if the situation was suitable for their involvement in deciding.

Other feedback from health professionals indicated a desire for more information about how to start advance care planning conversations with their patients and for clear information about the relevant legal frameworks.

Recommendations

Law reform

There is a need for changes in Victorian law to improve specific areas in relation to end of life law and advance care planning.

We support the Victoria Law Reform Commission's (VLRC) recommendations, 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.¹²

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

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. This would be particularly useful in emergency situations. This is consistent with recommendations made by the VLRC and in other stakeholder consultations.

The lack of consistency across jurisdictions highlights the need to harmonise laws relating to advance care planning across Australia.

Education and information

Equally important is the provision of appropriate education about advance care planning options and legal frameworks for people affected by cancer, their carers, substitute decision makers and health professionals.

Part of this may 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 will involve developing education tools to improve how health professionals, and lawyers, talk about death and dying.



Advance care planning education and information

Advance care planning webinars

To address the identified need for information and education about advance care planning and the law, we hosted web-based seminars (webinars). This method of delivery has the advantage that people from diverse geographic locations can take part. It allows participation from those who would be unable to physically attend a seminar in a metropolitan setting.

Additionally, recordings of webinars can be posted online and therefore the information is available to many more people for an extended period of time, and can readily be shared with friends and colleagues.

Advance care planning webinar for patients and carers

On 20 April 2015, we hosted a webinar titled 'Contemplating and communicating your future healthcare wishes: Advance Care Planning'.

This seminar was for people affected by cancer and their carers.

It was facilitated by the McCabe Centre's Sondra Davoren and featured a 30-minute presentation by McCabe Centre legal policy advisor, Dr Deborah Lawson, on the importance of advance care planning; ways the law facilitates advance care planning; and how to appoint an agent and record wishes to inform future health care.

A panel discussion followed, featuring Deborah, palliative care physician Dr Jenny Weil and oncology clinical nurse specialist Clem Byard responding to questions posed by participants at registration.

The webinar can be viewed at: https://www.youtube.com/watch?v=gMy_sXAMPnw

Advance care planning webinar for health professionals

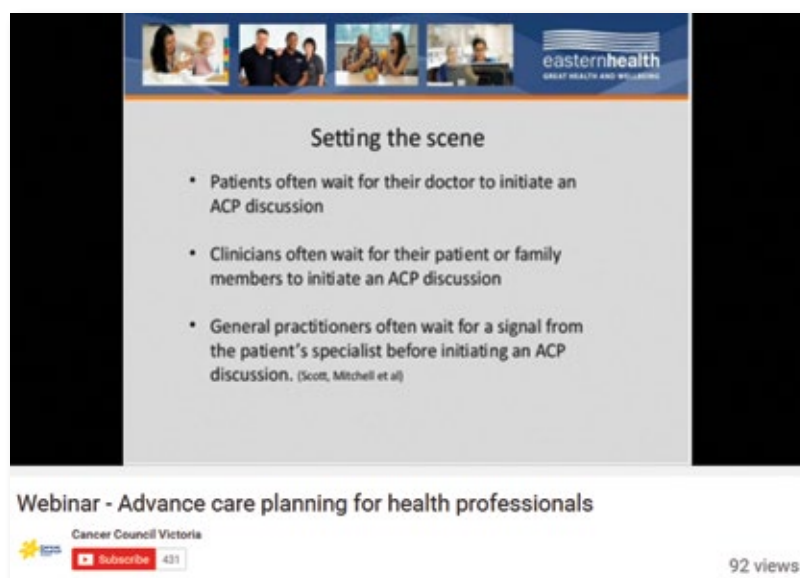
In July 2015, we hosted a second webinar on advance care planning, this one for health professionals. The webinar was titled 'Advance care planning for health professionals – starting the conversation and understanding the law'.

Dr Deborah Lawson introduced the context for the webinar before Eastern Health senior nurse and advance care planning program lead, Sam Brean, provided practical strategies to start advance care planning discussions with patients.

Office of the Public Advocate legal officer Claire McNamara presented on the law relating to advance care planning, including rights and responsibilities of substitute decision-makers and the legal status of advance care directives.

The presenters were joined for a panel discussion by Deakin University and CCV researcher Dr Anna Ugalde, who is currently investigating patient comprehension of advance care planning.

The webinar can be viewed at: <https://www.youtube.com/watch?v=zqu3lygGxDQ>



Participants and feedback

Almost 60 people took part in the live webinars. These included people affected by cancer, their carers and health professionals.

About one third of the participants in each of the webinars were from regional Victoria.

Evaluation suggested that participants gained an improved understanding of the importance

of advance care planning for end of life treatment decisions and the law relating to advance care planning, including knowledge of key documents and further resources.

Making webinar recordings available on CCV's YouTube channel has been found to be an effective means of expanding their influence, with more than 250 viewings of the videos to date.

Advance care planning education for regional health professionals

In partnership with the Gippsland Region Palliative Care Consortium (GRPCC), we developed and delivered advance care planning education sessions for regional GPs and practice nurses in Sale in 2014, and Wonthaggi in 2015.

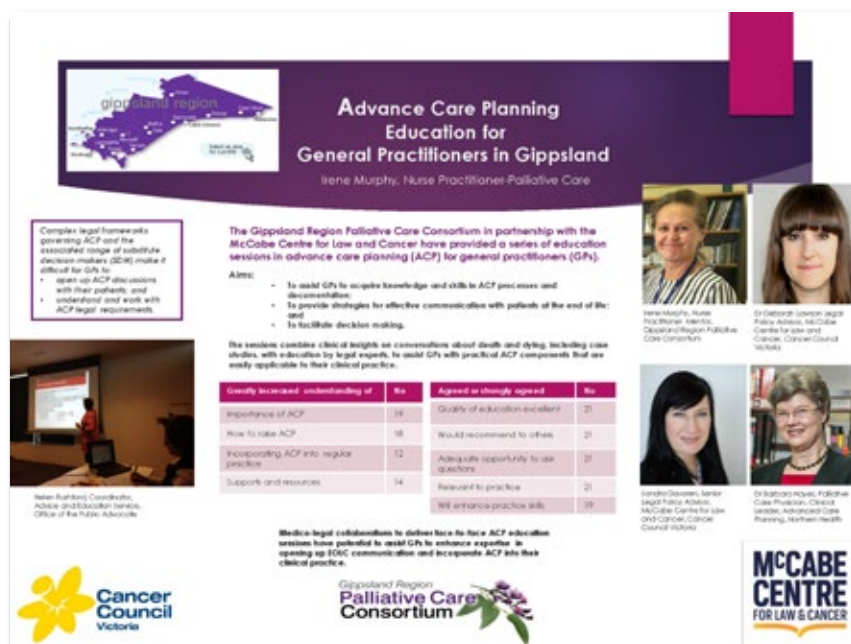
General practitioners, practice nurses, care coordinators and social workers attended the sessions.

The education program comprised of two 60-90 minute sessions at each of two GP clinics.

The first sessions were presented by palliative care specialist and Northern Health Advance Care Planning program lead Dr Barbara Hayes, who provided practical strategies for discussing and implementing advance care planning in general practice.

The second sessions were presented by representatives from the Office of the Public Advocate, who focused on the law relating to advance care planning, illustrative case studies and supports for health professionals with questions or concerns about advance care planning.

The sessions were evaluated positively by participants, who reported gaining a greater understanding of how to discuss and incorporate advance care planning into their practice, greater knowledge of the relevant laws and where to seek further information and support.



This work has been profiled internationally and locally in oral presentations at:

- International Conference on End of Life Law, Brisbane, August 2014;
- International Conference on Advance Care Planning and End of Life Care, Munich, September 2015 (attended by Deborah Lawson with the support of a travel grant from the Palliative Care Research Network of Victoria).
- National Advance Care Planning and End of Life Law Conference, Melbourne, November 2015.

We expect that these education sessions will be felt more widely, as participants take this information to their communities. As one participant said, "I work with elderly people who I can now pass some of this on to."

Case studies flow and narrative excellent. Capacity to consent to make decisions very important element I take home today..

Law reform submissions

Victorian Parliamentary Inquiry into End of Life Choices

Project staff led the development of CCV's submission to the Victorian Parliament's Inquiry into End of Life Choices in August 2015.

The submission emphasised that there is already a range of laws in Victoria that allow and support people to make informed decisions regarding their own end of life care and choices.

The submission discussed improvements required to clarify the law (to improve understanding and application) and to strengthen protection of patients' choices.

Key recommendations included:

- That the refusal of treatment certificate scheme be replaced with broader statutory advance care directives (in prescribed form) that can be made in respect of future as well as current conditions and provide for advance consent in addition to advance refusal.
- That legislation governing advance care directives should also clarify the relationship between substitute decision-makers and advance care directives, including the extent to which instructions in advance care directives are 'binding' or 'advisory'.

The submission can be read at:
http://www.parliament.vic.gov.au/images/stories/committees/lpic/Submissions/Submission_939_-_Cancer_Council_Victoria.pdf

Greater say for Victorians: Improving end of life care

A discussion paper on a framework for end of life care in Victoria

In December 2015, project staff led the development of CCV's submission in response to the Victorian Department of Health and Human Services discussion paper on a framework for end of life care in Victoria.

The submission supported the Government's commitment to strengthening end of life care planning through legal reform that enshrines advance care planning in law, and reiterated our recommendations in this regard to the Inquiry into End of Life Choices.

We made a number of other recommendations relating to the need for greater investment in and resourcing of palliative care services, and health workforce development.



Australian Research Council Linkage Grant

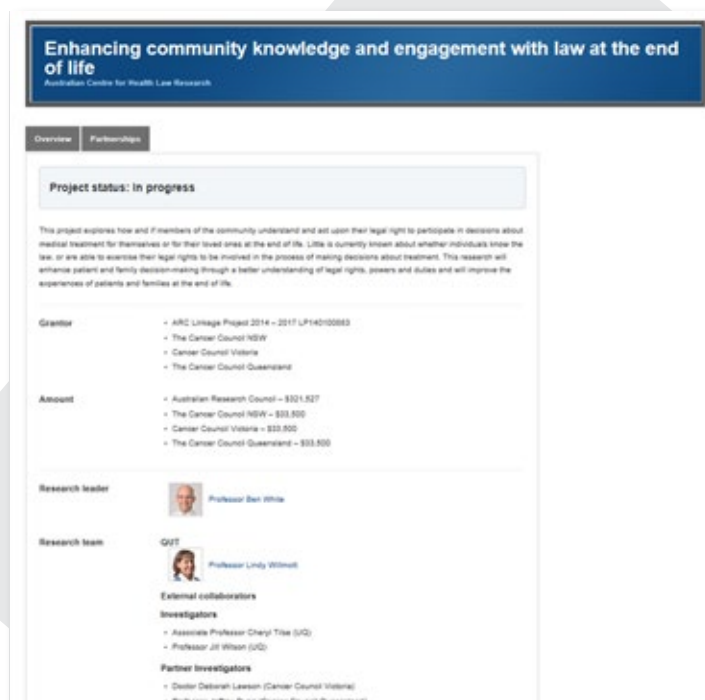
Enhancing Community Knowledge and Engagement with Law at the End of Life

In 2014, Queensland University of Technology (QUT), the University of Queensland (UQ) and Cancer Councils Victoria, NSW and Queensland were awarded an Australian Research Council Linkage Grant for the project *Enhancing Community Knowledge and Engagement with Law at the End of Life*.

The project is led by Chief Investigators Professors Ben White and Lindy Willmott from the Australian Centre for Health Law Research at QUT and Associate Professor Cheryl Tilse and Professor Jill Wilson from UQ. The McCabe Centre's Dr Deborah Lawson is the partner investigator for CCV and played a key role in coordinating and securing participation in the project and funding support from Cancer Councils Queensland and NSW.

This research aims to improve participation of patients and families in treatment decisions at the end of life. Increased participation will improve the experience of patients and families at this important time. The research promotes strategic alliances between established researchers at two universities and Cancer Councils in three states, where there is shared commitment to solving a significant and growing social imperative to improve how end of life treatment decisions are made.

Participation in this research has informed our work on end of life law, allowed for greater information sharing about the McCabe Centre's work in this area, and has fostered collaboration with other important stakeholders in this area.



<https://www.qut.edu.au/research/research-projects/enhancing-community-knowledge-and-engagement-with-law-at-the-end-of-life>

End of Year Symposium

Law and Cancer: research and implications for clinical practice

We collaborated with CCV's Clinical Network team to develop and host a symposium, *Law and Cancer: research and implications for clinical practice*, at the Melbourne Town Hall on 25 November 2015.

The symposium discussed the law in practice as it relates to the delivery of patient care, including the legal frameworks governing informed consent, medical negligence and end of life decision-making. It offered recent research findings and aimed to clarify the law, patients' rights and clinicians' responsibilities in these areas. The symposium was open to health, legal and other professionals.

The event was facilitated by Bill O'Shea, lawyer and radio contributor (previous General Counsel of Alfred Health). Dr Deborah Lawson presented *Informed consent in Victorian cancer care - some research findings*. Our ARC Linkage Grant partner Professor Ben White presented *Medical professionals' knowledge, attitudes and practice relating to the law on withholding/withdrawing life-sustaining treatment - survey results*.

Following the presentations, a robust panel and Q&A discussion explored when and how the law impacts on the provision of patient care through a case study.



Symposium panel members: Natasha Michael, Meron Pitcher, Ian Haines, Neill Murdoch and Ben White

The panel consisted of representatives from the legal and medical sectors:

- Associate Professor Ian Haines, Senior Medical Oncologist & Palliative Care Physician, Cabrini Health
- Associate Professor Natasha Michael, Director of Palliative Medicine, Cabrini Health
- Neill Murdoch, QC, Melbourne
- Ms Meron Pitcher, Unit Head of Surgery, Western Health (Sunshine Hospital)
- Professor Ben White, Director of the Australian Centre for Health Law Research at Queensland University of Technology

This event was highly anticipated, and very well-received. Approximately 70 people attended, comprising cancer clinicians, lawyers, allied health professionals, researchers, students and members of consumer advocacy and support groups.

Informed consent in Victorian cancer care

In Australia, except in cases of emergency or necessity, all medical treatment must be preceded by the patient's (or a substitute decision-maker's) consent.

Consent to treatment is valid if the decision-maker has capacity and gives their consent voluntarily once they've been informed in broad terms of the nature of the procedure which is intended. Treating in the absence of consent could result in legal action against a health professional for battery or assault.¹³

Health professionals also have a duty, actionable through the tort of negligence, to exercise reasonable care and skill in the provision of professional advice (and treatment) to their patients. In terms of the doctor's duty to inform patients, the leading Australian case is *Rogers v Whitaker*, in which the High Court of Australia stated that:

*"a doctor has a duty to warn a patient of a material risk inherent in the proposed treatment; a risk is material if, in the circumstances of the particular case, a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it or if the medical practitioner is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it."*¹⁴

In broad terms, the term 'informed consent' refers to a 'person's voluntary decision about medical care that is made with knowledge and understanding of the benefits and risks involved'.¹⁵ The aim of informed consent, also referred to as 'informed decision-making', is to enable patients to make decisions about their treatment based on an adequate understanding of their illness and available treatment options.

Informed financial consent is an important related concept, which describes the expectation that patients should be fully informed about medical costs prior to commencing a procedure or treatment, or a treatment path that may involve ongoing costs, as well as throughout any follow-up treatment.¹⁶ This allows patients to factor in any out-of-pocket costs (those not covered by Medicare or private health insurance) when deciding which tests or treatments to undertake.

Private hospitals and day procedure centres in Victoria are required to ensure that patients are given information about fees to be charged by the hospital or centre and any likely out of pocket expenses.¹⁷ General principles of contract law and the duty to inform in tort may also apply, in addition to some consumer protection laws.



Key concerns

The growing complexity of cancer care, and the rise of new, targeted and often expensive therapies, means that informed consent, including informed financial consent, is a critical issue for cancer patients. Failure to obtain informed consent can result in negative medical and/or financial outcomes for cancer patients, who may have chosen a different treatment path if fully aware of the benefits and risks of available treatment options and associated out-of-pocket costs. Failure to obtain properly informed consent can also have severe legal and professional ramifications for medical practitioners.

Australian and international studies, suggest that many people with cancer consider that they are not given enough information upon which to make informed decisions.^{18,19} Patients frequently display misunderstandings about their illness, prognosis and treatment;

for example, in one study a third of patients with metastatic cancer believed that their cancer was localised, and a third of patients receiving palliative treatment believed that their treatment was intended to be curative.²⁰

A recent Senate inquiry — *Out-of-Pocket Costs in Australian Healthcare* — reported that practices for obtaining informed financial consent are often inadequate.

It is known that out-of-pocket costs for cancer patients can easily reach tens of thousands of dollars,²¹ and that it is common for cancer patients to experience financial difficulties, including as a result of out-of-pocket costs.^{22,23}

Research - online survey and focus groups

To inform our understanding of how Victorian cancer patients experience informed consent processes, we undertook an online survey and commissioned two focus groups, with the aims of:

- Obtaining patient feedback regarding:
 - how well legally and medically relevant information is being provided to Victorian cancer patients, and whether individuals feel able to make informed decisions about their treatment
 - the barriers that may prevent individuals from sufficiently understanding the information they are presented with

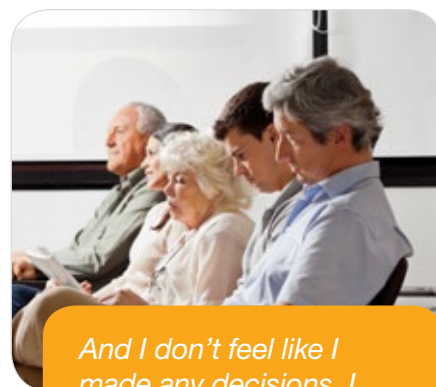
- Utilising this feedback to consider if, and how, informed consent and informed financial consent laws, professional guidelines and practices can be improved.

Eligibility for the survey and focus groups was limited to persons who had received a cancer diagnosis within two years of the date they completed the survey, or attended the focus group, and who received their medical care in Victoria.

In both the survey and focus groups, patients were asked questions about the information they were given by their medical practitioners regarding their diagnosis and treatment. These were designed to gauge whether patients had been given information consistent with legal and professional standards. The survey asked participants 'yes/no' style questions, and also provided 'comment' boxes, allowing them to explain their experiences in more detail and provide general comments about how the consultations with their medical practitioners could have been improved. Participation in the survey was anonymous to encourage candid responses.

The focus groups asked similar questions, but allowed us to explore participants' experiences in greater detail than was possible in the survey.

The survey was completed by 113 people who were diagnosed with cancer, 104 of whom had received treatment (Figure 2). Most respondents had private health insurance (Figure 3). Facilities that provided treatment were private, public or a mix of public and private (Figure 4).



And I don't feel like I made any decisions. I just went along but none that I was unhappy with or resisted.

Invitation to participate in the survey was extended through a range of means including email lists, newsletters and social media. The large proportion of participants with breast cancer, and to a lesser extent, prostate cancer, reflected the assistance of the Breast Cancer Network Australia and the Prostate Cancer Foundation Australia.

Most participants (79%) were between the age of 41 and 70. Eighty-four per cent were female. Sixty-eight per cent lived in metropolitan Melbourne and 32 per cent in regional Victoria.

The focus groups were conducted with the support of an external focus group provider. One group included women who had been treated for breast cancer, the other men who had been treated for prostate cancer. There were up to ten participants per group, with an

There wasn't a lot of time spent on the end result, what I would look like. There wasn't any pictures. After the reconstruction I was like 'I don't like them, they're awful'.

age range of 28 – 73 years, 45 per cent being between the ages of 51-60 years.

Due to the relatively small sample size of Victorian patients consulted for this report, and the predominance of respondents with breast or prostate cancer, the results need to be viewed as suggestive, rather than representative, of the views and experiences of all Victorian cancer patients.

Survey findings

Most respondents felt well informed about their diagnostic tests, the nature of their cancer, the expected benefits and outcomes of treatment and what their treatment would entail (see Table 1).

However, there were some less encouraging findings in respect of the proportion of respondents who felt that they had not received enough relevant information with regard to specific areas required by law, including treatment options and risks, recovery times and possible negative long-term outcomes, including side effects.

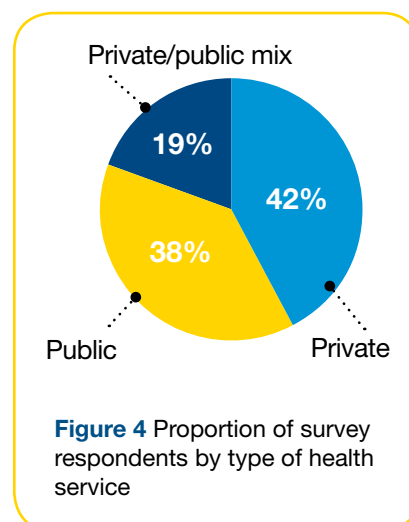
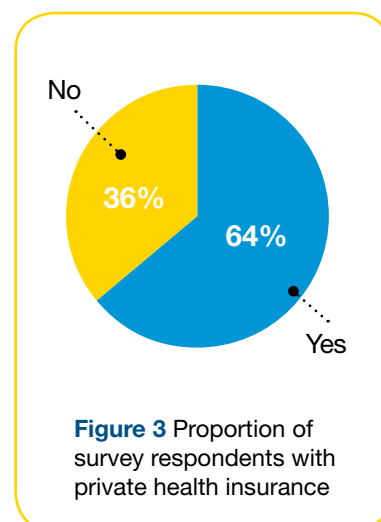
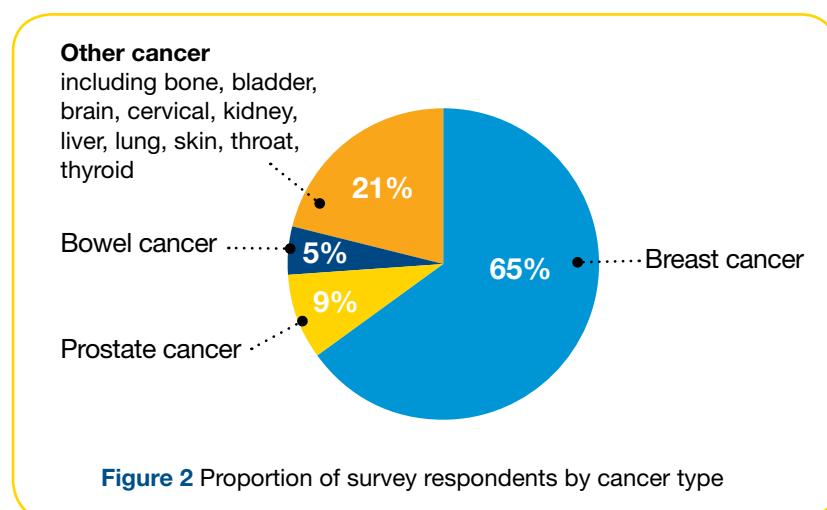
Perhaps of most concern is the finding that one in three (34%) respondents reported experiencing treatment side effects or harm that they were not warned about. Unexpected side effects ranged from:

- minor (10 respondents)
- moderate (25 respondents)
- severe (11 respondents)

and were:

- short term (8 respondents)
- medium term (9 respondents)
- ongoing (29 respondents)

Table 1. Percentage of survey respondents who felt that they were given enough relevant information about:	Yes %	No %
Expected benefits or outcomes of treatment	90	7
What treatment would involve	87	11
Diagnostic tests (e.g. biopsy, blood)	86	9
The nature of their cancer (e.g. type, how advanced)	80	12
Other treatment options, risks, benefits	39	50
Option of not having treatment	38	54
Any significant long-term physical, emotional, mental, social, sexual, financial or other outcomes	38	56
How long it should take to recover from treatment	26	64
Possible long-term side effects, including likelihood, seriousness	24	69



Focus group findings

Key issues for the women included:

- Receiving too much information, which resulted in many of the participants feeling overloaded and overwhelmed. This was partly due to the speed of diagnosis and commencement of treatment, which was less than one week for some women.
- Most reported being generally unprepared for their diagnosis, and were often alone at the time.
- Most felt that they had received adequate and clear information but that they had been unable to process it at the time.
- Participants felt that the treatment decision was generally made for them, but that this was appropriate.
- Few were given a choice of treatment approach (and none were provided with treatment options or the option of no treatment), but none felt pressured to follow the proposed plan. All but one participant went along with the proposed plan, and were happy and confident to do so.
- Except for disappointment with breast reconstructions, the respondents reported no regrets.

In terms of what was missing for the women participants, themes included:

- Clear simple information about their own cancer type, prognosis and treatment options (too much generic information)

- A support person at diagnosis
- Lack of information about side effects, including of diagnostic tests
- Recovery times
- Breast reconstruction outcomes.

Key issues for the men included:

- Not receiving enough information at diagnosis.
- Not having enough time during the initial diagnosis discussion to ask questions and understand their prognosis and options, resulting in feelings of being overwhelmed and ‘out of control’. However, the entire experience did allow most men time to discuss, digest information and seek multiple opinions.
- Managing the division of medical opinion on interpretation of PSA test results, and understanding the best approach for them.
- Being provided with their options and the literature with the direction to “go away, think about it, make a decision”. Many men felt that they had to go to considerable effort to pick the best option for them.
- Most felt that they made their own or a joint treatment decision with their doctor.
- None felt pressured or regretted their treatment.

In terms of what was missing for the male participants, themes included:

- Clarity and direction about the options, advantages, disadvantages, meanings of test results and a recommended approach

- Time at diagnosis to ask questions without feeling rushed
- A support person to help explain or discuss information about diagnosis
- Information about side effects
- Information on counselling and support groups, to take the load off partner and family.

Findings on informed financial consent

Focus groups

All but one person in each focus group were treated privately (and were insured). Patients were told that treatment in the public system was possible but that the waiting times, or lack of continuity of care, might impact on their outcomes.

Most participants were told to expect costs, but few were prepared for the extent of their costs.

For many, the treatment costs were explained and expected but not the costs associated with diagnostic testing. Many reported being sent from one test to the next, with no information about the likely costs.

However, there was a pervasive view that there was no real choice when it came to cancer diagnosis and treatment costs – it’s ‘a matter of life or death’, and the money becomes unimportant or irrelevant.

I do think the surgeon explained things very clearly. I was also happy with my oncologist.

Feedback about costs from survey respondents

- 79% had out-of-pocket costs
- Some or all costs were unexpected for 45%
- Out-of-pocket costs ranged from \$200 to \$20,000
- While most patients would still have chosen the treatment, knowledge of costs would have allowed shopping around, choosing to be treated as a public patient, better financial planning

Discussion

Feedback from the survey and focus group participants showed that there are a range of barriers that can inhibit or prevent informed consent from being obtained. These include patients feeling overwhelmed and in shock from their cancer diagnosis, a perceived lack of time for consultations, and the speed at which some patients progress from receiving a diagnosis to commencement of treatment.

These findings highlight the complexities in obtaining informed consent to cancer care. There are a number of challenges for health professionals.

The law requires that they consider the 'particular patient' when considering what information to provide (and how).

But there is a broad diversity of patient views and experiences regarding informed consent and how much information patients want.

Some report receiving far too much written information and feeling overloaded, while others report receiving insufficient information. Some patients prefer not to know much about their diagnosis, treatment and prognosis. Many reported that the distress they felt at diagnosis impacted on their ability to absorb information.

Health professionals need to be aware of the range of patient attitudes towards informed consent so that they can treat their patients as individuals and assess the best way to communicate the legally required and other relevant information to the patient in front of them.

A range of more objective factors also impact on patient experiences of informed consent, including cancer type, stage at diagnosis, treatment pathways and systems of care in place for different cancers. The findings of this research highlight significant differences between experiences of breast cancer and prostate cancer – these experiences are likely to differ again for other cancers.

There is a need for greater understanding of the systemic challenges to informed consent, including the differences experienced between cancer types, partly due to differences in screening, diagnosis, medical opinion, prognoses and treatment pathways.

The limited time between diagnosis and treatment for many patients, and the common patient perception that consultation times are too short, also present challenges.

Finally, the complexity of the healthcare funding and payment models in Australia make it difficult for both health professionals and patients to understand and predict out-of-pocket costs.

Recommendations

1. Greater consistency in informed consent processes is required. The challenge is to ensure that the good practices adopted by many health professionals are implemented across the board.
2. It seems likely that some health professionals require further education or training to improve their knowledge of the purpose of informed consent processes, their legal and professional obligations and best practice in the provision of information to patients.
3. Better informed financial consent mechanisms are required 'to ensure patients are fully informed about treatment costs, before initial treatment as well as throughout any follow-up treatment'.¹⁴

He ... gives you the diagnosis ... a lot of information but then in five minutes you're out the door. Pretty much you've got cancer and a box of books.

Regulation of complementary and alternative therapy providers

The term ‘complementary and alternative medicines’ (CAM) refers to a diverse group of healthcare practices, products and systems not presently considered to be part of conventional medicine (also known as mainstream, medical or orthodox treatments).

While ‘complementary’ therapies’ (also known as holistic, natural or traditional therapies, or traditional medicine) are often used together with conventional medicine, ‘alternative’ treatments (also known as unconventional treatment) are used in place of conventional medicine.²⁴

Studies show that between 17 to 87% of cancer patients use at least one form of CAM therapy while receiving conventional treatment.²⁵

Most cancer patients who use CAM do so as an adjunct to conventional cancer treatment (for example, surgery, radiotherapy, chemotherapy, hormone therapy, immunotherapy) and there is some evidence to suggest that some CAM therapies are beneficial in reducing common side-effects of conventional treatment as well as disease symptoms.²⁶

However, there can be risks in using some CAM, including the risk of adverse interactions with conventional cancer therapies.²⁷

Beneficial complementary therapies

- Chemotherapy-induced nausea may be relieved by acupuncture and acupressure
- Cancer-related pain can be reduced by acupuncture, hypnosis, therapeutic touch, and massage
- Fatigue may be lessened by exercise, therapeutic touch, meditation and relaxation techniques
- Stress may be reduced, and quality of life improved, by yoga, meditation and exercise
- Anxiety and depressive symptoms may be reduced by meditation and relaxation techniques.^{24,25}

One of the greatest risks is that patients may use alternative therapies in place of conventional treatment, reducing their chances of remission or cure.²⁶

Some alternative therapies, including those that have been promoted to cancer patients by unscrupulous providers (such as extreme diets; very high doses of vitamins and dietary supplements; and oxygen, ozone, water, magnets and microwave treatments) do not



have any evidence to support their effectiveness, and may be harmful, even if used as intended by the providers.²⁸

Key concerns

While the use of some complementary therapies is safe and may have benefits, there have been several high profile examples in the past decade of unscrupulous providers taking advantage of vulnerable individuals, often charging large sums of money for unproven or dangerous treatments.²⁹

These cases have highlighted gaps in the regulatory framework for CAM practitioners who are not members of a registered profession.

Whereas registered practitioners are governed by professional Boards with powers to discipline and de-register members who

fail to meet set professional standards, no such mechanism currently exists in Victoria for unregistered practitioners.

The regulatory framework for health practitioners in Victoria

Australia has a two-tiered legal framework for the regulation of health practitioners.

Registered health practitioners

The most rigorous form of regulation applies to health professionals who are registered under the National Registration and Accreditation Scheme (NRAS).

Each registered profession has a National Board with broad powers to regulate its members and to protect health consumers.

The Boards are supported by the Australian Health Practitioner Regulation Agency. In addition to setting requirements for registration of practitioners and the development of professional standards, codes of conduct and guidelines, one of the most significant features of the registration scheme is the authority given to the relevant body to discipline registered practitioners.

Lesser breaches of professional standards can be dealt with by the National Boards. Cases involving professional misconduct (the most serious breach) must be referred to the relevant state or territory tribunal. In Victoria, this is the Victorian Civil and Administrative Tribunal (VCAT)³⁰ which has the power to suspend or cancel

Professions currently registered under the NRAS

- Aboriginal and Torres Strait Islander Health Practice
- Occupational Therapy
- Optometry
- Dental practice
- Pharmacy
- Medicine
- Physiotherapy
- Chinese Medicine
- Osteopathy
- Chiropractic
- Medicinal Radiation Practice
- Podiatry
- Nursing and midwifery
- Psychology

a practitioner's registration or place conditions on their practice.³¹

Unregistered health practitioners

In the absence of a specific regulatory mechanism, unregistered practitioners in Victoria may be subject to different and overlapping legal frameworks, not all of which are directly targeted at health professionals.

Several of the laws described below apply equally to registered and unregistered practitioners. However, in the absence of the type of disciplinary powers available to the registered professions, such laws can serve a more significant regulatory function in relation to unregistered practitioners.

Many unregistered practitioners belong to **voluntary professional associations** that provide varying levels of self-regulation for their members. But ultimately their rules or orders are not enforceable by the courts and practitioners may choose not to join the relevant association, or may

cease membership, to avoid disciplinary procedures.

The **Australian Consumer Law** prohibits certain types of behaviour for persons or corporations engaged in trade or commerce, including health professionals.³²

Unlawful behaviour includes, among other things, engaging in misleading or deceptive conduct, including in relation to goods or services; unconscionable conduct; and unfair terms of contract.³³

Consumer protection law has proved to be a particularly important, although infrequently used, tool for regulators against unregistered health practitioners who provide unproven treatments to cancer patients.²⁹

All states and territories have independent **statutory health complaints entities**, the primary functions of which are the investigation, resolution and conciliation of consumer complaints against health service providers, as well as conducting investigations of health system failures.³⁴

.....

The relevant health complaints entity in Victoria is the Office of the Health Services Commissioner (OHSC), to which patients are able to make a complaint where a health provider (whether registered or unregistered) has acted 'unreasonably' in providing a health service.³⁵

The OHSC offers a useful alternative legal avenue for health consumers, allowing patients to seek remedies from a provider such as an explanation, apology, remedial treatment or compensation, without going to court.³⁶

However, the OHSC's role is currently limited by its lack of enforceable powers. It lacks the authority to suspend or prohibit a health practitioner from providing a health service, or to place conditions on how that service is provided.

Negative licensing schemes

Three Australian states (NSW, SA and Queensland) have implemented "negative licensing" schemes, which do not restrict entry to practice (like other business or occupational licensing schemes) but allow action to be taken against unregistered practitioners who fail to comply with standards of conduct or practice specified in a code of conduct.

A National Code of Conduct for unregistered health practitioners

The regulatory framework for unregistered health practitioners was examined by the Australian Health Ministers Advisory Council as part of a review conducted between 2010 and 2015.^{34, 37, 38}

The terms for a National Code of Conduct for Health Care Workers (the National Code) were agreed to by the Council of Australian Governments' health ministers on 17 April 2015.

The National Code aims to strengthen regulation of unregistered health practitioners by setting standards of conduct and practice, and providing for the mutual recognition of prohibition orders.

Further, Health Ministers have agreed to establish an online National Register of Prohibition Orders.³⁸

Key elements of the National Code include:

- A health care worker must not attempt to dissuade a client from seeking or continuing medical treatment (code 3(2)).
- A health care worker must not claim or represent that he or she is qualified, able or willing to cure cancer or other terminal illnesses (code 8(1)).
- A health care worker who claims to be able to treat or alleviate the symptoms of cancer or other terminal illnesses must be able to substantiate such claims (code 8(2)).

- A health care worker must not engage in any form of misinformation or misrepresentation in relation to the products or services he or she provides or the qualifications, training or professional affiliations he or she holds (code 9(1)).
- A health care worker must not financially exploit their clients (code 12(1)).³⁸

The National Code, once enacted in a state or territory, applies to any unregistered health practitioner (and in some circumstances to NRAS registered practitioners who are providing services outside the typical scope of their registered profession).

Each state and territory is responsible for progressing legislative changes to give effect to the National Code.

Recommendations

1. We support the negative licensing model and National Code of Conduct as it appears to provide a cost-effective means of protecting the public from incompetent, unethical or impaired practitioners.
2. It is essential that the Office of the Health Services Commissioner (or a newly named body) is provided with sufficient resources to adequately administer and enforce any future Code of Conduct that may be adopted in Victoria.
3. It is essential that any future negative licensing scheme is closely monitored to ensure that it meets its intended purpose and does not have any unintended negative consequences.

Advocacy activity

In July 2015, we were invited to make a submission to a targeted stakeholder consultation on the *Modernising Victoria's Health Complaints Legislation* consultation paper. Our submission supported an inclusive purposive approach to the jurisdiction of the Health Services Commissioner in order to capture previously unheard of or emerging alternative and other 'health services'.

We proposed a definition of 'health service' that incorporated language that would capture the claims (whether express or otherwise) of health services, in addition to the actual services provided, to provide stronger protection against unfounded and unethical claims with respect to curing cancer.

Our submission also recommended that:

- the Commissioner be able to refer a practitioner, whether registered or unregistered, to an appropriate body to address issues of conduct, competence or health
- legislation be introduced to address the regulatory gap regarding unregistered practitioners, which should include a code of conduct for unregistered practitioners and powers for the Commissioner to issue public warning statements and prohibition orders preventing practitioners from continuing the conduct
- the Commissioner should have 'own motion' investigatory powers' where he or she becomes aware of a matter about which someone could but hasn't made a complaint.



Developments

A new *Health Complaints Bill 2016* was introduced in Victoria in February 2016, which incorporates a more inclusive definition of 'health service', capturing the intentions and claims of a wide range of activities that may be offered as health services. The Bill also includes a code of conduct for non-registered health service providers (and those offering services outside of the scope of their registration), based on the National Code of Conduct. The (newly-named) Health Complaints Commissioner is given power under the Bill to place conditions on or prohibit practice by unregistered health service providers where s/he believes it is necessary to do so to avoid a serious risk to the health, safety or welfare of a person or the public. We expect the Bill to be passed in the first half of 2016.

Education activity

On 6 October 2015, we co-hosted a webinar with CCV's Clinical Network team to support health professionals who want to know what action they can take when they're concerned about alternative therapies offered to their patients.

Participants in the webinar, *Alternative therapies in cancer care - regulation and risk webinar*, heard:

- a clinician's perspective on discussing alternative therapies with patients, including useful resources
- how unregistered health practitioners are regulated in Australia, with a focus on avenues for making complaints about unethical or unsafe alternative therapy providers
- about the role of the Australian Competition and Consumer Commission in responding to healthcare complaints
- about the functions and powers of Victoria's Health Services Commissioner with respect to unethical or unsafe alternative therapy providers.

Participants were able to submit questions and topics they wanted the presenters to cover, and could also participate in an interactive 30 minute Q&A session at the end of the webinar.

Thirty-seven people took part in the webinar on the night, including 14 nurses, nine allied health professionals, two radiation oncologists, a medical oncologist, and a person who had experienced cancer.

The webinar recording has been viewed more than one hundred times on CCV's YouTube channel.

We intend to run an updated webinar on regulation of alternative therapy providers in 2016, should the anticipated reforms be introduced.



Next steps

The work in treatment, supportive care and the law initiated through the *Making the law work better for people affected by cancer* project has been integrated into CCV's programs across multiple teams, including the McCabe Centre for Law and Cancer, the Cancer Information and Support Service, Strategy and Support, the Clinical Network and the Office of the CEO. This outcome reflects the value of the work which has been made possible by the major grants received from the Victorian Legal Services Board.

The resulting strengthened collaborations, in particular with the Clinical Network, have greatly enhanced our ability to improve the understanding among health professionals of legal rights and responsibilities for people affected by cancer, their families and health professionals.

Next steps to build on this work include:

- A consultation comprised of our VPTAS advocacy alliance members and others, to inform the Department of Health and Human Services' biennial review of the VPTAS scheme.
- Two further advance care planning education sessions for regional GPs in Bairnsdale and Traralgon in April, in partnership with the Gippsland Region Palliative Care Consortium. A further session is planned for Warragul in June.
- Two events in Law Week, May 2016. Both are open to the public:
 - the first focuses on how the law intersects with cancer care and the rights and responsibilities of clinicians, incorporating an extended discussion of a range of case studies by an expert panel of clinicians and lawyers (Wednesday 18 May, 6 – 7.30 pm, Telstra Conference Centre)
 - the second focuses on advance care planning, exploring, in a sensitive way, how the law can be used to support better decision-making at end of life. The primary target audience is people affected by cancer and those who care for them (Thursday 19 May, 6 – 7.30 pm, The Wheeler Centre).
- Reviewing and updating our factsheets: *Travel Insurance and Cancer*, and *Employment and Cancer*.
- Development and delivery of more webinars in conjunction with the Clinical Network in the latter half of 2016. The likely focus will be anticipated reforms to Victoria's healthcare complaints legislation and legal frameworks governing end-of-life decision-making in Victoria.
- Publishing the findings regarding informed consent in Victorian cancer care in a high-impact peer-reviewed journal.
- Continuing to work with our ARC Linkage grant partners on the project *Enhancing Community Knowledge and Engagement with Law at the End of Life*.
- A 90 minute symposium at the 2016 World Cancer Congress in Paris highlighting how the law can be used to improve patient and family experiences, through illustrative case studies from four different countries.

All of these activities are aimed at achieving the three objectives we articulated at the beginning of this project

Objective 1

Supporting people affected by cancer by improving access and equity in treatment and support options during and after cancer treatment.

Objective 2

Improved understanding of legal rights and responsibilities for people affected by cancer, their families and healthcare professionals.

Objective 3

Law reform to clarify and improve the laws and systems that impact upon the experiences and outcomes for people affected by cancer, their families and healthcare professionals.

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2013 steering committee members

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

Nicola Bruce, Cancer Action Victoria

Professor David Hill, AO, CCV

Associate Professor Michael Jefford, Peter MacCallum Cancer Centre

Dr Carolyn Lethborg, St Vincent's Hospital

Louise Milne-Roch, Victorian Mental Illness Awareness Council

Dr Paul Mitchell, Austin Health Cancer Services

Peter Noble, Loddon Campaspe Community Legal Centre

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

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2014 expert advisory groups

Dr Ian Freckelton QC

Jeanetta Gogol, Australian Natural Therapies Association

Paul Grogan, Cancer Council Australia

Kerry Haynes, CCV

Professor David Hill, AO, CCV

Associate Professor Michael Jefford, Peter MacCallum Cancer Centre

Helen Leaf, Monash University

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Professor Michael Weir, Bond University

2015 advisory group members

Dr Anna Boltong, CCV

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Jonathan Liberman, McCabe Centre for Law and Cancer

Nicola Quin, CCV

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615 St Kilda Road
Melbourne Vic 3004 Australia

T +61 3 9514 6100

W www.cancervic.org.au

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