



Informing the next Victorian Cancer Plan

Cancer Council Victoria Submission **December 2019**



**Cancer
Council**
Victoria

Contents

1	Messages from the CEO and Chair
2	Introduction Inequity in cancer outcomes
3	Cancer in Victoria
4	Achievements
5	Priorities for urgent action
6	Theme 1: Equitable access to treatment and care Embedding optimal care Care coordination
9	Theme 2: Reduce the cost of cancer Informed financial consent Victorian Patient Transport Assistance Scheme Improve access to financial counselling Hospital parking Out-of-pocket costs
14	Theme 3: Invest in primary prevention Obesity Alcohol Tobacco Skin cancer Occupational and environmental cancers
18	Theme 4: Access to screening, early detection and immunisation Bowel cancer screening Cervical cancer screening and HPV immunisation Liver cancer prevention Primary care
23	Theme 5: Invest in supportive care Multidisciplinary care Navigating the health system Psycho-social support Survivorship support Support for carers Palliative and end-of-life care
29	Theme 6: Increase investment and diversify cancer research Better access to clinical trials Low survival cancers Diversify research
32	Theme 7: System improvements Integration Innovation Investment Intelligence Workforce
37	Summary
38	Appendices
42	References

Messages from the CEO and Chair

Message from the CEO

Our extensive consultations across Victoria have highlighted the huge impact cancer has on patients, their support providers and the health system more widely. Our efforts have shown that, despite some of the best survival outcomes anywhere in the world, clinicians and community members continue to report inequity and inconsistencies in Victoria's cancer control system and Australia's universal health care system.

Cancer Council Victoria is uniquely placed to bring together the collective voice of those experiencing and responding to the everyday challenges of a cancer diagnosis. Our submission regarding the next Victorian Cancer Plan provides the evidence and recommendations to support the Victorian Government's target to save 10,000 lives by 2025. Our recommendations have been derived from widespread stakeholder engagement and our work more broadly at Cancer Council Victoria.

Our submission covers the systemic reforms and investment required to achieve population-wide behavioural changes, and improvements in the treatments and care offered to all Victorians. It is interlaced with quotes and experiences

of some of the many hundreds of Victorians who responded to our public surveys and community consultations.

Cancer inequity forms a major theme of our submission. We know outcomes remain poor for people from Aboriginal communities, culturally and linguistically diverse communities, the LGBTIQ+ community, people with disabilities and for people living in rural and regional communities who struggle to access cancer services. Our submission has a specific focus on delivering culturally safe and appropriate prevention programs and support services, and investment in research to improve five-year survival for people with all cancers, including rare cancers.

We believe our recommendations outline the action required to ensure the best cancer outcomes for all Victorians.

Todd Harper



Message from the Chair of the Board

Victoria's growing and ageing population make it imperative that we put in place structures and build capacity to install the foundations for a system that responds to the Victorian Government's long-term vision in cancer control.

Our submission presents a framework to continue to improve cancer prevention programs, foster research to improve quality of life and survival, and facilitate optimal care and treatment for people living with and affected by cancer. We have made over 90 recommendations for change and identified priorities to be considered in implementation. They are strongly informed by evidence and best practice and were consistently identified as key areas of concern.

Our recommendations complement and align with the Government's other health plans, including the Public Health and Wellbeing Plan, the Health & Medical Research Strategy, the Koolin Balit – Aboriginal Health

Strategy, the Public Health Performance Monitoring Framework, the End of Life and Palliative Care Framework and the Mental Health Plan.

We have focused on issues that are fundamental to shift the system over the next four years to improve outcomes across the continuum of cancer control.

Cancer Council Victoria is well placed to work with the Victorian Government and the broader cancer sector to support implementation of a number of recommendations and looks forward to working collaboratively with all stakeholders as we strive towards a cancer-free future.

Professor Jeremy Millar



Introduction

While significant progress has been made to reduce the overall burden of cancer, we need to address critical areas to tip the scales in achieving equity in cancer prevention, care, and survival.

The current Victorian Cancer Plan sets out ambitious targets to demonstrate improvements in cancer prevention and outcomes. We believe achieving these will only be possible through co-production of a cancer control system that draws on the experience of community and clinicians.¹

With this as our core principle, our submission unites the voice of experience with evidence to identify priorities for the next Victorian Cancer Plan and beyond. The experiences of the community and clinicians deepen our understanding of the cancer control system across the state.

To inform our submission, we consulted with more than 600 community members and clinicians across Victoria. Workshops, interviews and online surveys were conducted between June and September 2019. See Appendix 1 for the full consultation schedule.

A total of 344 community members and 100 clinicians completed our online surveys. To identify shared priorities between both groups we asked survey respondents to rank priorities to be addressed in the next Cancer Plan. Survey findings are in Appendix 2.

Along with these consultations, we have referred to the latest evidence and examined data from the Victorian Cancer Registry, Victorian Tumour Summits, and other notable data sources to inform this submission.

Inequity in cancer outcomes: we need to balance the scales

The burden of cancer is not evenly spread in Victoria. People experiencing socio-economic disadvantage, Aboriginal and/or Torres Strait Islander communities, culturally and linguistically diverse communities, people living with a disability, and those who live in regional and rural areas of Victoria have poorer cancer outcomes.

The data shows:

- Cancer incidence and mortality outcomes are worse for Aboriginal Victorians. Overall mortality rates were significantly higher for both Aboriginal men and women (220.4 and 277.9 deaths per 100,000, respectively) than for non-Aboriginal men and women (73.1 and 102.0 deaths per 100,000 men and women, respectively).²
- Victorian patients with head and neck cancer living in the most socio-economically disadvantaged areas have almost 70% greater risk of death than those living in the most advantaged areas.³
- Cancer screening rates are lower in people living with a disability, affected by socio-economic disadvantage, or from Aboriginal or culturally and linguistically diverse populations.^{4,5}
- LGBTIQ+ Australians experience poorer cancer outcomes and are more likely to engage in behaviours that increase cancer risk such as alcohol and tobacco consumption.⁶ There is also evidence to suggest that clinicians who treat this population lack knowledge of their unique health issues.⁷
- Overall, cancer survival rates are higher for residents of metropolitan Melbourne (70%) compared to the rest of Victoria (66%).²

Evidence demonstrates that if members of groups associated with poorer outcomes can access high-quality cancer care, their outcomes are comparable to members of non-disadvantaged groups. This supports the need to invest in models of care for marginalised groups that enable timely referral and access to high-quality treatment.^{8,9}

Cancer in Victoria

Thanks to investment in improving cancer outcomes, great progress has been made in the last four decades, with the overall five-year survival rate increasing from 48% to 69%. However, cancer remains Victoria’s largest disease burden and more needs to be done. Cancer deaths outnumber all other large categories of mortality in Victoria and the average age of death is younger than that from any other large category, including heart disease.¹⁰



THIS YEAR, ANOTHER **35,000** VICTORIANS WILL BE DIAGNOSED WITH CANCER and over **11,000** will die from the disease.



THE FIVE MOST COMMON CANCERS IN VICTORIA

PROSTATE, BREAST, BOWEL, LUNG AND MELANOMA



Collectively accounting for **57%** of all new cancers and **46%** of all cancer deaths.

By 2029–2033, nearly **48,000 VICTORIANS** will be diagnosed with cancer every year.

DEATHS WILL INCREASE BY APPROXIMATELY **20%** TO MORE THAN **13,000** ANNUALLY.



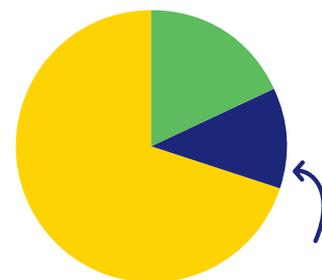
This increase is in part due to the growth and ageing of the population,

AS WELL AS AN INCREASE IN CANCERS CAUSED BY PREVENTABLE RISK FACTORS SUCH AS **OBESITY AND ALCOHOL.**

CANCERS WITH THE LOWEST SURVIVAL

- LIVER** (23%)
- LUNG** (21%)
- CANCER OF UNKNOWN PRIMARY** (13%)
- PANCREAS** (11%)
- MESOTHELIOMA** (6%)

OF ALL CANCER DEATHS: Lung cancer accounts for **19%**



Bowel cancer accounts for **11%**

THESE DEATHS ARE ALMOST **ENTIRELY PREVENTABLE**

Cancer is a leading burden of disease in Victoria with **96** new diagnoses **EACH DAY** (or one every 15 minutes).

Achievements

Throughout our consultations we heard many positive stories of effective models of care making a real difference to Victorians with cancer. Our submission highlights the efforts of dedicated and hardworking health professionals across all disciplines in cancer, working tirelessly to improve patient care. We have included first-hand accounts and case studies of innovative care, some of which are pilot models requiring new funding in this Cancer Plan for upscaling and sustainability.

Cancer Council Victoria acknowledges that great progress has been made on patient outcomes in the last decade thanks to the Victorian Government's commitment to cancer reform. Achievements include:

Prevention and early detection

- Investment in the Shade Grants Program and community education campaigns.
- Tobacco reform including legislation changes to smoke-free areas and the sale, display and advertising of tobacco products – all resulting in the steady decline of smoking rates in some populations in Victoria.
- Reducing the burden of breast cancer through state-of-the-art mobile breast cancer screening and supporting the rollout of digital mammography technology.

Access to treatment

- Continued support and investment in our work on the Optimal Care Pathways.
- Sustained investment in multidisciplinary meetings, including a successful pilot integrating primary care into these meetings.
- Supporting the adoption of the symptom and urgent review clinic (SURC) model of care.
- Investment in the Victorian Tumour Summits which identify work to be undertaken at a local level to improve variations in cancer care.

Access to supportive care

- The 2019/20 Budget recognises the urgent need for increased investment in end-of-life care. Actions include a systems approach to delivery of palliative care, more support for home-based palliative care in rural and regional Victoria, investment in regional palliative care consultancy as well as a 24-hour support line.
- Victorian cancer survivors have benefited from sustained investment in the Victorian Cancer Survivorship Program.
- Recognising the importance of carers with more respite and support as outlined in the 2019/20 Budget.

Research

- Investment has led to Victoria becoming a leader in cancer research. This has improved diagnosis and treatment of cancers such as breast and bowel. Dedicated funding for low survival cancer research will help reduce inequities in cancer outcomes.

Priorities for urgent action

Through our consultations, we have identified key recommendations we would urge the Victorian Government to address. All priorities must target the community groups that experience poorer cancer outcomes: to balance the scales.

Cancer Council Victoria is well placed to partner with the Victorian Government on many of the initiatives outlined in this report. Our international reputation for innovative work in cancer research, prevention and support combined with our status as the leading independent, not-for-profit cancer organisation in Victoria means we can play a leading role in reducing the impact of all cancers on all people.

Victorian priority: Provide equitable access to treatment and supportive care



ACTION: Embed optimal care

We know there are disparities in cancer outcomes across Victoria. Health services to embed quality standards and work together to respond to patient needs.



ACTION: Improve care coordination

Cancer treatment is complex, and people need help to get the best outcomes.

Invest in care coordination to improve treatment and support.



ACTION: Help accessing support

As more people survive cancer, the need for support is increasing.

Dedicated liaison nurses to assist people to access services.

Victorian priority: Reduce the cost of cancer



Cancer treatment has unexpected costs with the highest burden affecting the most vulnerable. **ACTION: Reduce costs and improve transparency to guide decision making.**

Victorian priority: Prevent cancer and detect it early



ACTION: Prevent obesity

Victoria's obesity and overweight rates are not declining.

Invest in obesity prevention campaigns to reduce the risk of cancer.



ACTION: Bowel cancer screening

Only 43% of Victorians participate in the National Bowel Cancer Screening Program.

Targeted media campaign to improve screening rates.



ACTION: Eliminate cervical cancer

With commitment we could eliminate cervical cancer in 10 years.

Increase rates of vaccination and screening.



ACTION: Liver cancer prevention

Liver cancer is the fastest growing cancer in Australia, particularly affecting migrant communities.

Invest in a strategic response to liver cancer.



ACTION: Prevent lung cancer

Lung cancer is Victoria's leading cause of death but is almost entirely preventable.

Strengthen education campaigns to ensure at-risk populations receive support.

Victorian priority: Better access to clinical trials



Less than 6% of adults with cancer participate in clinical trials.

ACTION: Improve access to clinical trials by investing in awareness campaigns and systems.

Theme 1: Equitable access to treatment and care

“Treatment is a postcode lottery. If you are not in the right postcode, you won’t get the same care”
– Cancer clinician consultation, August 2019

“The inequity of what is provided to people who attend (a metropolitan treatment centre) compared to what we can offer people up here (in a regional hospital) is extreme.”
– Regional clinician consultation, September 2019

The greatest inequities in access to cancer treatment exist for rural patients, culturally and linguistically diverse communities, Aboriginal communities and disadvantaged Victorians. This is reflected in the current disparities in cancer outcomes for these groups.

Clinicians noted many positive aspects of cancer care in regional areas, including care closer to home, access to community-led support for patients, and rapid professional development for clinicians. However, the community and clinicians also discussed the barriers to cancer care in regional areas, predominantly associated with travel, limited workforce, constrained resourcing and inadequate communication within the health system.

Embedding optimal care

“My top issue for the next plan is navigating the health system – public versus private, knowing who to see, judgement of skill and ability to access quotes without costing a fortune, uniform, high quality, free cancer treatment system in place and ensuring no one falls through the gaps”
– Community consultation, August 2019

“We keep seeing delays in the Optimal Care Pathways, because we think they should be following in this trajectory, but they hardly ever do ... whether it’s their appointments or their treatments ... care isn’t happening in the way it was intended in terms of timing.”
– Clinician consultation, August 2019

What we know

The Victorian Government has provided leadership through its commitment to the Optimal Care Pathways (OCPs). Endorsed by the Council of Australian Governments, the OCPs provide a standard of high-quality cancer care that all Australians should expect and fosters greater collaboration between health professionals and people affected by cancer.

However, more needs to be done to ensure all Victorians with cancer, no matter where they live, have timely access to the best treatment. The Victorian Cancer Plan 2016-20 was underpinned by the principles of the OCPs. We recommend that the next plan goes further to implement and embed these pathways. There is a need for strategic planning to enable individuals to receive optimal care from the most suitable centre of expertise for their needs. This requires communication and referral pathways between different health services.

The Victorian Government has previously explored mechanisms to connect people with the best care for their unique needs. This project piloted the development of a Cancer Service Capability Framework which would describe the services and treatments available at health services of different sizes, and support pathways to optimal treatment and care. Disappointingly, the pilot has not been implemented across Victoria. Cancer Council Victoria believes this is a missed opportunity. The existing Victorian Palliative Care Service Capability Framework offers lessons we can leverage.

People facing a new diagnosis of cancer are also vulnerable to the influence of private providers marketing their services with claims of better outcomes. In the absence of public performance data, this leads to misconceptions

regarding the potential for lower levels of care in the public system. Without adequate regulation or incentives that drive collaboration with the public sector, private sector providers will continue to work in isolation with the ultimate cost born by patients.

Recommendations

1. Continue to invest in implementation and embedding the Optimal Care Pathways.
2. Implement a Victorian Cancer Service Capability framework, developed in partnership with clinicians and community. This should include identification of minimum standards, and outline requirements for workforce, infrastructure and resourcing to deliver optimal care.

Care coordination

“We need to move the conversation away from how we can afford a care coordinator model of care for Victoria to how can we afford to continue to deliver fragmented care.”

– Oncology clinician, July 2019

Case study: Excerpt from an opinion piece: *The Guardian*, 23 April 2019, Dr Ranjana Srivastava

While Karen was undergoing treatment for breast cancer, her husband, Bill was diagnosed with bowel cancer. This is the discussion that followed about support systems in place for Bill’s treatment, with an oncologist.

Karen: “So you’re saying his cancer is less important than mine? Don’t worry Bill, your nurse will help you like mine does.”

Oncologist: “I’m afraid he won’t have a nurse.”

Karen: “Then we’ll just share mine,” she shrugs.

Oncologist: “That won’t work. Your nurse can’t be involved in his care. Your husband doesn’t have breast cancer therefore he cannot use your nurse. Your breast cancer nurse is funded to help breast cancer patients.”

Karen: “So what do we do if he feels sick?”

Oncologist: “You try to get help over the phone, but most likely, you come into emergency.”

Karen: “But that would be so frightening. How do the other patients manage?”

What we know

One of the strongest messages we heard from the community was the challenge of understanding the complex cancer care system. They were reliant on clinicians as the experts to help them understand what to expect and where to get support. Access to care coordination, system navigation and supportive care should not depend on where you live or the type of cancer you’ve been diagnosed with.

Patients facing the greatest inequity have multiple care requirements. Cancer treatment is complex, involving multiple clinicians, tests, scans and health services. In addition to the physical, cancer impacts on psycho-social and practical aspects of a person’s life, leading to a range of supportive care needs. Effective coordination of care across different clinicians, teams and health services is an essential element to high quality cancer care.¹¹ While various titles are used to refer to these health professionals, in this document we will refer to ‘care coordinators’ and ‘care coordination’ when referencing these clinically based roles.

Care coordinators are a recognised resource embedded within the multidisciplinary team. They coordinate acute treatment to ensure better end-to-end care. In addition, they assist other acute care professionals in assessing and providing referral to primary, community and supportive care services as appropriate.

Evidence collected through a range of Australian and international studies shows that cancer care coordinators are instrumental in improving patient experiences across the entire treatment trajectory by helping them navigate complex health systems and ensuring their clinical care is comprehensive and cohesive.^{12, 13, 14}

However, there is inadequate research outlining a blueprint for implementing effective, equitable and sustainable care coordination in Victoria. Currently these roles are not embedded equally in the system and some of our most vulnerable patients with the highest needs are missing out on the support provided by care coordinators.

Access to these critical roles depends heavily upon the type of cancer a person has or the health service they attend. Advocacy groups have been instrumental in ensuring patients in some tumour streams are supported by care coordinators with some roles funded by charities, but this has led to inconsistency especially for those with rarer cancers.

Inadequate care coordination is associated with poor symptom control, medical errors, higher costs and, ultimately, poorer outcomes. In the absence of these roles, care is fragmented, and Victorian patients and their families are falling through the gaps.¹²

Poor coordination impacts most heavily on patients with complex needs. We call for care coordination programs in settings and populations that currently do not have access to these roles. New roles should focus on patient groups where we see the greatest inequity in outcomes including Aboriginal people, rural and regional patients, and those with rare cancers, low survival cancers and other complex health problems.

An increasing body of evidence shows that patient reported outcomes (PROs) can help with the identification of symptoms and supportive care needs, and have been used to help coordinate patient care, communication and engage patients in their disease management. PROs can help clinicians measure and respond to the issues that matter most to people with cancer, particularly issues that are not assessed as part of routine clinical care. Other states and territories in Australia are exploring routine collection of PROs using electronic systems, with results enhancing clinical decisions and supporting patient self-management. We recommend investment in Victoria that will add to the evidence regarding how PROs can improve patient care and outcomes.

Recommendations

Address inequities in access, based on geographical location or cancer type.

1. Invest in a pilot to fund regional cancer care coordinators to enable care delivery that is aligned with the OCPs, with a focus on those regions experiencing greatest inequity. This should include:
 - a. Care coordination roles to support patients of any tumour-type who do not currently have access to a care coordinator.
 - b. Robust methodology and evaluation to measure impact on patient reported outcomes and economic impact to the healthcare system.



Theme 2: Reduce the cost of cancer

“We have a responsibility to those we care for, to make sure we are doing everything we can to minimise financial stress, and to engage them in decisions about their treatment. That includes transparency about out-of-pocket costs, as well as advice about options in the public system.”

– Clinician consultation, November 2019

“Getting sick with cancer is a costly exercise. It doesn’t just tax you physically and mentally – financially it destroys you.”

– Bowel cancer patient, 12 months post diagnosis.

Despite Australia’s universal health care system there are many unexpected and hidden costs that accompany a diagnosis of cancer and can seriously impact patients and their families.¹⁵ While it is impossible to reduce all out-of-pocket costs, more must be done to minimise the impact on those with the fewest resources.

Five areas that could influence the cost of cancer are:

- Informed financial consent
- Victorian Patient Transport Assistance Scheme
- Financial counselling
- Hospital parking
- Out-of-pocket treatment costs

Informed financial consent

What we know

Costs can include medical appointment gap payments, scans or tests, medicines, medical devices, travel and personal care. Addressing transparency around the cost of treatment is an urgent priority for Cancer Council Victoria. We believe all patients have a right to know what costs they will incur following a diagnosis in Australia. Cancer Council Australia, alongside Breast Cancer Network Australia, CanTeen and Prostate Cancer Foundation of Australia, is leading the way in advocating for the implementation of an informed financial consent standard.

Recommendation

1. Endorse and incentivise the implementation of Cancer Council’s informed financial consent standard and encourage Victorian clinicians and health services to sign up to the standard.

Victorian Patient Transport Assistance Scheme (VPTAS)

What we know

Victorians in regional and rural areas experience financial disparity when diagnosed with cancer. The hidden cost associated with parking, travel and accommodation for cancer treatment is a burden felt particularly by these patients, which has an impact on psycho-social and financial wellbeing. VPTAS is lagging behind other jurisdictions and is failing to adequately compensate those in need, meaning Victorians pay more to access treatment than many interstate peers.

Recommendation

1. We ask the Victorian Government to conduct bi-annual reviews of VPTAS in partnership with the VPTAS Alliance to address current inequities and to expand the eligibility criteria for VPTAS to include patients enrolling and participating in clinical trials.

Case study: "Help ease the burden": Lynne

Lynne lives in Benalla with her partner. She has thyroid cancer, which has metastasised to her bones and lungs.

"We're both in our 70s and we have to factor all this into our pension. We have to be very budget conscious, but we manage."

She was already under the care of cardiologists at St Vincent's and so chose to have her cancer treated there too.

"I don't have access in town to the specialist services so if I chose to have the cancer dealt with locally it would almost certainly have to be either Wangaratta (32kms) or the cancer centre up in Albury (118kms) and either one of those to me would be more difficult than going to Melbourne to see the people I'm used to.

Lynne and her partner take the train and then a tram, which takes about four hours door to door.

"I see five different specialists at St Vincent's and because they all want to see me more than once a year, it gets quite involved with travel and accommodation. Train fares are normally somewhere around \$85 return for the two of us and then we can be looking at \$200-260 a night and often that's two or three nights in a row. So, over the course of the year it's several thousand dollars, it's not just a few hundred."

"I think what's really lacking in metropolitan areas is some clean, inexpensive accommodation for country patients who are in my position. It's really hard to find those things at a reasonable price and usually when you do, they're booked out weeks ahead anyway. It's challenging."

Four years into her cancer treatment, Lynne still hasn't been advised about VPTAS.

"It would help to ease the burden if there could be some system available for (especially, but not exclusively) accommodation support."

Improve access to financial counselling

What we know

Oncology social workers provide a wealth of support and information to cancer patients and their carers but not all social workers are trained to provide financial counselling to patients and families. For little investment, the Victorian Government could make large improvements to the cost of cancer by training more oncology social workers in financial counselling. Implementing referral pathways that integrate with Cancer Council’s Information and Support line would also help people to navigate the existing financial support services.

Recommendation

1. Invest in training oncology social workers in financial counselling to assist in addressing the high cost of cancer to Victorians affected by cancer.
2. Embed referral pathways to community supports offering financial support such as Cancer Council Victoria.

Hospital parking

“While my husband was having brain surgery for glioblastoma, the parking costs were huge.”
 -Community consultation, August 2019

What we know

Cancer Council acknowledges the Victorian Government’s work in implementing its election commitment to reduce the burden of car parking fees for vulnerable patients who frequently attend health services. However, patients continue to routinely identify parking as a source of distress that negatively impacts on their experience of care.

Cancer Council Victoria’s investigation of parking at cancer treatment centres across metropolitan and regional Victoria demonstrated substantial disparity between information provided by public and private hospitals, subsidy and transport schemes and a disconnect between operators of hospital car parks. While we commend Western Health, which provides free parking for all patients undergoing chemotherapy and radiotherapy treatment, this is an isolated model. It is a sad reality that it costs less to park at Cabrini, the largest private hospital in Melbourne offering cancer services, than at many of our public hospital cancer services.

Recommendation

1. Improve transparency around parking costs.
2. Ensure timely assessment of cancer patients to enable access to a parking card that provides subsidised or free parking.

Out-of-pocket costs

“It should be a priority to develop knowledge about the differences between public versus private care relating to quality of care and cost.”

– Community consultation, August 2019

What we know

Too many people experience unnecessary worry and anxiety, and potentially incur avoidable out-of-pocket costs. Research shows half of Australians with cancer including those treated in the public system have out-of-pocket costs in excess of \$5,000.¹⁶ Our research of over 500 callers to 13 11 20 found that one in three (29%) callers reported greater than expected out-of-pocket costs. Substantial costs were experienced by most callers, with median costs of \$1,500 in the past three months, and costs as high as \$25,000 were reported in some studies.

Case study: “It’s the financial side that’s the killer”: Kristine

Kristine is a 45-year-old mother of three and grandmother of five. She lives in the Hume region with her husband and their 16-year-old daughter. When Kristine found a lump in her breast, her GP referred her for a scan at the local public hospital, who diagnosed her with breast cancer.

Despite not having private health insurance, Kristine was referred to a private surgeon locally and then to a private oncologist 45 kilometres away, as there’s no public oncologist in her town.

Deciding on the best treatment path was confusing. Kristine’s oncologist suggested that she call her surgeon to discuss the right treatment plan. At no point were options discussed around public or private treatment and the expected costs.

“There were no options given. Until recently, I wasn’t aware that there’s public and private and that people elsewhere aren’t paying \$150 per week. That’s just what has to be done and that was never discussed - the finance of it.”

Kristine’s now receiving weekly chemotherapy at the public hospital in her town. She is booked in to see a private oncologist at the hospital each week, which has out-of-pocket costs of about \$60 per visit. Sometimes she needs additional appointments between the surgeon and oncologist in the same week.

Kristine is just over halfway through chemotherapy and had to give up work while undergoing treatment “because my treatment plan kept changing”.

“It’s the financial side of it that’s been a killer to be honest - you’re losing an income and gaining all of these expenses.”

In just four months, Kristine is already about \$1,680 out of pocket for appointments and medications. She needs a mastectomy, but she’s yet to learn the details, which will be at a Melbourne public hospital.

“I want a breast surgeon who offers reconstruction and there’s none [nearby] so I’m seeing a specialist in Melbourne,” she said. “I’m hoping for reconstruction - double mastectomy and reconstruction at the same time. We haven’t gone into how long I’ll be in hospital in Melbourne for - but I know that all the after care has to be done in Melbourne.

“My heart breaks for people who don’t have a little bit of savings behind them. I don’t know how they do it. Do they not go? What are their options? I don’t know that they know.”

Private health care

Out-of-pocket expenses vary according to the doctor, hospital, treatment, private health fund, policy and the policy excess. It is alarming that for all conditions and treatments, 7% of Australian doctors are charging 200%+ of the Medicare Benefits Schedule (MBS) – however this accounts for 85% of all medical gaps. That is, of the \$39 million spent by Australian private patients in gap payments, \$33 million fell into the bracket of those charging more than 200% of the MBS.¹⁷ Increased transparency through informed financial consent can help patients avoid egregious billing.

Acknowledging the current federated model of healthcare in Australia, it will be important for the Victorian Government to liaise with the Commonwealth Government to address the urgent need for system improvements in private hospitals and private billing. There is an important opportunity for state and federal governments to champion this reform.

We commend the commitment of the Victorian Government to improving regional access to cancer services through infrastructure and partnerships with private services. However it is concerning that in some regions, including border towns, patients have to choose between increased costs for private treatment or substantial travel to access public services. We call on the government to extend the shared-care radiation oncology model to medical oncology treatments, so that public patients can access private regional services with no out-of-pocket costs.

Fertility treatments

Some cancer treatments are known to impact a person's fertility, resulting in life-long impacts. However, fertility preservation is costly for many. As survival rates improve, there is an expectation that patients' reproductive potential should be considered and protected as much as possible.¹⁸ Too many patients report the high costs associated with assisted reproductive technology treatments inhibit their ability to preserve their fertility. More needs to be done to help ensure patients with cancer are not denied the ability to have a family in the future should they desire to do so.

Lymphoedema

The side effects of cancer and its treatment can also incur costs during and beyond treatment. For some cancers, over 20% of patients experience lymphoedema, the painful and disfiguring swelling of the limbs, due to treatment-induced blockages of the lymphatic system.¹⁹ This often requires life-long treatment. The Australian Government recently announced a national lymphoedema garment subsidy scheme. The scheme is yet to be implemented and it is not clear how it will complement the existing state-wide program or whether it will extend to all patients.

Recommendations

1. Develop regional public-private shared care models for all cancer treatment modalities so that public patients can access private regional services with no out-of-pocket costs.
2. Investigate regulatory and other mechanisms to protect patients from excessive out-of-pocket costs.
3. Reduce the high cost of fertility preservation for people undergoing treatment for cancer and prioritise cancer patients in any public system IVF models developed by government.
4. Review and improve current public lymphoedema services and referral pathways and expand the number of publicly accessible lymphoedema clinics in Victoria.

Theme 3: Invest in primary prevention

“Prevention campaigns – we need to ramp up efforts to communicate the risks to members of the public.”
– Community consultation, August 2019

One-third of all cancers can be prevented through lifestyle changes. Population-wide change requires the development of, and investment in, culturally appropriate, respectful and accessible prevention and early detection programs to save both lives and health costs.

Three in ten cancer deaths in Victoria are due to bowel and lung cancers. Nearly all of these deaths are preventable through powerful, evidence-based initiatives in tobacco control, bowel screening and prevention campaigns in obesity, diet, exercise and alcohol. The current Cancer Plan sets ambitious targets of halving the proportion of Victorians diagnosed with preventable cancers by 2040. Significant investment in prevention campaigns will be needed to achieve such goals. While the up-front costs of such campaigns might seem high, these investments will not only reduce the number of Victorians diagnosed with cancer but also impact on many other diseases caused by the same risk factors.



Obesity

Two-thirds (68.3%) of Victorian adults are overweight or obese and more than one-fifth (22.6%) of Victorian children are above a healthy weight (14.9% overweight and 8.0% obese).²⁰

What we know

Obesity increases the long-term risk of a number of chronic diseases including 13 types of cancer.²¹ In Victoria alone, the economic cost of obesity was estimated to be \$14.4 billion in 2008.²²

Recommendations

1. Protect children from unhealthy food and drink marketing. This includes prohibiting advertising, promotion and sponsorship in publicly owned and managed places. Priority should be given to areas around schools, children’s sporting events and activities, and public transport.
2. Implement a state-wide public education campaign to encourage healthy eating. This should focus on population groups with the highest rates of overweight and obesity.
3. Increase the scope of and strengthen compliance with the School Canteens and Other School Food Services Policy. This should take a whole-of-school approach, be reflected in the curriculum, and be backed by a monitoring and enforcement framework.
4. Develop and mandate a whole-of-government healthy food procurement policy. This should incorporate the Healthy Choices guidelines and apply to all publicly owned and managed places.
5. Create healthy places for learning, working and living. Continue to support and invest in programs like the Achievement Program that encourage schools, workplaces and healthcare settings to develop healthy eating policies and environments.

Alcohol

Alcohol has been classified by the World Health Organization’s International Agency for Research on Cancer as a Group 1 carcinogen – meaning it is carcinogenic to humans.

What we know

Alcohol is a proven risk factor for cancer of the mouth, pharynx, larynx, oesophagus, bowel, breast, liver,²³ and stomach.²⁴ The level of risk increases with the level of consumption.^{25,26,27} Long-term alcohol consumption is responsible for more than 3,200 (or 2.8%) of the cancers in Australia each year. A survey undertaken by Cancer Council Victoria found that only 39% of Australian adults surveyed were aware that regular alcohol consumption increases the risk of cancer.²⁸

Recommendations

1. Implement public education on the health impacts of long-term alcohol consumption. There is a need for a multi-faceted state campaign to help Victorians understand the link between alcohol and cancer and empower them to reduce their cancer risk.
2. Improve regulation of alcohol supply in Victoria. Research shows an increase in alcohol outlets in an area is associated with a higher incidence of long-term health problems²⁹. Cancer Council Victoria strongly supports improved regulation to limit the excessive availability of alcohol in Victoria including:
 - a. A stronger test for new Victorian liquor licences, which requires applicants to show that a new liquor licence will not contribute to harm and is in the public interest.
 - b. Restricting new alcohol outlets in local areas that already have high numbers of outlets.
 - c. Improved regulation of the online sale and home delivery of alcohol.
3. Prohibit irresponsible marketing and promotion of alcoholic products. Victorian alcohol outlets and venues aggressively market their products in the Victorian community. There is a need to prevent Victorian alcohol outlets from irresponsibly promoting their products, including through price incentives that encourage excessive consumption of alcohol.

Tobacco

Lung cancer remains Victoria's leading cause of death, despite being almost entirely preventable through evidence-based prevention programs. The evidence that tobacco smoking causes lung cancer is indisputable. Tobacco is the leading cause of preventable death and disease in Australia, responsible for 9.3% of the disease burden in 2015.³⁰ The population attributable fraction (PAF) of Australian cancer deaths due to smoking tobacco, plus exposure to a partner's smoke, was 13% in 2010.³¹

What we know

While smoking rates have declined, there are still hundreds of thousands of Victorians who smoke, and some population groups, such as Aboriginal Victorians, and people with mental illness or identifying as LGBTIQ+, are over-represented.

Smoking has a negative impact on treatment outcomes for cancer patients, with a higher likelihood of recurrence and lower survival rates.³² Cancer patients who smoke are also at increased risk of treatment toxicity and complications, medication side effects, and hospitalisation.^{33,34,35,36}

Without tobacco control, 1.9 million Australians will die (67% of lung cancer deaths) by the year 2100.³⁷ A continued comprehensive approach to tobacco control is warranted to reduce rates of smoking-related cancer including lung cancer.

Recommendations

1. Strengthen television-led public education campaigns. Multiple studies have shown television-led education campaigns prevent uptake by teens and young adults, motivate quit attempts and help former smokers remain quit.³⁸ A minimum level of exposure is required to reduce smoking across all population subgroups.
2. Embed smoking cessation care as part of routine practice in oncology as a focus of work to embed smoking cessation across the broader health system. A model of care that systematically identifies people who smoke, promotes cessation and facilitates access to best practice cessation care has been shown to increase successful quitting.³⁹ Stopping smoking after a diagnosis of cancer has been shown to reduce side effects of treatment, and increase both the effectiveness of therapy and the five-year survival rate. This model of care could be implemented immediately in Victorian health services (in collaboration with Quit Victoria).

Skin cancer

Melanoma is the fourth most common cancer in Victoria. Non-melanoma skin cancer is the most common cancer. Each year, more people die from skin cancer than from transport accidents, despite it being one of the most preventable cancers.

What we know

SunSmart is estimated to have prevented more than 43,000 skin cancers and 1,400 deaths between 1988 and 2010. SunSmart is also cost-effective, returning \$2.22 for every dollar invested. Melanoma incidence is now stabilising or declining for all age groups under 60 in Victoria thanks to decades of prevention. Sustained investment is needed to maintain this progress and protect future generations.

Cancer Council Victoria is concerned about anecdotal reports of skin cancers being misdiagnosed through skin clinics. There is currently no accreditation standard for such clinics which can be confusing for consumers.

We also support data collection on this issue to inform an evidence-based approach to the early diagnosis of skin cancer and to support delivery of the Optimal Care Pathway for melanoma.

Recommendations

1. Continue investment in the SunSmart program to reduce the significant human and financial impact of skin cancer on the Victorian community.
 - a. Target the program based on evidence: to children, youth, men, outdoor workers and health professionals.
 - b. Develop a health professionals strategy to support delivery of the Optimal Care Pathway for melanoma, ensuring efforts to support the early diagnosis of skin cancer are evidence-based.
 - c. Avoid strategies that are not supported by evidence, including population-based screening for skin cancer
2. Continue to invest in paid social marketing to ensure the Victorian community is motivated to protect themselves from over-exposure to UV radiation.
 - a. Develop a new campaign targeting men with prevention and early detection messaging as they are more likely to be diagnosed with and die from melanoma than women.
3. Deliver school and community shade grants to enable local communities to create safe, shady environments.

Occupational and environmental cancers

What we know

Cancer attributed to occupational and environmental exposures is largely preventable, through appropriate regulation and control of exposures. Cancer Council Victoria supports research, education, regulatory and legislative measures that effectively prevent workplace or environmental exposure to substances likely to cause cancer.

Recommendations

1. Implement, monitor and enforce compliance of health-based workplace exposure standards, and especially for known carcinogens including respirable crystalline silica and diesel engine exhaust.
2. Support the national strategic plan for asbestos management and awareness and continue to implement a schedule and process for the prioritised safe removal of asbestos containing materials from public buildings, as per national target three.
3. Improve awareness of occupational carcinogens through a community awareness campaign that increases the adoption of safe work practices and control measures for known carcinogens.

Theme 4: Access to screening, early detection and immunisation

“I am homebound and it’s a major trip involving an ambulance and approximately a month’s recovery time for me to get to a gynaecologist or mammography centre ... If the hospital could arrange for the tests to be done while I’m there anyway for something unavoidable, I would GLADLY get screening tests done, but this isn’t something they ever do.”

– Community consultation, 2019

The current Victorian Cancer Plan strives to double the improvement in one- and five-year survival of Victorians with cancer by 2040 and save 10,000 lives by 2025. To achieve such goals, continued efforts are needed to screen for and detect cancer early, particularly for cancers where early intervention can save the most lives at a population level, such as bowel screening.

Over half of eligible Victorians participate in regular cervical and breast screening (56.8% and 54.1% respectively), while less than half participate in bowel cancer screening (43.2%).⁴

Unfortunately, the health benefits of screening, early detection and immunisation are not realised by all Victorians. Participation rates reflect the inequities in Victorian society. Communities who are more likely to experience social disadvantage have lower participation in breast, bowel and cervical screening programs.

In order to see improvements in cancer outcomes in Victoria it will be vital to prioritise equitable access to cancer screening outcomes for all Victorians and to invest in research to further explore emerging cancer screening and early detection initiatives.

Lung cancer screening

Screening is an emerging approach to detecting early stage lung cancer, leading to better care pathways and improved survival. Cancer Australia has been commissioned by the Commonwealth Government to lead an inquiry into the prospects, process and delivery of a targeted national lung cancer screening program. They are expected to report back in late 2020. Should the evidence show this is a feasible intervention, the Victorian Government will likely have an important role in advancing screening opportunities to prevent lung cancer deaths and improve survival.



Bowel cancer screening

Bowel cancer is the second biggest cause of cancer-related deaths in Victoria with 1,244 deaths from the disease in 2018.² It is the third most common cancer across our state, with over 3,900 Victorians diagnosed annually. If detected early, the 5-year survival for bowel cancer is more than 90%.

What we know

Of the 4.1 million Australians invited to participate in the National Bowel Cancer Screening Program (NBCSP) in 2016-2017, 41.3% completed their free screening test (in Victoria, 43.2% from 442,744 invitations sent).⁴ Increasing participation to 60% would save 83,800 lives across Australia and substantially reduce health system costs, now and into the future.⁴⁰

Nationally, among Aboriginal and/or Torres Strait Islander people, the rate of participation is half that of non-Aboriginal Australians (20%), while among people living with a severe or profound disability, the rate is estimated to be 36%. It is also estimated that only 25-34% of Australians who do not speak English as the main language at home participate in the NBCSP.⁴

Recommendations:

1. Commit to ongoing investment in mass media campaigns to increase public awareness and change social norms about bowel cancer screening across Victoria. This must include an emphasis on increasing participation among priority population groups.
2. Working with the NBCSP to explore alternative ways of distributing the bowel screening kit, such as in community health services and Aboriginal Community Controlled Health Organisations, as an ongoing approach to the national program.
3. Ensuring that all Victorians with a positive bowel screening result, regardless of where they live, have timely access to high-quality colonoscopy in accordance with the *Victorian Colonoscopy Categorisation Guidelines 2017* and the National Health and Medical Research Council *Clinical practice guidelines for the prevention, early detection and management of colorectal cancer 2017*.
4. Ensuring all public health services providing endoscopy services make reasonable adjustments to the way services are delivered to ensure they are accessible for Victorians with a disability.
5. Reach for a Victorian NBCSP participation rate of 60% by 2024 including for Aboriginal and/or Torres Strait Islander peoples, people from culturally diverse backgrounds and people living in socioeconomically disadvantaged areas.

Case study: “The initial diagnosis was horrendous”: James.

James says the bowel cancer screening test may sound unappealing, but it’s nothing compared to the emotional, physical and financial consequences of finding out you have cancer. The 52-year-old lawyer was diagnosed with stage three bowel cancer in 2016 and required aggressive treatment to fight the cancer that had spread to his lymph nodes.

He didn’t complete the home screening test, but believes if he had, his cancer may have been detected sooner and he could have avoided aggressive treatment, which included one round of radiotherapy, two rounds of chemotherapy, three major surgeries, as well as multiple minor surgeries.

James says his story shows why it’s vital that people don’t put off screening for bowel cancer.

“The initial diagnosis was horrendous. You think, I’ve got cancer, I’m going to die,” said James.

“Finding bowel cancer early can increase your chance of successful treatment, and ultimately, survival. If you’re aged 50-74 and receive the home test in the mail, do it. Or, if like me, you have any symptoms speak to your doctor immediately. Don’t put it off like I did - the test is free and sent to your home. You’d be stupid not to do it.”



Cervical cancer screening and HPV immunisation

Australia can become the first country in the world to eliminate cervical cancer as a public health problem within 20 years if vaccination for the human papillomavirus (HPV) and cervical screening coverage are maintained at their current rates. Victoria is well positioned to be the first state in Australia to achieve this significant milestone.

Latest research predicts that cervical cancer rates will drop to less than 6 in 100,000 by 2022 - meaning that it will soon be considered a rare cancer.⁴¹ However, continued investment, particularly on increasing cervical screening and HPV vaccination in priority communities, is required to ensure that all Victorians reap these benefits.

What we know

In December 2017, the renewed National Cervical Screening Program (NCSP) was introduced and is expected to lower the rate of cervical cancer cases and deaths by at least 20%.⁴² However the latest Australian Institute Health and Welfare report (2019) states that the NCSP participation rate in Victoria is just 56.8%, with research indicating it's even lower for Aboriginal and/or Torres Strait Islander and culturally and linguistically diverse women.⁴³

If we are to achieve cervical cancer elimination, increased efforts are required to improve cervical screening participation and HPV vaccination rates, especially among Aboriginal and/or Torres Strait Islander communities and other priority populations. Cervical cancer cannot be a disease of the disadvantaged.

Recommendations:

1. Invest in mass media public education campaigns to inform Victorian women and to support their participation in the renewed National Cervical Screening Program.
2. Invest in tailored communications and targeted place-based approaches to reach unscreened and under-screened women, particularly Aboriginal and/or Torres Strait Islander women, women from culturally diverse backgrounds and people from LGBTIQ+ backgrounds.
3. Invest in health care provider cultural safety training and education in the renewed cervical screening program, including the availability of self-collection for under-screened women.
4. Ensure all Victorian women have access to timely, quality colposcopy services by monitoring geographical inequalities in wait times for diagnostic services.
5. Invest in community engagement, place-based initiatives and public education campaigns to increase uptake of HPV vaccination to all at-risk populations, including Aboriginal and/or Torres Strait Islanders and adolescents with disabilities
6. Developing systems to report HPV vaccination coverage for Aboriginal and/or Torres Strait Islander populations and those from culturally diverse backgrounds.
7. Extending HPV vaccine eligibility criteria to men who have sex with men (MSM) and immunocompromised people (including people with HIV).



Liver cancer prevention

Liver cancer is the fastest increasing cancer in Australia, with a 378% age-standardised increase from 1.8 to 8.6 per 100,000 persons between 1982 and 2019. Furthermore, liver cancer is a low survival cancer (5-year survival is 18%) as it is rarely detected early and is one of the top 10 contributors to the burden of cancer (3.5% of cancer DALY).⁴⁴

What we know

Chronic hepatitis C and B infections and alcohol are the leading cause of liver cancers, with non-alcoholic fatty liver disease (NAFLD) related liver cancer increasing rapidly. The risk factors for NAFLD are obesity, type 2 diabetes and metabolic syndrome.

The biggest challenge is that liver cancer is often diagnosed late when there are limited successful treatment options available. It is a largely preventable condition if risk factors are diagnosed at an early stage and guidelines-based care is provided. Early detection and management of patients with viral hepatitis; public health programs to reduce alcohol consumption, obesity, smoking and diabetes; needle and syringe programs; and referral of at-risk patients into a liver cancer surveillance program are all investments that will contribute to the long-term goals of the Victorian Cancer Plan to reduce the proportion of Victorians diagnosed with preventable cancers and improving one- and five-year cancer survival rates.

Recommendations

1. Develop Victoria's strategic response to liver cancer that is underpinned by implementation drivers and adequately resourced. This response should be equity focused, co-designed by community and comprehensively cover primary and secondary prevention of liver cancer, detailed below.
2. Invest in the primary prevention of liver cancer through:
 - a. Reduction of alcohol-related harm, obesity and smoking, and improve diabetes prevention through implementation of recommendations from the Obesity, Alcohol and Tobacco sections of this submission, with particular emphasis in investing in public and primary care education on the link between alcohol misuse, obesity, diabetes and smoking to liver cancer.
 - b. Early diagnosis and management of viral hepatitis by:
 - Funding the implementation, monitoring and evaluation of the current Victorian Hepatitis B and C Strategies (2016-2020), while concurrently investing in the development and resourcing of the next Victorian Hepatitis B and C Strategies, implementation plans and evaluation frameworks. Activities within the current strategies to be progressed urgently include:
 - Mandating the follow up of all Hepatitis B and C notifications, ensuring all affected patients are provided with follow-up testing and management plans.
 - Investing in culturally appropriate public education campaigns (through community engagement and targeted media campaigns) to increase knowledge around viral hepatitis infection and its link with liver cancer, increase confidence to seek early diagnosis and address both internal and external stigma.
 - Investing in primary health engagement initiatives to increase early detection and guideline-based management of Hepatitis B and C through upskilling of nurses, GPs and community workers with a lived experience; and funding nursing and community-based models of care.
3. Invest in the secondary prevention of liver cancer through:
 - a. Investing in the education of the primary care sector to identify and screen all at-risk patients for cirrhosis and ensure guideline-based care.
 - b. Lead discussions with the Federal Government on:
 - Improving targeted screening of at-risk patients for cirrhosis and referral to surveillance.
 - The feasibility of a national registry for all cirrhosis and Hepatitis B patients, as well as a liver cancer registry to enable a comprehensive and consistent approach to an equitable surveillance program.

Primary care

“I was diagnosed unexpectedly due to the diligence of a very young doctor.”

– Community online survey July 2019

What we know

Currently, pathways for the triage and referral of a person with a suspected cancer are poorly integrated, making it difficult for primary health professionals to support early diagnosis. With rapid developments and sophistication of diagnostic technologies in cancer care the need for timely and appropriate work-up will be integral to achieving optimal cancer outcomes in Victoria.

Recommendations:

1. Integrate and embed the Optimal Care Pathways into existing primary health triage and referral systems and foster collaborative relationships between Integrated Cancer Services, Primary Health Networks and the primary care workforce.
2. Improve primary health practitioner awareness of the appropriate triage, diagnostic work-up and referral pathways for suspected cancer diagnoses including clearly defined referral pathways for rare and less common cancers.
3. Improve community awareness of the common symptoms of cancers and clear pathways for appropriate medical investigation.

Theme 5: Invest in supportive care

Comprehensive supportive care is an all-encompassing term that includes essential care services from diagnosis through to end of life. The provision of supportive care is integral to the Optimal Care Pathways yet there is an unmet need for appropriate supportive care referral at all stages of the disease. This is compounded by a limited understanding of the support services and resources available to clinicians and people affected by cancer and the fragmented referral pathways described earlier in this submission.

The current cancer care funding allocation system does not align with the move towards ambulatory care and care close to home (when safe and appropriate), nor does it adequately enable the integration of evidence-based supportive care services. There is an opportunity to demonstrate the return on investment of enabling comprehensive supportive care to strengthen capability for self-management and to direct resources to those unable to self-manage because of more complex needs.

Multidisciplinary care

“True multidisciplinary care should involve the social worker, the nurse, the dietitian, the exercise physiologist – actual true multidisciplinary meetings.”

– Community consultation, August 2019

“The consumer preference is often to be treated in the community, but all of our systems, supports and workforce are not geared towards this perspective.”

– Clinician consultation, August 2019

What we know

Multidisciplinary care is a key principle underpinning the Optimal Care Pathways. Multidisciplinary care includes multidisciplinary team meetings (MDMs) and supportive care. Our consultations told us that patients are missing out on these critical elements of care, particularly those treated in smaller rural centres and some private centres.

Geographic location or health service size should not be impediments to the delivery of multidisciplinary care for patients with cancer.⁴⁵ Telehealth and videoconferencing have supported multidisciplinary regional patient care. However, access is inconsistent, and some rural patients told us there are no telehealth services in their regions.

The Victorian Government has supported substantial work in MDMs and Cancer Council Victoria calls for further investment in this area including investment in models that improve capacity for integration with primary care.

Case study: How multidisciplinary cancer care can include primary care providers

Western Health, with the support of a Western Central Integrated Cancer Services grant, demonstrated an effective model to integrate primary care providers into multidisciplinary cancer care. They engaged two representative GPs to attend MDMs for a 12-week pilot. The pilot enabled timely and relevant two-way communication between the community and hospital care and demonstrated an impact on the care provided by GPs.

Recommendations:

1. Invest in innovative pilots that address barriers to multidisciplinary care including incorporating supportive care and primary care into all MDMs.
2. Invest in and prioritise telehealth and videoconferencing services for rural Victorians through funding and policy mechanisms as well as infrastructure.

Navigating the health system

“Patients should be referred to the Cancer Council as a first point of reference – this should come from GPs, specialist etc.”
– Community consultation, August 2019

“All I can say is I had to beg for follow-up and was given no information.”
– Community consultation, August 2019

What we know

We heard strongly from the community that finding support is difficult. They did not expect one clinician to deliver all their treatment and supportive care needs. However, they did expect their clinical team would help them navigate to the most appropriate services and support. This ranged from referrals to allied health and psycho-oncology through to community-based supportive care services such as Cancer Council’s 13 11 20 Information and Support line.

Victoria has extensive community supports, many of which are provided by cancer specific non-government organisations (NGOs). With a rise in these organisations providing various levels of support and information, clinicians told us it is hard to keep up to date with all the new services. Referral pathways to community support are not integrated into hospital systems. As a result, patients and families attempt to find their own way and frequently report wishing they had known about services earlier.

Cancer Council Victoria has a strong track record in providing supportive care navigation to the community. Cancer Council’s 13 11 20 cancer nurses play a critical role in assisting those affected by cancer to understand their diagnosis, treatment and the services available to support them within the clinical, non-clinical and community settings. Our nurses spend time assessing a caller’s unique needs and make referrals with the support of our service directory. Perhaps most critically, Cancer Council can assist a person to understand and navigate to not only services offered by Cancer Council, but to any and all other services offered by other NGOs, clinical, primary or community care settings. We act as a key point of intake, triage and navigation - this is our unique offering to the cancer community.

There are excellent patient navigation models for Victoria to leverage. In New South Wales, an innovative pilot is placing Cancer Council liaison nurses within the clinical setting, alongside care coordinators, to ensure that those who are most vulnerable will receive timely and cohesive referrals to supportive care services. These face-to-face roles provide the current missing link between clinical and NGO settings, ensuring streamlined referral for anyone affected by cancer.

Cancer Council Victoria see itself as an integral partner in responding to the needs of the cancer community and proposes a similar pilot in Victoria to bridge the gaps in care experienced by those living in rural and regional areas, those who frequently report fragmented care as they move between health systems and those who are currently lacking referral to supportive care services. Additional investment in a dynamic state-wide online service directory would ensure that evidence-based information and services are transparent, and readily accessible by both people affected by cancer and the health professionals who support them, regardless of their geographic location.

Recommendations

1. Invest in a pilot to test the placement and integration of Cancer Council liaison nurses in regional and metro health services where access to supportive care referral or care coordination is limited:
 - a. Develop and define the scope and referral pathways between Cancer Council liaisons and their integration with care coordinators and other multidisciplinary staff.
 - b. Robust evaluation to measure impact on patient reported outcomes and economic impact to the healthcare system.
2. Partner with Cancer Council Victoria in the development and maintenance of a central online services directory that supports clinicians and patients to understand services available and referral pathways for access. This service directory will provide the technology required to support the integration of Cancer Council liaison nurses and care coordinators in our proposed model of care.

Psycho-social support

“My answer to “how can we afford psycho-oncology?” is – how can we afford not to?”
– Clinician, September 2019

What we know

During cancer diagnosis, treatment, survivorship and palliative care, people may experience psychological distress ranging from normal fear, worry or sadness to severe anxiety, depression and despair.^{46,47}

While many people live well after cancer treatment, a significant minority will experience a range of psychological issues that negatively impact their quality of life.^{48,49,50,51} The most frequently reported unmet needs of Australian cancer survivors are physical and functional support and access to and help with psycho-social issues.⁵²

There are now several high-quality studies demonstrating that effective psycho-social support improves quantity as well as quality of life for people with cancer.⁵³ Studies have shown that long-term investment in psychosocial care is likely to be cost-effective, however is highly dependent on a range of resourcing factors.⁵⁴

Routine distress screening and associated referrals for support have been proven to improve access to psycho-social care.⁵⁵ Our community and clinician consultations identified barriers to access psycho-social care including limited funding for outpatient services and the lack of confidence among community psycho-social services for the provision of cancer-specific support.

Recommendations:

1. Establish a taskforce to develop a state-wide plan for psycho-oncology services.
2. Fund enhanced access to psycho-oncology care across the acute and community settings and correct substantial inequities in the availability of services.
3. Invest in workforce education to increase the capacity of community services to respond to the mental health of people living with cancer.

Survivorship support

“Knowing what to expect is important, what you might experience on your journey and understanding that. Often no one tells you what might come next or how you might feel or what you’re going to go through.”
– Community consultation, August 2019

What we know

It is well recognised that the number of people surviving cancer for longer periods has increased. Cancer survivorship support provides a focus on the health and wellbeing of a person living with and beyond cancer. Family members and caregivers are also part of the survivorship experience. Secondary prevention and ongoing medical follow-up care are important aspects of supporting people to be as healthy as possible after treatment.

Victoria has benefited from sustained investment from government via the Victorian Cancer Survivorship Program. This program has led to the development and implementation of local pilots of new models of care, development of new resources, recognition of opportunities for secondary prevention, and identification of new referral pathways.

While the 2019 evaluation report is pending, Cancer Council Victoria would reinforce the feedback that has already gone to government from multiple stakeholders regarding ongoing funding for successful pilots to support integration and dissemination.

Feedback from stakeholders indicates that existing models of care for cancer survivors are not survivor-centred, coordinated, or accessible. Nor do they effectively manage and minimise the burden of disease and treatment related to symptoms and side effects.⁵⁶

Cancer Council Victoria consultations have consistently reinforced the importance of building cross-sector models where GPs and community health teams can take a major role in supporting people after initial treatment.

This is a key focus of international survivorship research and clinical innovation but requires increased flexibility in funding models.

Several Victorian research pilots have successfully focused on educating and supporting mental health self-management. Support for self-management requires further integration into the system. Health care services and systems are not resourced in their efforts to meet the needs of the growing cancer survivor population. Community organisations and primary care are under-utilised partners in this domain.

Recommendations:

1. Develop cross-sector policies that will deliver patient-centred and systematic models of supportive care, commencing with the most under-resourced services.
2. Allocate resources for secondary cancer prevention, with a focus on community-based programs that support cancer survivors.

Support for carers

“It wasn’t until after my son’s cancer treatment that my own mental health steadily declined. I was anxious about things that wouldn’t normally worry me, it affected my work and I withdrew socially. Eventually I was told I had post-traumatic stress disorder (PTSD).”

– Carer, November 2019

Distress and depression can be just as common in family carers, including children of cancer patients. A life-threatening diagnosis can have a greater negative psychological impact on the family members than the patients.⁵⁷

With the increase in life expectancy for cancer patients, the number of carers is expected to increase. Victorian carers make a substantial economic contribution to healthcare⁵⁸ and Cancer Council Victoria commends the Victorian Government in recognising the importance of carers in its 2019/20 Budget. However, it remains highly concerning that 12–59% of carers experience depression⁵⁹ and 30–50% experience anxiety.⁶⁰ Future efforts must consider the support and wellbeing of the carers of patients with cancer.

In September 2019, Cancer Council Victoria made a submission to the Royal Commission into Victoria’s Mental Health System, capturing the issues cancer patients, their family and carers experience. We reiterate the recommendations made in our submission and look forward to the Commission’s recommendations around priorities for change to ensure more timely and appropriate access to psychological services is made available to cancer patients.

Recommendations:

1. Build on the *Supportive Care in Cancer Resource Refresh* project to:
 - a. Facilitate earlier detection of supportive care needs to avoid issues escalating.
 - b. Extend supportive care screening to carers, particularly those caring for patients travelling longer distances for treatment.

Palliative and end-of-life care

“There needs to be more investment in this and change the perception of palliative care.”

– Community consultation, August 2019

***“My partner’s final days were poor, with no communication between staff.
After his death I was offered no support at all, nothing.”***

– Community survey, June 2019.

What we know

The increased projection of cancer diagnoses and cancer deaths outlined earlier in this report will put an increased demand on palliative services.⁶¹

Victoria’s *End of Life and Palliative Care Framework* (2016) recognises that palliative care is the responsibility of all health professionals and that all Victorians deserve the best possible end of life to relieve pain and provide support. Great progress has been made in accepting how important palliative care is, however, our consultation shows that access to quality palliative care is challenging and the concept of earlier integration of palliative care is currently not achievable due to inadequate resourcing and investment.

Barriers to palliative care referral are exacerbated by palliative care being poorly understood by clinicians and the community. There remain significant misperceptions by patients, family and carers that palliative care is only directed at end of life. Clinicians are often required to care for patients needing palliative care because specialist services do not exist. However little or no palliative care training is received meaning clinicians are poorly equipped to deliver this care.

Cancer Council Victoria commends the Victorian Government for recognising the urgent need for increased investment in end-of-life care in the 2019/20 Budget, including home-based palliative care in rural and regional Victoria and regional palliative care consultancy as well as a 24-hour support line. Too many times we hear stories like Jake’s below, where patients missed out on essential palliative care services and died alone and in pain.

Cancer Council Victoria acknowledges the introduction of the Victorian *Voluntary Assisted Dying Act 2017*. The Victorian Government must continue to work with the oncology sector to ensure equitable access for all Victorians, particularly those who live outside of the metropolitan area. It is imperative that palliative care services and workforces are supported and work alongside and in conjunction with the voluntary assisted dying system.

Case study: “His death should have been a lot easier.” – Jill.

Jake was diagnosed with pancreatic cancer in 2014 when he was only 35 years old. Jill cared for her son until sadly he died just three months later.

“The lead up to his death was a nightmare with no communication between doctors and specialists,” Jill said.

“I know his life couldn’t be saved, but his death should have been a lot easier.”

For Jill and Jake, the nearest treatment centre was in Traralgon, 80kms away. Support services weren’t offered, and she expressed feeling alone and isolated.

“Everywhere we went I looked for information about pancreatic cancer and all that you get is breast cancer, but to find out about pancreatic cancer was a whole different ballgame.

“We had another friend die of cancer a couple of months before and he was just so well looked after. I kept saying to Jake don’t worry now they’ve got people to look after you - you won’t be in pain and everything... and he was, it was just awful.”

Recommendations

1. Partner with key stakeholders to invest in building community awareness and engagement with palliative care and upskill oncology clinicians in end-of-life and palliative care.
2. Continue to invest in research and capacity building to produce more evidence and interventions in reducing inequalities in access to palliative care.

Theme 6: Increase investment and diversify cancer research



Better access to clinical trials

“Clinical trials are a lifesaving option but when patients have difficulty locating them, it could be the difference between life and death. Not all doctors are familiar with all trials available to patients leading to patients self-navigating.”

– Community consultation survey, July 2019

There is a need for increased investment in infrastructure for clinical trials. There are disparities that exist between different precincts and a very high proportion of clinical trials are centralised and not available equally across the state. Monitoring clinical trial activity is made difficult by inconsistent data collection across treatment sites and challenges maintaining and accessing real-time data including open and closed status of current trials.

What we know

Clinical trials play an important role in providing treatment options for people affected by cancer, as well as providing opportunities for psychological, supportive and palliative care. Despite this, recruitment of patients in clinical trials remains an ongoing challenge for the Victorian healthcare sector. Currently less than 6% of Victorian adults with cancer participate in clinical trials; a figure that is even lower amongst marginalised groups. However, as Victoria does not currently collect non-interventional clinical trial data, including supportive care and palliative care trials, it may be possible that this figure is higher.

Cancer Council Victoria seeks to work collaboratively with government and the sector to help patients access clinical trials that may help them to live well and live longer. To do this we need investment in a centralised data repository that captures supportive care and palliative care trials and links to patient-facing tools such as Cancer Council’s Victorian Clinical Trials Link (VCTL). Cancer Council believes we are best placed to develop and support patient-facing tools, but we need technological investment to deliver this at a state level.

Currently, many barriers exist to increasing clinical trial participation including: limited awareness and understanding of clinical trials from clinicians and the public; inequities in accessing clinical trials, including for Aboriginal and/or Torres Strait Islander populations, people from rural and regional areas and of culturally and linguistically diverse backgrounds; and limited systems and metrics to accurately measure, compare and report on clinical trial activity and impact in Victoria.⁶²

Cancer Council Victoria facilitated a Clinical Trials Roundtable in October 2019 to discuss how state-wide monitoring and access to clinical trials could be improved in Victoria. The aim of the discussion was to identify and explore considerations for a more integrated approach to the collection and reporting of cancer clinical trial data in Victoria. The recommendations provided in this plan were considered as part of this discussion.

New technology, such as that being used in the Victorian Cancer Registry, offers the potential to fast-track patients to clinical trials. There is value in using this software to address current poor recruitment rates to clinical trials.

Case study: “All I want for Christmas is cancer research”: Caitlin

At the age of 34, I was diagnosed with stage 4 bowel cancer. It came completely out of the blue – no family history and our first child had just been born. The terror I felt when I read the five-year survival statistics is indescribable. My future seemed very tiny and very bleak.

Like most of us, prior to my diagnosis, I’d given little thought to clinical trials. The extreme outcomes – the miracle cures or the catastrophic deaths reported in the media – were my only exposure to clinical trials. In between the miracle cure and the catastrophic are many patients using them to buy more time.

Over the last four years, I’ve had over 70 rounds of chemotherapy and targeted therapies, but in June 2019, my luck began to run out. The protocol I was on stopped working, and I was faced with only one line of standard treatment left. I made the decision that it was time to look for a clinical trial.

There is a misconception that the time for a clinical trial is when you’ve completely run out of options. I don’t agree with this. I think it is far better to take the opportunity of one when you are still relatively healthy and when you have a backup line of treatment left.

I’m not expecting this current or any future trial to produce a miracle. Instead, I’m hoping for time. This trial has already given me a few more months, hopefully it will continue to do so, as will the next trial and the next.

As I celebrate my fifth Christmas since diagnosis, my family and I will be thinking gratefully of those scientists, doctors and patients whose hard work, intelligence and courage have meant that people like me are here at least a little longer than we might have been.

Recommendations:

1. Develop and manage a centralised data repository for state-wide reporting on clinical trials, including non-interventional trials, which links to established clinical trial management systems and digital platforms to improve access for patients.
2. Support Cancer Council Victoria through funding investment to strengthen the Victorian Clinical Trials Link to provide patients and their families with information about clinical trials open in Victoria, including supportive care and palliative care trials.
3. Establish key performance indicators to monitor and report on a broad spectrum of clinical trial performance including recruitment of underrepresented groups and improve data collection standards across health services, cancer registries and researchers.
4. Improve equity of access by investing in telehealth infrastructure to support regional clinical trials.
5. Improve clinician and patient awareness of clinical trials through education campaigns that support patients and clinicians to discuss clinical trials as a standard component of care.
6. Invest in and leverage the Victorian Cancer Registry’s Artificial Intelligence (AI), natural language processing and case ascertainment infrastructure to support prospective recruitment into cancer clinical trials in Victoria, linking hospital, pathology and biobank data to a centralised data repository for clinical trials.

Low survival cancers

“Patients stalked by death don’t have expectations, but they do have aspirations.”

– Low survival cancer survivor, community consultation survey, July 2019

What we know

Overall, cancer survival rates are increasing in Victoria however, there are still large variations in cancer survival outcomes in some cancer types such as liver, lung, cancer of unknown primary, pancreas and mesothelioma. Cancer Council Victoria commends the investment in low survival cancer research through the current Cancer Plan.⁶³

Half of all cancer deaths in Victoria are from low survival cancers. While survival for some common cancers has improved to 90%, five-year survival rates for other cancers are as low as 6%. Furthermore, survival outcomes in certain low survival cancers such as lung cancer are exacerbated in those living in lower socioeconomic regions.³

Recommendation:

1. Continue commitment to collaborative, dedicated, long-term funding approaches to increase research and research sector capacity in low survival cancers to drive improvements in survival.

Diversify research

“There are variations in care and outcomes, but we don’t know why.”

– Clinician consultation, August 2019

“Approximately one-third of people diagnosed with cancer will die of the disease. Yet palliative care only receives approximately 2% of the cancer research dollar.”

– Clinician consultation, September 2019

What we know

There are clear discrepancies in funding across different types of cancer research with some cancer types being funded disproportionately more than others. In addition, there is increasing consensus that patient engagement in clinical research provides benefits for patients, researchers, industry, regulatory bodies, and policy makers yet the prevalence and depth of patient engagement in cancer research in Victoria remains low. As the largest not-for-profit funder of cancer research in Victoria, Cancer Council is well placed to assume a leadership role in research grant governance and to help incorporate the consumer voice in determining research investment across the state.

Recommendations:

1. Continue to fund cancer research by focusing on investment that builds capacity and collaboration and addresses priority areas including prevention, treatment, supportive care, palliative care and low survival cancers.
2. Continue to invest in essential research infrastructure that is vital for the integration of new research into clinical care such as data platforms and biobanks.
3. Support patient engagement in clinical research by funding education programs to build consumer capacity to participate in research grant funding governance. Cancer Council Victoria is well placed to lead this work.

Theme 7: System improvements

“People are not being told, what, when, where, how and why they are getting their treatment.”
– Community consultation, August 2019

“The inequity of what is provided to people who attend (a metropolitan treatment centre) compared to what we can offer people up here (in a regional hospital) is extreme.”
– Regional clinician, September 2019

Our consultations called for state-wide planning to enable individuals to receive optimal care from the most suitable centre of expertise relevant to their unique needs. Partnerships will be fundamental in developing sustainable models of care. Clinicians and the community want to be partners in the development and delivery of an improved cancer control system, alongside health services and organisations.

Integration: Working together to improve the system

“Cancer can affect anyone. I believe that all cancer patients are entitled to access the best possible treatments, no matter if they live in Melbourne or in regional Victoria.”
– Community consultation, August 2019

“There is inequity of access to services, whether this in clinical trials or supportive care services, public versus private etc. The next plan must link all sectors of care through models of care, funding, pathways and standards, to enable health equality across Victoria.”
– Clinician consultation, August 2019

What we know

There is a need for strategic planning to better coordinate and integrate service delivery. Supporting national cancer strategies, Victoria led a pilot of a service capability framework, which defined the criteria and capabilities required for health services to achieve safe and supported clinical service delivery.⁶⁴ While well received, disappointingly the pilot has not been implemented across Victoria. Cancer Council Victoria believes this is a missed opportunity. We note that within the context of broader health system reform, the Department of Health and Human Services has progressed other frameworks, including palliative care.

We also note that cancer service capability frameworks have been implemented in South Australia, providing planners and clinicians with a consistent approach to the way clinical services are described and identify interdependencies that exist between clinical areas.⁶⁵

Recommendation:

1. Develop a state-wide cancer service capability framework, in collaboration with clinicians and community, for all Victorian cancer services. This should include identification of minimum standard requirements for associated workforce, infrastructure and resource requirements to deliver optimal care.

Innovation: Support models of care to improve outcomes

“Mandate consistent systems and processes for information and support to improve the patient experience and outcomes – physically and mentally.”

– Community consultation, August 2019

“Effective models of care across the continuum have been piloted but not supported and implemented as routine care across services.”

– Clinician consultation. September 2019

What we know

The health workforce is supporting growing numbers of patients with increasingly complex needs. Victoria has a history of investing in pilots of innovative models of care.

Case study: How innovative care can work: Symptom and Urgent Review Clinic (SURC)

Systemic anti-cancer therapy (SACT) refers to all drugs that have a direct anti-tumor action including conventional cytotoxic drugs, monoclonal antibodies and targeted treatments. The number of SACT occasions of service in Victoria has grown in recent years and there is an increasing trend for chemotherapy to be administered in the ambulatory environment.

Under-reporting and under-treatment of SACT side effects are well described within the literature. This results in a number of sub-optimal outcomes for patients experiencing chemotherapy toxicities including presenting unwell on the day of their next cycle of chemotherapy which may cause treatment delays, unplanned presentations to the Emergency Department (ED) and additional visits to their General Practitioner (GP) who is unfamiliar with the expected side effects and appropriate management of presenting symptoms.

The SURC model was initially piloted in the Chemotherapy Day Unit (CDU) at Western Health in 2014 to support patients receiving SACT. The clinic, staffed by experienced cancer nurses, provides structured chemotherapy education prior to the first cycle of chemotherapy and functions as a telephone/walk in clinic for patients and carers (on self or clinician referral) to provide symptom assessment and management for patients experiencing treatment-related side effects.

Cancer Council Victoria commends the Department of Health and Human Services for supporting the successful adoption of the SURC model of care across the state throughout the term of the current Cancer Plan.

Recommendation:

1. The Victorian Government provides incentives for health service providers to implement successfully proven pilots into models of care across Victoria.

Investment: In infrastructure, outcome-focused service models and research

“The top issue to be addressed is developing systemic approaches to measure patient/community well-being.”

– Community consultation, August 2019

“Funding and models of care not aligned with patient-centred care or evidence base. Funding constraints and at times perverse funding incentives focused on episodic care rather than integrated care.”

– Clinician consultation, September 2019

What we know

Our consultations consistently identified that the current activity-based funding model inhibits the delivery of an innovative and flexible cancer service and fails to support evidence-based care such as multidisciplinary care, care close to home, and access to supportive care services.

A fundamental issue that also inhibits our current system that needs to be addressed is the high level of economic rents paid for care. Economic rents are the financial rewards over and above the level required to induce the desired supply of goods, services, land, and labour; in this case for provision of cancer care to the Victorian population. They are caused by regulatory, legal, organisational-structural, and market failures, and the Government is the only stakeholder with the capacity and scope of control to make changes to affect this problem. Cancer Council Victoria believes economic efficiency is necessary in order to optimise cancer control in Victoria.

Recommendation

1. Victorian and Commonwealth Governments work together to implement funding reform that integrates supportive care beyond inpatient care into the ambulatory and community allied health settings.

Intelligence: Better access to and use of data to drive continuous improvement

“Cancer databases need to be shared across various parties to promote better outcomes.”

– Community consultation, August 2019

“We always measure, measure, measure, but there is never one measure specifically about cancer, despite that being a major impact to our hospitals ... until a Key Performance Indicator (KPI) around cancer is developed there is not impetus to change current practice.”

– Clinician consultation, August 2019

What we know

There is a need for improved data sharing across health services. There are increasing numbers of tumour-specific clinical-quality registries collecting demographic, diagnostic, treatment, mortality and patient-reported outcome data. There are also biobanks containing rich information on biological predictors of cancer survival which are not harmonised with clinical datasets, such as from the Victorian Cancer Registry. Currently, we are unable to maximise the potential use of this data. Tumour summits, although well received, do not currently support ongoing service improvement efforts across all tumour types.

More needs to be done to better understand the impact of unmet supportive care needs on patient experiences of care and associated health outcomes. Clinical-quality registries provide capacity to collect clinically relevant data (including supportive care) and deliver feedback to healthcare providers to implement practice changes of clinical and economic significance.⁶⁶

Recommendations

1. Collaborate with key stakeholders to develop and implement routine data collection and reporting of health service quality indicators relevant to all cancers and tumour types and aligns with the Victorian Health Services Performance Monitoring Framework.
2. Undertake a mapping exercise, with key organisations, of all Victorian cancer clinical data registries, to inform a framework that centralises important data to inform and improve quality of cancer care.
3. Invest in collecting imaging data to facilitate more effective information on stage at diagnosis and to enable reporting of cancer progression and recurrence.
4. Invest in developing capability for genomic information relevant to cancer prognosis to be better integrated with population-based cancer datasets such as the Victorian Cancer Registry.

Workforce: ensuring a workforce that can meet the future needs of cancer prevention and care

“Once treatment has finished, you need to be able to go back to your GP ... so that your GP can initiate a cancer care program for you in the community. It takes the pressure off the hospitals and sends the patients back into the community where they can access their care close to home.”

– Community consultation, August 2019

“We are facing a crisis, we have had the same size workforce for the last ten years, but we have seen a dramatic increase in patients and in treatment.”

– Clinician consultation, August 2019

What we know

It is estimated that there will be almost 1.9 million people living with or beyond a diagnosis of cancer in 2040, that is, 1 in 18 Australians will have been diagnosed with cancer in their lifetime. More than half (58%) of Australians with a personal history of cancer will be aged 70 years or older in 2040.⁶¹ Maintaining a skilled workforce is critical to quality and safety outcomes.

Recommendations

1. Increase capacity of primary health services to take a greater role in educating patients about cancer prevention and in the care of patients after completion of cancer treatment. This should include identification of minimum standards, associated workforce, infrastructure and resources needed to deliver optimal care.
2. Invest in and incentivise clinicians to undertake professional development in technological advances in diagnostics and treatments, geriatric and palliative care approaches, especially in outer metropolitan and regional centres.
3. Establishment of a communication skills standard for clinicians.

Summary

Cancer Council Victoria's submission for the 2020-24 Victorian Cancer Plan has been informed by the latest evidence and developed through extensive consultations with clinicians, researchers, policy makers and the community.

With one of the highest cancer survival rates in the world, Victorians are well supported by a high-quality healthcare system. And our consultations reflected this, with the community emphasising the value they place on the efforts and care of clinicians.

Our consultations have identified ten priorities for urgent action and over 70 recommendations that are opportunities to strengthen our system even further.

The greatest opportunity to reduce cancer incidence and mortality is through prevention, screening and early detection. We can do this by continued investment in mass media campaigns that educate the public about cancer risk, improving access to cancer screening and developing Victoria's first Liver Cancer Strategy.

Reducing the cost of cancer is vital, so that people no longer need to borrow money, increase credit limits, access superannuation, and mortgage assets to meet treatment costs and everyday living expenses. Cancer Council's informed financial consent standard can help improve transparency around the cost of cancer and we recommend expanding support for people travelling to treatment to cover more of the parking, travel and accommodation costs.

Improved links between rural, regional and metropolitan cancer services and primary care can address variations in cancer care, and the development of a state-wide cancer services framework will address minimum standards of care.

Effective coordination of care across clinicians and health services is needed to tackle inequitable outcomes. We recommend investing in navigation support, the missing link between clinical and community-based information and support.

Supportive care needs to be prioritised at all stages of the cancer trajectory, including survivorship and end-of-life care. The current cancer care funding allocation system needs to align with the move towards ambulatory care and care close to home.

Investing in infrastructure to link clinical trial information to the population-based Victorian Cancer Registry would significantly enhance clinical research and improve access to clinical trial opportunities.

We look forward to collaborating with the Victorian Government on the 2020-2024 Cancer Plan. The collective voice of community, clinicians, government and researchers fosters innovative change to address disparity and balance the scales - leading to better outcomes for all Victorians affected by cancer.

Appendix 1. Consultation Schedule

More than 600 people were consulted from June to September 2019 through a variety of methods. Below is a summary of the consultation process.

Community consultation

Community Town Halls

34 community members attended town hall events held at Wangaratta and Cancer Council Victoria

Community online survey

344 community members completed the online survey

61% were from metropolitan Melbourne

39% were from regional or rural Victoria

16% were currently experiencing a cancer diagnosis or undergoing treatment

34% had previously experienced a cancer diagnosis or undertaken treatment

26% were carers

16% were a combination of the above descriptions

8% were “other”

Clinician consultation

Clinician Town Halls

77 clinicians attended town hall events held at Cancer Council Victoria, Peter McCallum Cancer Centre, Monash Health and Latrobe Regional Health.

Clinician meetings

81 clinicians were consulted via teleconference or face-to-face meetings.

Clinician online survey

100 clinicians and researchers completed the online survey

76% were from metropolitan Melbourne

24% were from regional or rural Victoria

28% were nursing

27% were medical (GP, medical oncologist, radiation oncologist, palliative care physician etc)

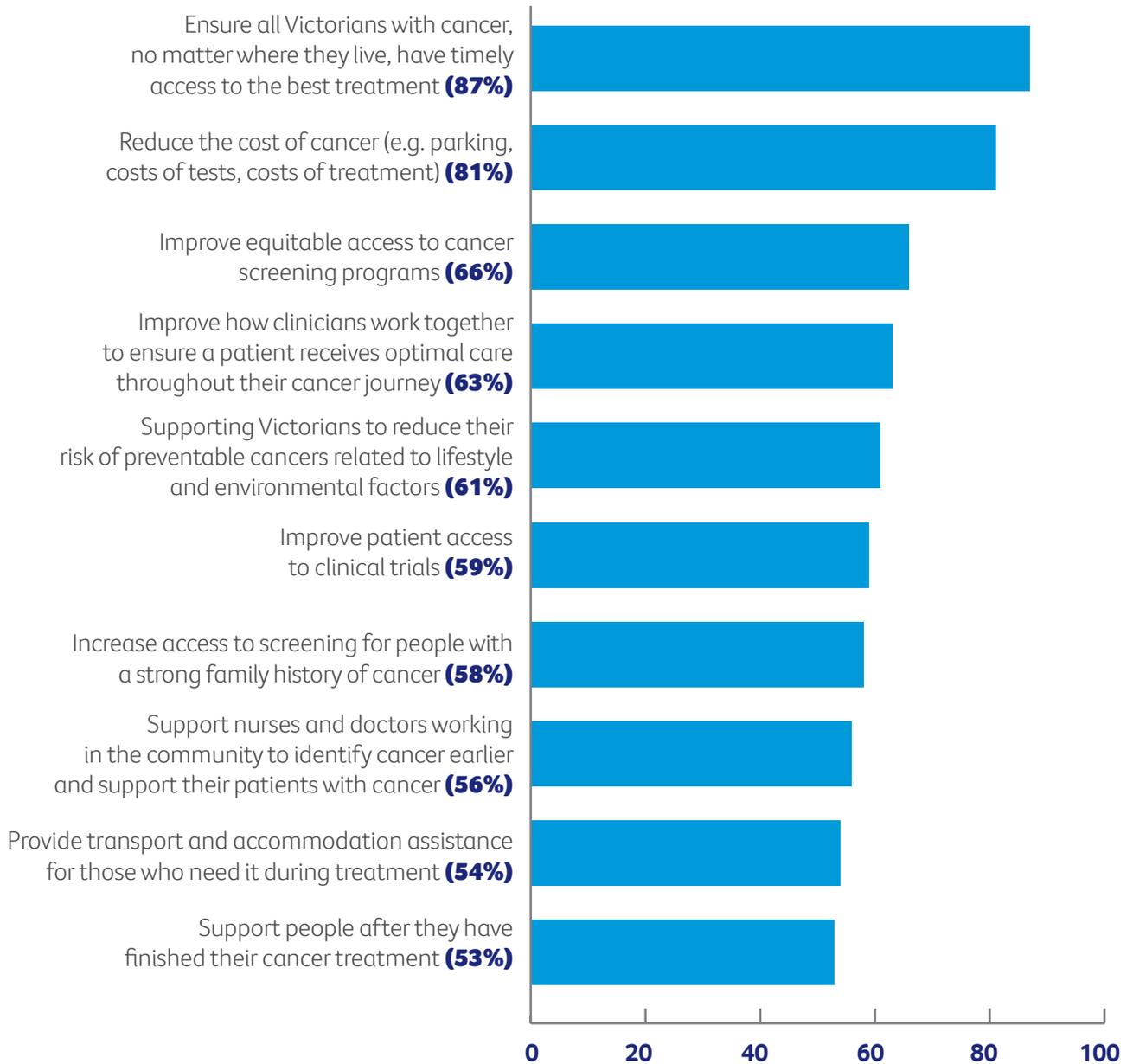
14% were allied health

5% were researchers

26% were “other”

Appendix 2a. Community survey results

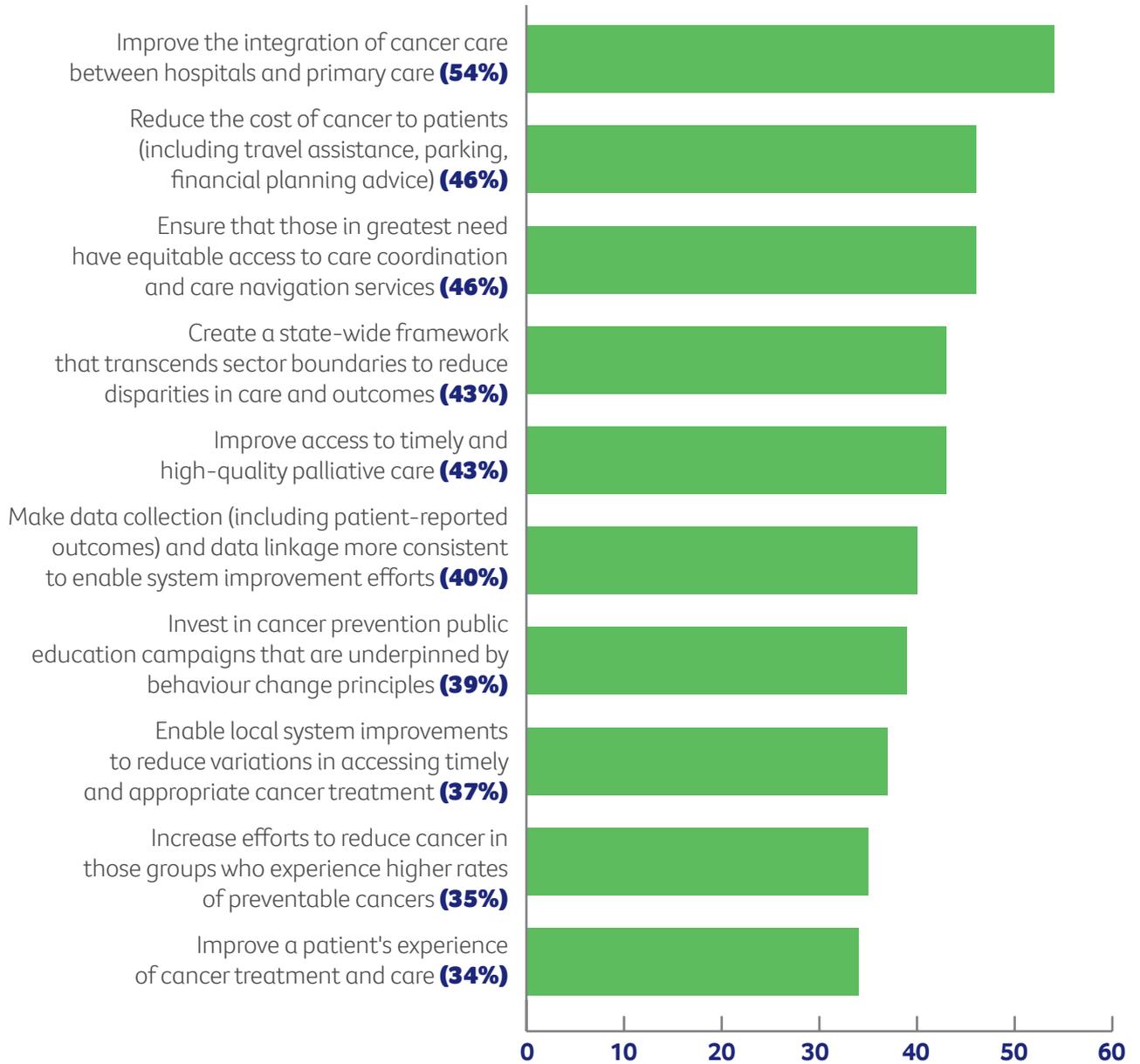
Percentage selecting priority to be addressed in the next Victorian Cancer Plan (Community survey, n= 344)



Percentage selecting priority (Community survey, n= 344)

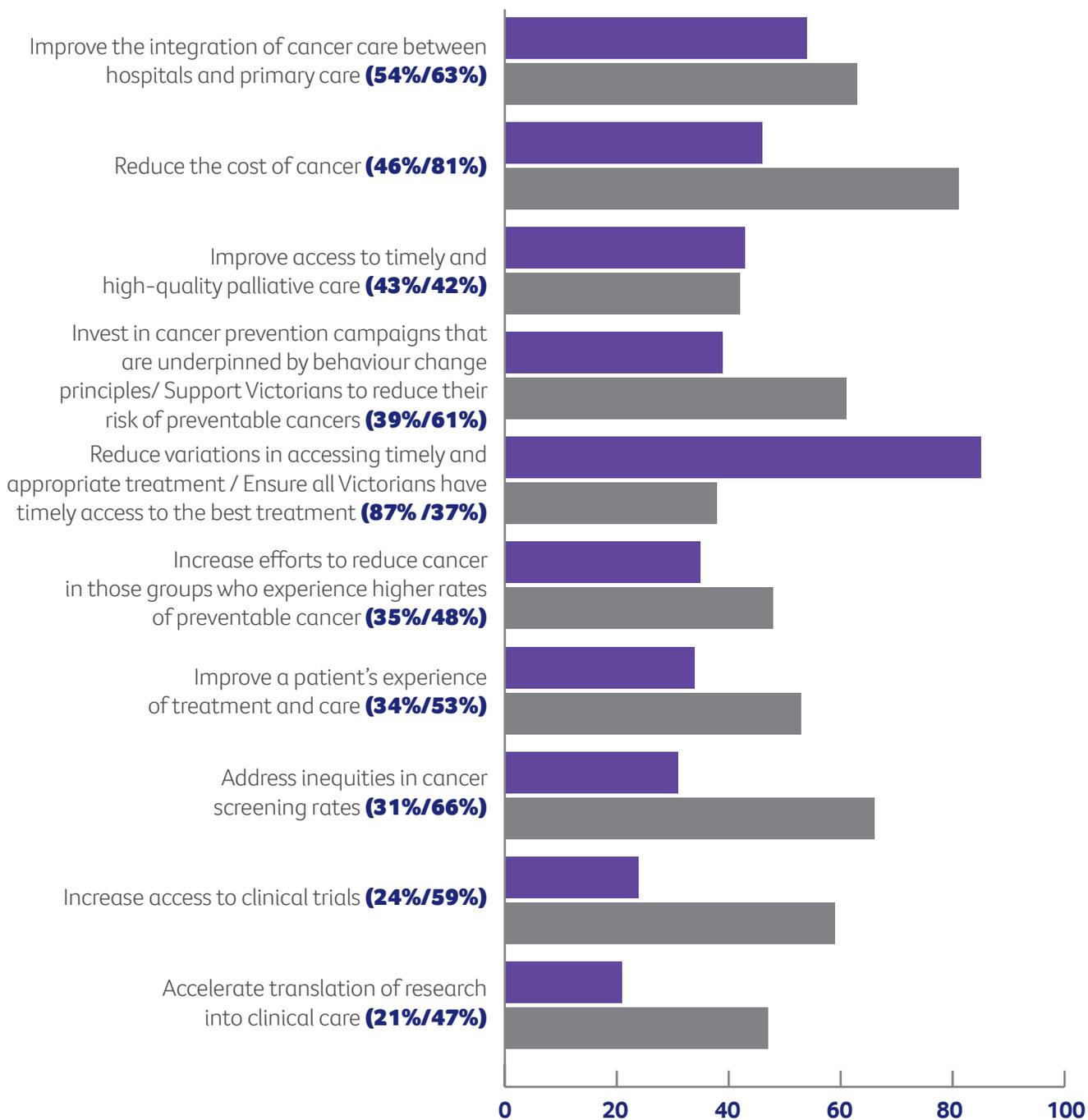
Appendix 2b. Clinician survey results

Percentage selecting priority to be addressed in the next Victorian Cancer Plan (clinician survey, n= 100)



Percentage selecting priority (clinician survey, n= 100)

Appendix 2c. Top 10 common clinician and community



■ % Community selecting priority to be addressed in the next Victorian Cancer Plan

■ % Clinicians selecting priority to be addressed in the next Victorian Cancer Plan

References

1. For the purposes of this report, we will use community to reflect the voice of patients and other people affected by cancer. We will use clinician to reflect the voice of the health workforce including doctors, nurses, allied health professionals, scientists and researchers.
2. Thursfield V. and Farrugia, H. (2019). *Cancer in Victoria: Statistics & Trends 2018*. Melbourne, CCV.
3. This data is based on research done by Nina Afshar as part of her PhD
4. Australian Institute of Health and Welfare. (2019). *National Bowel Cancer Screening Program Monitoring Report*. Canberra, AIHW.
5. North Western Melbourne PHN (2018). *Local cancer screening community profile*. Retrieved 24th September 2019, from https://nwmpnhn.org.au/wpcontent/uploads/2018/08/CLCSP_NWMPHN_LocalCancerScreeningCommunityProfile180413_v1.1.pdf
6. Australian Human Rights Commission. (2015). *Resilient Individuals: Sexual Orientation, Gender Identity & Intersex Rights: National Consultation Report*. Sydney, AHCR.
7. Tamargo C., Quinn G., Sancez J., et al (2017). Cancer and the LGBTQ Population: Quantitative and Qualitative Results from an Oncology Providers' Survey on Knowledge, Attitudes, and Practice Behaviours. *J Clin Med* 6(10): 93.
8. Dess R., Hartman H., Mahal B., et al (2019). Association of Black Race With Prostate Cancer-Specific and Other-Cause Mortality. *JAMA Oncol* 23: 1-2.
9. Optenberg S., Thompson I., Friedrichs P., et al. (1995) *Race, treatment, and long-term survival from prostate cancer in an equal-access medical care delivery system*. *JAMA*, 274(20):1599-605.
10. Australian Institute of Health and Welfare (2019). "Deaths in Australia." from <https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/trends-in-deaths>
11. Bowles A., Tuzzio L., Wiese C., et al (2008). *Understanding high quality cancer care: a summary of expert perspectives*. *Cancer* 112(4): 934-942.
12. Gorin, S., Haggstrom, D., Han, P., et al (2017) *Cancer Care Coordination: a Systematic Review and Meta-Analysis of Over 30 Years of Empirical Studies*. *Annals of Behavioural Medicine*, 51:532-546)
13. IOM (Institute of Medicine) (2013) *Delivering high-quality cancer care: Charting a new course for a system in crisis*. Washington, DC: The National Academies Press.
14. Australian Commission on Safety and Quality in Health Care (2012). *National Safety and Quality Standards*, Canberra, Available at: <http://www.safetyandquality.gov.au/publications/nationalsafety-and-quality-health-service-standards/>
15. ME Bank (2019). *Household financial comfort report*. Melbourne. Accessed 22 June 2019 https://www.mebank.com.au/getmedia/899ccb18-7fe5-4868-b51b-b64ad2b467cf/216317_HFCR-Jan-2019_V11-WEB.pdf
16. Deloitte Access Economics (2016) "The financial impact of breast cancer in Australia" accessed 15th November 2019 from <https://www.bcna.org.au/media/5608/financial-impacts-of-breast-cancer-deloitte-access-economics.pdf>
17. Australian Prudential Regulation Authority (2019), *Statistics- Private Health Insurance Medical Gap, June 2019* (released 20 August 2019), retrieved 31st October 2019 from https://www.apra.gov.au/sites/default/files/private_health_insurance_medical_services_june_2019.xlsx
18. Anazodo A., Catharyn J., et al. (2016). *A Study Protocol for the Australasian Oncofertility Registry: Monitoring Referral Patterns and the Uptake, Quality, and Complications of Fertility Preservation Strategies in Australia and New Zealand*. *Journal of Adolescent and Young Adult Oncology* 5(3): 215-225.
19. DiSipio T., Rye S., Newman B., et al (2013) *Incidence of unilateral arm lymphoedema after breast cancer: a systematic review and meta-analysis*. *Lancet Oncol* 14 (6) pp. 70076-7.
20. Australian Bureau of Statistics (2018) *National Health Survey: First Results 2017-18*. Canberra, ABS
21. Lauby-Secretan, B., Scoccianti, C., Loomis, D., et al (2016) *Body fatness and cancer—viewpoint of the IARC Working Group*. *New England Journal of Medicine*, 375(8), pp.794-798.
22. VicHealth. (2016). *Obesity and healthy eating in Australia Evidence summary*. Retrieved 11th June 2019 from <https://www.vichealth.vic.gov.au/-/media/ResourceCentre/PublicationsandResources/healthy-eating/Obesity-and-healthy-eating-in-Australiasummary.pdf?la=en&hash=D09D216292443BEE9FF6C16693488657A6CC64F7>
23. Cancer Council Victoria. (2016) *Alcohol and cancer risk fact sheet*. Melbourne, CCV.
24. World Cancer Research Fund, American Institute for Cancer Research (2018) *Diet, Nutrition, Physical Activity and Cancer: A Global Perspective. Continuous Update Project Expert Report 2018*. Washington DC, AICR
25. Corrao G., Bagnardi V., Zambon A., et al (2004) *A meta-analysis of alcohol consumption and the risk of 15 diseases*. *Preventive Medicine*, 38(5), 613-9.
26. Hamajima N., Hirose K., Tajima K., et al (2002) *Alcohol, tobacco and breast cancer--collaborative reanalysis of individual data from 53 epidemiological studies, including 58,515 women with breast cancer and 95,067 women without the disease*. *British Journal of Cancer*, 87, 1234-45.
27. Allen N., Beral V., Casabonne D., et al (2009) *Moderate alcohol intake and cancer incidence in women*. *Journal of the National Cancer Institute*, 101, 296-305.
28. Wakefield M., Dunstone K., Brennan E. (2017) Unpublished national data from NHMRC Project grant.
29. Livingston M. (2011) *Alcohol outlet density and harm: Comparing the impacts on violence and chronic harms*. *Drug and Alcohol Review*, 30:515-523.

30. Australian Institute of Health and Welfare (2019) *Australian burden of disease study: Impact and causes of illness and death in Australia 2015*. Australian Burden of Disease, Canberra: AIHW. Available from: <https://www.aihw.gov.au/getmedia/c076f42f-61ea-4348-9c0a-d996353e838f/aihw-bod-22.pdf.aspx?inline=true>
31. Pandeya N., Wilson L., Bain C., et al (2015) *Cancers in Australia in 2010 attributable to tobacco smoke*. *Australian and New Zealand Journal of Public Health*. 39(5):464-470.
32. International Agency for Research on Cancer (IARC), World Health Organisation (WHO), The University of Newcastle Australia. (2018) *Tobacco 39 knowledge summaries. Tobacco and cancer treatment outcomes*. Available from: <https://www.who.int/tobacco/publications/knowledge-summaries/cancer-treatment-outcomes/en/>
33. Gold E., Flatt S., Pierce J., et al (2006) *Dietary factors and vasomotor symptoms in breast cancer survivors: the WHEL Study*. *Menopause*. 13:423-33.
34. Ehlers S., Gastineau D., Patten C., et al (2011) *The impact of smoking on outcomes among patients undergoing hematopoietic SCT for the treatment of acute leukemia*. *Bone Marrow Transplant*. 46:285-90.
35. Mason D., Subramaniam S., Nowicki E., (2009) *Impact of smoking cessation before resection of lung cancer: A Society of Thoracic Surgeons General Thoracic Surgery Database study*. *Ann Thorac Surg*. 88:362-71.
36. Zevallos J., Mallen M., Lam C., et al (2009) *Complications of radiotherapy in laryngopharyngeal cancer: effects of a prospective smoking cessation program*. *Cancer*. 115:4636-44.
37. Luo Q., Steinberg J., O'Connell D., et al (2019). *Lung cancer mortality in Australia in the twenty-first century: How many lives can be saved with effective tobacco control?* *Lung Cancer* 130: 208-215.
38. Australian National Preventive Health Agency (2013) *Tobacco control and mass media campaigns*. Canberra, ANPHA. Australian National Preventive Health Agency
39. West R., Raw M., McNeill A., et al (2015) *Health-care interventions to promote and assist tobacco cessation: a review of efficacy, effectiveness and affordability for use in national guideline development*. *Addiction*, 11: 1388-1403.
40. Lew J., St John D., Xu X., et al, (2017) *Long-term evaluation of benefits, harms, and cost-effectiveness of the National Bowel Cancer Screening Program in Australia: a modelling study*. *Lancet Public Health*. Jul 1;2(7):e331-40.
41. Hall M., Simms K., Lew J., et al (2018) *The projected timeframe until cervical cancer elimination in Australia: a modelling study* *Lancet Public Health* 4(1): 19-27
42. Lew J., Simms K., Smith M., et al (2017). *Primary HPV testing versus cytology based cervical screening in women in Australia vaccinated for HPV and unvaccinated: effectiveness and economic assessment for the National Cervical Screening Program*. *Lancet Public Health* 2(2): 92-107.
43. Australian Institute of Health and Welfare & Cancer Australia (2018) *Cancer in Aboriginal & Torres Strait Islander people of Australia*. Canberra: AIHW. Available at <https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians/contents/cancer-type/cervical-cancer-c53> (accessed 24 October 2018).
44. Australian Institute of Health and Welfare (2019) *Cancer in Australia Report 2019*. Canberra, AIHW available at: <https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2019/contents/summary>
45. Lamprell K., Arnolda G., Delaney G. et al (2019) *The challenge of putting principles into practice: Resource tensions and real-world constraints in multidisciplinary oncology team meetings*. *Asia-Pacific Oncology Review*. 15:199-207
46. Vehling S., Kissane D., et al. (2017) *The association of demoralization with mental disorders and suicidal ideation in patients with cancer*. *Cancer* 123(17): 3394-3401..
47. Holland J., H. C., Breitbart W., et al, (2015). *Psycho Oncology*. New York, Oxford University Press.
48. Pitman A., Suleman S., Hyde N., et al (2018). *Depression and Anxiety in Patients with Cancer*, *BMJ* 361: 1415.
49. Miller K., Seigal R., Lin C, et al (2016). *Cancer Treatment and Survivorship statistics*. *CA: A cancer journal for clinicians* 66(4): 271-289.
50. Jefford M, W. A., Lisy K., Lacey K., et al (2017). *Patient-reported outcomes in cancer survivors: a population wide cross sectional study*. *Support Care Cancer* 25(10): 3171-3179.
51. Beatty L. and Kissane D., (2017). *Anxiety and depression in women with breast cancer*. *Cancer Forum* 41(1): 4.
52. Lisy K., Langdon L., et al. (2019). *Identifying the most prevalent unmet needs of cancer survivors in Australia: A Systematic Review*. *Asia-Pac J Clin Oncol*. June(18): 1-11.
53. Spiegel D. (2013). *Minding the body: Psychotherapy and cancer survival*. *Br J Health Psychol* 19(3): 465-485.
54. Jansen F., van Zwieten V., et al. (2016). *A Review on Cost-Effectiveness and Cost-Utility of Psychosocial Care in Cancer Patients*. *Asia Pac J Oncol Nurs* 3(2): 125-136.
55. Lee S., Katona L., et al. (2010). "Routine screening for psychological distress on an Australian inpatient haematology and oncology ward: impact on use of psychosocial services." *Med J Aust*. 193(5): S74.
56. Clinical Oncology Society of Australia Model of Survivorship Care Working Group (2016). *Model of Survivorship Care: Critical Components of Cancer Survivorship Care in Australia Position Statement*, Clinical Oncology Society of Australia.
57. Geng H., Chuang D., et al. (2018). *Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis*. *Medicine* 97(39)
58. Hudson P. and Aranda S. (2014). *The Melbourne Family Support Program: evidence-based strategies that prepare family caregivers for supporting palliative care patients*. *BMJ Supportive & Palliative Care* 4: 231-237.
59. Hudson P., Thomas K., et al. (2011). *Psychological and social profile of family caregivers on commencement of palliative care*. *J Pain Symptom Manage* 41: 522-534.

60. Grunfeld E., Coyle D., et al. (2004). *Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers*. Can Med Assoc J 170: 1795-1801.
61. Cancer Council Victoria (2018). *Australians living with and beyond cancer in 2040*. Melbourne, CCV.
62. Cancer Council Victoria & Victorian State Government (2018). *Clinical trials roundtable: final report*. Melbourne.
63. The Hon Jill Hennessy MP (2019) *Fighting Low Survival Cancers*. Minister for Health and Minister for Ambulatory Services. Melbourne
64. The Australian Government (2018). *National action- cancer control*. Retrieved 15th September 2019, from <https://www1.health.gov.au/internet/main/publishing.nsf/Content/cancer-national>.
65. Government of South Australia (2016). *Clinical Services Capability Framework*. Retrieved 25th September 2019, from <https://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/Clinical+resources/Clinical+Services+Capability+Framework/>
66. Australian Commission on Safety and Quality in Healthcare (2014) *Framework for Australian clinical quality registries*. Sydney, ACSQH.

