ALL.CAN CANCER INITIATIVE:

# AN EXPLORATION OF THE CANCER PATHWAY IN AUSTRALIA

All.Can
Changing cancer care together

# ACKNOWLEDGEMENTS

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All.Can Australia commissioned Community and Patient Preference Research (CaPPRe) to conduct the research and prepare this paper.

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# EXECUTIVE SUMMARY

## Overview

Optimising the distribution of resource in the cancer pathway, within and between each of the stages (prevention, screening, diagnosis, treatment, palliation and survivorship), is a major challenge. This system-wide evaluation of Australian cancer care provides insight into key stages of the patient journey and discusses areas where improvements could be made to create better patient outcomes.

## Methods

Research was carried out by independent researchers between August 2018 and March 2019, and was compiled using mixed methods; a literature review, a quantitative online survey, desk-based research, and in-depth interviews with stakeholders (including: senior clinicians, policy influencers, researchers, nurse practitioners, a patient advocate, a member of the Pharmaceutical Benefits Advisory Committee, a chief executive surgeon at a cancer institute, a chief nursing officer at a cancer institute, and a former member of the Department of Health).

## Findings

Cancer care in Australia is of a high standard, but as is inevitable with something so complex there are areas of weakness (and areas of strength) which could be made stronger.

### Weaknesses across the pathway

- The pathway can be disjointed, with patients struggling to navigate their way through the system. Moving between health care providers and across sectors can be very challenging.
- Inequalities within patient groups disadvantage those in remote or regional areas, low SES persons and minority cultures.

### Areas of weakness within the pathway

- Treatment overall is an area of strength, but there are areas of over-surveillance and unnecessary intervention, and the cost of medicine is expensive (in some cases this can be reduced).
- There is insufficient use of palliative care, meaning patients experience poor quality of life in the final stages of life and they may be given unnecessary, expensive treatments.
- Prevention and survivorship are overlooked in favour of other elements of the pathway.

## Priorities for Action

**01** Implement value-based health care for Australian cancer patients. While complex logistical and measurement challenges are involved, placing the patient at the centre of the health care delivery service model will improve patient outcomes.

**02** Implement strategies to assist patients navigate the health care system, by considering the funding of cancer care coordinators and the adoption of technology based approaches to ensure patients are provided with access to relevant networks and the right information, at the right time, so they can make informed decisions about their treatment.

**03** Ensure patients are provided with accessible information on their disease and their treatment options so they can make informed decisions for their health care.

**04** Address geographical inequalities by considering the range of measures appropriate to such circumstances, including but not limited to improving access to clinical trials for those in remote and regional areas.

**05** Make more use of palliative services; make referrals timely.

**06** Move towards a model where the relationship between patients and clinicians is more transparent and collaborative by ensuring consumers are both involved and engaged not just in the provision of health care, but in an assessment of the evidence-base, resource allocation, service prioritisation and design as well as measurement and analysis of outcomes.

# ABOUT ALL.CAN

**All.Can is a global initiative that engages patients, health care professionals and other key stakeholders across health services and the broader health system about the need to improve efficiencies in cancer care.**

Their intention is to retain a clear focus on contributing to better patient outcomes through reviewing existing cancer treatment modalities to identify ways to reduce waste and improve outcomes.

The All.Can initiative began in Australia in late 2017 and was officially launched on World Cancer Day (4 February) 2018. The patient-focused initiative aims to gather insights from the cancer community and sharpen the focus on delivery of care truly of value to patients. The Australian chapter plans to identify improvements to the cancer patient care pathway through the health care system.

The overarching goal for All.Can is to help contribute to sustainable resource allocation in cancer care so that funding is directed to interventions which create the most value for patients. This reflects the global reforms in health care that are moving away from volume-based care and focusing on improving patient outcomes.

One of the key projects for All.Can in Australia is the development of a research report that provides system-wide evaluation of Australian cancer care, giving insight into key stages of the patient journey, with a focus on areas that would benefit from improvement or attention to create better patient outcomes.

# THE PREVALENCE AND IMPACT OF CANCER

**The Australian Institute of Health and Welfare (AIHW) report ‘Cancer in Australia’ projected 144,713 newly diagnosed cases of cancer in 2019 (excluding basal and squamous cell carcinoma of the skin) with 54% in men.**

Cancer incidence rates have been moving in a downward trend since 2008, when incidence peaked at 508 cases per 100,000; the estimated incidence rate for 2019 is 483 per 100,000. Survival rates have also improved, and mortality continues to drop, with male mortality decreasing by 92 deaths per 100,000 males since 1989 and female mortality decreasing by 35 deaths per 100,000 females. The most commonly diagnosed cancers are breast, prostate, colorectal, melanoma and lung[1].

It is estimated there will be 49,896 deaths from cancer in Australia in 2019, with 87% of deaths in men and 85% in women occurring among those over 60 years of age. The overall five-year relative survival rate for all cancers was 69% from 2011-2015, which is very strong by international standards, and has risen from 50% in the period 1986–1990[1].

The Australian Government notes that these improved outcomes are due to the benefits of research, prevention, early diagnosis and high quality care[2]. However, five-year survival varies dramatically by cancer site, ranging from 98% for testicular cancer to 6.1% for mesothelioma. Survival for bladder and laryngeal cancer has decreased over time[1].

Cancer also poses a significant cost and resource burden, accounting for 19% of the total burden of disease in Australia, compared with 15% from cardiovascular disease[1].

### Understanding the cancer care pathway

The All.Can Australia Steering Committee commissioned this study to explore a system wide evaluation of the Australian Cancer care pathway with the aim of providing insight into the key stages of the patient journey that need improvement, in order to create better patient outcomes.

**Main objectives:**

- Establish a baseline understanding of the patient cancer journey at a health system-wide level by reviewing existing resource allocation.
- Identify and gather evidence of the major inefficiencies in the Australian health system that impact patients’ value of care in cancer.
- Suggest ways to reallocate resources across the various cancer care stages, throughout the pathway, and define what sustainable resource allocation in cancer care may look like.

The study was approved by the Bellberry Limited Human Research Ethics Committee.

# OUR APPROACH

## STUDY DESIGN

### Mixed method approach

Mixed methods research is a methodology for conducting research that involves collecting, analysing and integrating quantitative (for example, surveys) and qualitative (for example, focus groups, interviews) research. To meet the studies aims and objectives, the most appropriate method for was a mixed-methods approach.

## Phase one: Literature review

This report includes findings from a rapid evidence review (available on request) undertaken in August 2018. The rapid review seeks to find the best available evidence in a limited period, to answer several research questions outlined by the All.Can Australia Steering Committee.

## Phase two: The survey

The survey was made up of a mix of open-ended and closed questions, as well as a resources exercise option (based on the current resourcing identified in the literature and pilot survey) to identify preferences for resource allocation or re-allocation. Development of the survey was based on existing literature on cancer care and input from the All.Can Australia Steering Committee. The 30-minute online survey was sent out to key opinion leaders/ stakeholders identified by the All.Can Australia Steering Committee, as well as CaPPRe contacts.

## Phase two: Qualitative research

The qualitative element comprised semi structured interviews (45-90 mins), which sought to investigate in-depth, stakeholders' opinions of the cancer pathway. Most of the interviewees were recruited via the survey, where participants had the option to 'opt-in' for an interview. CaPPRe and the All.Can Steering Committee also reached out to relevant contacts.

Interviews took place from October 2018 to March 2019.

Ten interviews were conducted electronically via Zoom Meeting, two over the phone, one was in-person.

## Phase three: Desk-based funding research

In order to gain more depth on the financial inefficiencies within the health system grey literature and white paper searches were carried out.

## Participants

A total of 23 participants completed the online survey and 13 participants completed the in-depth interviews. The participants were able to withdraw at any time without penalty or prejudice, including prior to commencing the survey or during survey completion.

## Analysis

The data was cleaned, and no participants were removed from the descriptive and demographic analysis; descriptive statistics were used to examine the participant responses and demographic characteristics.

# THE FINDINGS

## Demographics and survey sample

**The All.Can Australia Steering Committee commissioned this study to collect insights from a range of key health system stakeholders.**

Participants were made up of: surgeons, nurses, oncologists, a pharmacist, researchers (both in academia and advocacy settings), cancer advocacy group representatives, senior leadership (chair and directors of cancer related associations) and policy makers. People diagnosed with cancer were not part of the target sample for this research, but the patient advocate participants did include people diagnosed with cancer, who participated from an advocacy standpoint'. A separate survey was conducted by the global All.Can group to collect insights from a patient perspective from people diagnosed or previously treated for cancer on what needs to improve or change in the delivery of care. Australia participated in this global patient survey and the results will be made available in a separate document.

More than half of this study's participants were female (61%), two thirds were aged between 51 and 70 years of age. All States, except Tasmania, were represented; the majority of participants came from Victoria (39%) and New South Wales (26%). Most came from metro locations (87%), which is representative of the medical workforce at population level[3]. For a complete breakdown of the demographics (see Table 3).

Participants worked across the cancer pathways; research (61%), treatment (57%) screening (43%) and policy making/funding (43%) were the most popular areas (see Table 1). A complete breakdown of demographic data is displayed in Figure 1 and Table 2.

## Table 1 Involvement in stages of the cancer pathway

| Cancer Stage* | N (%) |
|---|---|
| Research | 14 (60.87) |
| Treatment | 13 (56.52) |
| Screening | 10 (43.48) |
| Policy-making / funding | 10 (43.48) |
| Diagnosis | 9 (39.13) |
| Palliative care | 9 (39.13) |
| Survivorship | 9 (39.13) |
| Prevention | 8 (34.78) |

## Figure 1 Participant segment

## Gender, age and state

### Table 2 Demographic characteristics (unweighted data)

| Demographic characteristic | | N (%) |
|---|---|---|
| Gender | Female | 14 (60.87) |
| | Male | 9 (39.13) |
| Age | 18-30 | 1 (4.35) |
| | 31-40 | 4 (17.39) |
| | 41-50 | 3 (13.04) |
| | 51-60 | 12 (52.17) |
| | 61-70 | 2 (8.70) |
| | 71-80 | 1 (4.35) |
| State/Territory | ACT | 3 (13.04) |
| | NSW | 6 (26.09) |
| | VIC | 9 (39.13) |
| | SA | 2 (8.70) |
| | WA | 3 (13.04) |
| Area (participant-reported) | Metro/City | 20 (86.96) |
| | Regional | 2 (8.70) |
| | Rural | 1 (4.35) |

### In-depth interview sample

Participants had varied backgrounds and all stakeholder areas were represented. They were made up of: senior clinicians (two professors, one specialist oncologist), policy influencers, researchers, a lymphoedema practitioner, a nurse practitioner, a patient advocate, a member of the Pharmaceutical Benefits Advisory Committee, a chief executive surgeon at a cancer institute, a chief nursing officer at a cancer institute, a former member of the Department of Health, a medical director and a former surgeon at a health insurer.

*Multiple response question, percentages do not sum to 100%

# DISCUSSION

## Cancer care pathway overview

Survey participants and interviewees are in strong agreement that the **standard of health care delivery in Australia, across the variety of cancer pathways, is high and continues to move in the right direction**.

Overall patients are “very satisfied with their journey”(Int1), “Australia is well placed, and Optimal Care Plans delineate [the] ideal journey” (survey), and the health system provides “excellent care” (survey).  “Survival rates are amongst the best in the world” (Int6, Int5). People who work in cancer are united in their aims and “everyone wants to do better”(Int3), “Australia is close to being a world leader in almost all aspects of support services for cancer”(Int 10), “‘The quality of the treatment you will get…Australian results are world class and comparable with anywhere in the world, or better than anywhere in the world in terms of survival”(Int11).

**However, the complexity of cancer, and therefore the cancer care pathway, means optimisation of the pathway is incredibly challenging.** It has to compete with other areas of health for funding, each area with its own agenda(Int 10). Interviewees recognise it is hard for the Government to know “where to cut the pie”(Int 11, Int 13), they also acknowledge that, relatively, cancer does well in terms of funding: “Cancer is one of the highest funded areas of health in the country… one of the highest levels of drug support is oncology” (Int 10), “cancer care gets a pretty good deal…at least in terms of State Government, you know, public hospital funding”(Int 12). This is reflected by the high standard of care patients in Australia receive, but there are areas where improvements could be made, where money could be saved or shifted to optimise each individual’s pathway. This will be explored in more detail later in the report.

> *"I think our public health system in Australia is, I think our public health system in Australia is world's best. I think that the equity issue in Australia is so much more reasonable than what we see in other countries around the world, and I think the standard of the education of our clinical leadership and our hospital and health system leaders in workforce, is unparalleled."*(Int9)
>
> *There is a feeling that, overall, patients have good access to services, and that the funding allocated to the different pathway stages is being used efficiently, particularly in the private sector."* (Int2)

## Prevention

Prevention is **one of the most contradictory areas of the cancer pathway.** By 2025 there may be 170,000 new cancer diagnoses per year, but an estimated one third to one half of all cancers could be prevented by healthy lifestyle and regular screening[4].

We know that prevention of some colorectal, lung, and skin cancers is possible by: avoiding alcohol and tobacco, ultraviolet light, inactivity, dietary risk factors, and occupational exposures[5]. Aspirin may prevent colorectal cancer in those at high risk[6], cervical cancer is preventable through HPV vaccination, and it is encouraging that HPV vaccination coverage rates in Australia are now well over 70% for both boys and girls[2]. Despite this evidence, and the acknowledgment that investment in this area would reduce costs downstream, **it is an area of weakness in the pathway.** The potential for a favourable return on investment is there; for example a cost-effectiveness analysis of the SunSmart skin cancer campaign indicates that it prevented more than 43,000 skin cancers in Victoria between 1988 and 2010, a net cost saving to hospitals of $92 million[7].

However, "prevention initiatives can be hard to evaluate in terms of long-term population level impact, because much of it is intangible"(Int6), and it is difficult to know where efforts would be best focused(Int 10). This could be what is contributing to current under-funding. Survey results also suggest that the funding currently allocated to prevention is not being used efficiently; it is rated 6.35 out of 10 by survey participants (in a survey task where 0 = not efficient at all and 10=extremely efficient), this is the second worst score after survivorship.

## Screening

Screening is well established in Australia; programs are well funded and have expanded in recent years[8].

Australia has three national organised, systematic and integrated programs of testing for cancer in asymptomatic populations. These are the national bowel (incidence 58 per 100,000)[9], breast (313 per 100,000) [10] and cervical (10 per 100,000)[8] cancer screening programs. These programs are effective, although uptake could be improved[11].

Despite successes, **this is a divisive area**; one participant calls for more screening tests for at-risk patients, another participant suggests more of the population should be screened (if participation rates for those eligible for programs increased, this may result in less cost pressure further along the pathway). However, these participants were outnumbered by those who recommended savings could be made here because they consider us to be over-screening(survey, Int4, Int5).

## Diagnosis

Diagnosis is a **relatively strong point on the pathway**, but several interviewees posited that we over-diagnose.

Over-diagnosis can lead to a significant resource burden without gains in outcomes. For example, the thyroid cancer incidence rate has increased 392% in the period 1982-2019, likely due to an increase in medical surveillance and the introduction of new diagnostic techniques[1]. However, recent thyroidectomy rates have doubled, yet mortality from thyroid cancer has remained static. Modelling shows that reducing unnecessary detection and a conservative approach could lead to millions of dollars in savings and reduced harms (e.g. potentially avoidable thyroidectomies) to patients from over-diagnosis[12].

Furthermore, not all interventions to improve diagnosis are efficient. The Improving Rural Cancer Outcomes Trial showed no benefit of a complex intervention to reduce time to diagnosis in rural cancer patients in Western Australia. This highlights the need to evaluate proposed diagnostic pathways carefully and conduct cost-effectiveness studies[13].

> *“I think we are doing so much better with diagnosis now, but I think we are over-diagnosing. There’s over surveillance and that worries me that we are going too far the other way. But I do think that we’re doing diagnosis really well, and I think that there is good follow-up.”(Int3).*

## Treatment

It is agreed that **Australia does treatment very well**. It is consistently talked about by interviewees in gold standard terms(Int 10, Int 11, Int 12, Int 13); the level of oncology expertise is high, access to drugs is generally good and time from diagnosis to treatment is short(Int1).

Respondents score this stage of the pathway highest for meeting patient and organisational needs; 7.83 at patient level and 8.52 at organisational level (10=needs being completely met). The lower score for patients most likely reflects the fact that there are patients who could benefit from treatments, but they do not have access to them. Two Interviewees discussed frustrations at medicines not being listed on the Pharmaceutical Benefits Scheme (PBS), or taking too long to be listed, for example, Ribociclib for breast cancer (Int6). A great frustration for one interviewee is (expensive) medicines being listed for certain cancers, but not others(Int7).

The costs associated with treatment are huge and rising as demand for cancer treatment services in Australia increases. In 2012–13, cancer accounted for 6.6% of hospital admitted patient expenditure, with growth of 30% since 2004–05[14]. From 2001-02 to 2016–17, the age-standardised cancer-related hospitalisation rate increased by over 20% from 367 to 443 per 10,000[1]. In 2016-17, 72% of cancer-related hospitalisations were for same-day care and chemotherapy was the most common treatment[1]. In 2014, 60,398 people received about 1.8 million Medicare-subsidised radiotherapy services. Demand for radiation therapy services is projected to increase significantly[15].

There is overall agreement from participants that resources within this sector of the pathway are being used efficiently. Notably, treatment scored highest for this within the public sector at 7.69 (10=extremely efficient). However, this is most commonly cited as the area where cost reductions could be made. Interviewees discussed the funding in this sector going towards complex and expensive treatments, which only benefit limited numbers of patients:

> *"I think there are lots of other things here that we could fix before we start spending… ten thousand dollars per patient on sequencing their cancer genome without actually making any difference, when we don't have anybody to make appointments for them or to… guide them through what's happening."*(Int4)

## Survivorship

Survivorship focuses on the health and wellbeing of any person living with and beyond cancer.

At the end of 2014, it was confirmed that 431,704 people were alive who had been diagnosed with cancer (excluding basal cell and squamous cell carcinoma of the skin). This represents 1.8% of the Australian population[1]. Early detection and improvements in treatments mean more of these people are living with cancer longer. There is a need to address the long-term health and wellbeing of all people living with cancer, which includes services such as: person-centred care, support for living well, evidence-based care pathways (i.e. survivorship care that falls in line with Optimal Cancer Care Pathways), coordinated and integrated care, data-driven improvements and investment in research[16].

**There is conflict in this section of the pathway.** Participants agree that we are not currently meeting the needs of the patient or organisations; it scored lowest for this of all the sectors at 5.30 for the patient and 6.25 for organisations (10=needs being completely met).

However, when respondents are asked how they would distribute funds they allocate the lowest level of funding to survivorship, a mean of 6.50 'points' from a pool of 100. When respondents have to trade-off in this way survivorship suffers; **it is seen as important, but it is an area where respondents are willing to compromise, in favour of other points on the pathway.**

## Palliation

Palliative care aims to improve the quality of life for patients and their families in the face of life-threatening illness.

**The use of palliative care services in Australia is increasing. There was a 49% increase in palliative care-related services between 2001–02 and 2010–11 (all patients, not cancer specific)**[17]. In 2016–17 there were 77,369 cancer-related hospitalisations where palliative care was provided, and 51% of these hospitalisations ended in death[1].

There is a feeling among participants that w**hen palliation works, it works well, but there are concerns it is underfunded**, that referrals to palliative care can be too slow, and that health professionals have not been equipped with the skills or knowledge needed to have end of life conversations:

*"…the nurses in palliative care hospitals are brilliant and people get lots of information"*(Int2).

*"It is underfunded, and clinicians fail to refer people in time; which can have devastating consequences"*(Int3).

*"…people… feel very pressured or very focused on spending money or raising money or getting support to access drugs, I don't necessarily think that's always the wise spend at an individual patient level. I think often the final end of life decisions should be more nuanced to have a conversation about some other ways of either spending the money or using one's time before the end"*(Int 9).

## Research

Clinical trials are a passion point for many respondents, there is a demand for gold standard trials, with cross-country or international collaboration, involving multidisciplinary teams, and good access for patients regardless of location (currently Sydney and Melbourne are hubs for trials(Int 10)).

It is widely acknowledged that **Australia already does research well**, with strong cross country and international collaborations, plus excellent research institutes(Int1, Int 5, int 7, survey) **but we can, and must, strive for more.**

Between 2016–2018, the Australian Government provided 74% of $252 million (over $186 million) in funding to 589 individual cancer research projects[18].

From 2013–14 to 2016–17 a total of $43 million ($26 million from the Government) has been provided through Cancer Australia's Priority-driven Collaborative Cancer Research Scheme (PdCCRS)[2].

Participants agree that this kind of funding is important, with 61% of respondents advocating more expenditure in this area.

## Policy

Participants often take a realist approach to policy.

**The political context is frustrating for many, for a range of reasons**; the changes in Government, cyclical funding (which can result in funding getting withdrawn) and difficulties with politicians not being close enough to the processes and issues are all recognised by participants.

**However, the majority approach this pragmatically, and to an extent, accept these confines, as well as acknowledging Governments have a complex landscape to navigate**(Int 10, Int 11, Int 12).

> *"I think health leadership is often distracted because of the sense of immediate funding pressures and environments that are very politicised. I think Ministers are often scared to make those sort of brave decisions because of the trouble selling the message or scared of some of the outcry from the particular lobby groups. I mean health is one of the most contested spaces in Australian policy, let's face it, so I think that's a real issue. I don't think it's just about funding I think it's about resource allocation." (Int9)*

**74%**
of research funding came from the Government in 2016-18

**49%**
increase in palliative care-related services between 2001–2002 and 2010–2011

**1.8%**
of the Australian population were alive in 2014 after surviving cancer*

**1.8m**
Medicare-subsidised radiotherapy services were received in 2014

*excluding basal cell and squamous cell carcinoma of the skin

# Areas of weakness along the pathway

## Navigating the pathway

Difficulty navigating the cancer pathway is a strong, recurrent theme. There is a feeling that the health system is disjointed, or "too siloed", with patients being "lost" as they transition between health care sectors. There is confusion over "who to access and when" which causes distress and frustration"(survey).

> *"Patients face [physical] difficulty moving between sites for different components of care"(Int4).*
>
> *"...for a lot of people their first experience of having to navigate what's quite a complicated non-integrated...system, is when they're seriously ill and worried they might be about to die from cancer. So they're not in a good psychological state to deal with that"(Int8).*
>
> *"I think individual components are actually working quite well it is just that they don't integrate well together"(Int8).*
>
> *"Patients struggle with understanding the pathway and awareness of options and opportunities and how to access these"(survey).*
>
> *"It can be really confusing for patients at the moment when there's difference of opinion in the clinical expert sector around you know what are the best treatment responses and what are the best treatment approaches. I mean I think it's quite hard for a patient ... hearing or reading about another option or another drug being discussed, or if you like promoted in another setting. And I think that's confusing"(Int9).*
>
> *"...those transition points... those referral points to palliative care, those transitions, those are the hard parts, I think"(Int3).*

## Lack of education

Difficulty navigating the pathway is partly due to not being given the right information at the right time.

"Essentially many patients don't know how to navigate the health system because they don't know enough about how it works"(survey). **There is also a lack of education around the disease itself:**

"The information is out there, and it's good. It needs to be packaged properly and health professionals need to ensure it is getting to patients. It should be given at the point of diagnosis"(Int2).

**Several participants suggested this is because clinicians, right through the pathway, do not have enough time to spend with patients:**

"The time available at the hospital is not enough for patients and carers to feel fully informed"(survey).

# Inequalities: Geographical

**Inequalities within the pathway are a big issue.** Australia faces immense, and unique, geographical challenges:

"...we are a tiny population across a huge land mass, how do you even begin to address that, I am not quite sure how to do that one"(Int6).

People in rural Australia don't have the same treatment options, or access to clinical trials, as those in metropolitan areas. There are numerous examples of this.

"If a person has a rare cancer they will most likely have to go to a centre of excellence, where they have a multidisciplinary team, not just one specialist, a whole group of support staff"(Int7).

"In rural areas the only imaging and pathology services might be private ones, which people may or may not be refunded for by the Government"(Int5).

"Blood cancer experience is different at both the acute or chronic stages and whole of person care (treatment, financial, emotional, return to work, carer support...) is inconsistent across the states and from the metro to rural/regional areas"(survey).

There is a lack of breast and reconstructive surgeons in regional centres, with some older women not being offered reconstruction at all.

"Particularly for older women because there is an assumption that you know her breasts are no longer important to her which of course we know is garbage, but there are assumptions that it's not worth offering"(Int6).

"Reconstruction is another good example of where there is a lot of gaps and not good funding, it is very patchy across the country where the access is. And so, for example, in the far north of Queensland women can wait up to ten years to get a breast reconstruction because they have no reconstructive services there"(Int5).

State government control means there are also inequalities between states. For example, in the ACT there is funding for cancer care coordinators in the public system, which other states are not privy to, "you're better off to get cancer if you're in the ACT.... we are very lucky here"(Int3).

Then when it comes to palliative care one interviewee claimed Western Australia does this much better than the other states, with most people in the state dying at home(Int 12). Even within States there is a feeling that patients can 'get lucky' with their journey, or not. "They may come across a practitioner who is willing and able to take on the 'co-ordinator' role, and an emotional support role, but they may not"(Int2).

*"In short, living somewhere remote can be massively problematic. The burden of travel can be huge."* (survey)

*My understanding of the current health system is that breast cancer care varies significantly in Australia. Some Australians affected by breast cancer have affordable (or free) access to high quality care delivered with thoughtfulness and compassion; others do not receive this 'gold standard' of care or find that they pay high out-of-pocket costs."*(survey)

# Inequalities: Cultural and socio-economic issues

> “There are subgroups of people yes who… have poorer access, poorer support and present later.”(Int5)

Minority cultures can struggle in the current health system. These individuals may not have English as a first language, and their beliefs about cancer and health care may result in the need for more help and support, which they may not receive.

> “…if you are Chinese and you are told you’ve got cancer they believe it’s a devil, and if they tell people they’ve got cancer then I have a devil inside me and I shouldn’t tell people because they’re going to not want to know me and I’m bad for them and I shouldn’t be in their house”(Int2).

Poor health literacy can be a large barrier to having a successful cancer journey. Interviewees claim those patients with higher health literacy get treated quicker, as do those with private health care insurance (Int2, Int6, Int7).

Conversely, those patients who advocate and are incredibly health literate can become part of the process themselves, they understand what’s going on, they know the weaknesses and they push for change, and they know how to navigate the current health system (Int7), but these patients are, of course, in the minority.

When asked what causes most distress for patients, respondents often cite financial worries, “out of pocket costs, that’s a big concern,” (Int6).

This is associated with socio-economic status (although is by no means exclusively a problem for this group), and for patients who are perhaps already struggling with their disease and the health system this financial toxicity, can add significant additional burden.

> *“There needs to be a broader improvement in health literacy because it kind of underpins a lot of the difficulties that people can have with communicating with their care team.”* (Int6)
>
> *“Those in the public system can get “lost” and “just get dropped off the list’… I’ll say to them now, when are you seeing your surgeon and radio-oncologist, and these people are ‘oh I don’t know I’m waiting for a letter.”* (Int2)

# Cancer care pathway sector weaknesses

The following describes the specific areas of weakness within the cancer pathway.

## Prevention

Lack of education around risk factors was mentioned on several occasions. More specifically, there was a call for better health education in schools (Int6), and for more to be done to tell the public about the causes of cancer, for example, obesity and alcohol (survey, Int 10, Int 11).

"…there's a lot that can be done in terms of helping people live risk reducing lives around cancer. So we know that you know exercise, good nutrition, maintaining a healthy body weight, all of those things are within our control, we know that those account for part of the burden of disease."(Int6)

## Screening

Several respondents claim there is over-screening in the health system(Int4, survey). For example, in prostate cancer, a watch and wait strategy in the early phase, or active surveillance of low risk patients could reduce costs and is a clinically reasonable approach[19-21].

## Diagnosis

**It is thought that the time to diagnosis from presentation to the GP can be too lengthy(Int2, Int4):**

"[we are still seeing] patients whose diagnosis is missed or delayed due to failure to recognise early symptoms in at risk populations… [these people] can have delayed diagnosis despite engagement with primary health physicians"(survey).

**Another area of weakness that was cited is over-diagnosis across a range (but not all) cancers:**

"I think we are doing so much better with diagnosis now, but I think we are over-diagnosing… there's over surveillance and that worries me that we are going too far the other way. But I do think that we're doing diagnosis really well, and I think that there is good follow-up…" (Int3).

"over diagnosis is an increasing burden across many cancers"(survey).

## Treatment

As discussed, this is the area with the highest expenditure, which is rising rapidly, driven largely by the cost of medicines. Although cancer accounts for only 6.6% of hospital admitted patient costs, cancer medicines account for one sixth of total PBS costs. A 2018 Australian review argues that the 10-fold increase in cost of oncology medicines over 10 years is rapidly becoming a serious threat to patients and health systems [22]. There is also the question of spending money on complex and/or expensive treatments, which only benefit a handful of patients:

"We've got a lot of top-heavy support and funding. I really like biology and I'm into molecular biology, but I think there are lots of other things here that we could fix before we start spending ten thousand dollars per patient on sequencing their cancer genome without actually making any difference, when we don't have anybody to make appointments for them or to guide them through what's happening." (Int1)

Several respondents suggested that clinicians are too quick to intervene (Int 3, survey), when 'watch and wait' might be more appropriate. One interviewee commented that some Australian states are more likely to intervene, or 'treat to the death', than others, which are better at 'seeing the patient." (Int 10)

Another observed that, "there can be an issue with patients receiving too much treatment. So patients go through months of chemotherapy then when the patient dies the family ask 'why did we go through all that' 'there is no doubt about this". The interviewee did say clinicians spend a lot of time talking to their patients about treatment, but patients "faced with their own mortality... they cling to it." (Int 11)

Interviewees were quick to say this is an area where reductions could be made, but could not expand on this at the time. The following 'Funding' section, where desk research was used, aims to investigate this area further.

## Survivorship

One interviewee had considerable knowledge in survivorship, but only a small number of other respondents had experience in this area.

This may reflect the fact that the support services for survivorship are limited, and "patchy"(Int8). A clinician who makes referrals to survivorship programmes commented on difficulties finding the right resources:

"You [Clinicians] need to know how to source those resources but... I think that they're not bad"(Int1).

A survivorship survey of 483 patients with bowel cancer in New South Wales indicates a range of potential inefficiencies in follow-up care. Few patients had a written care-plan, many were receiving follow-up from multiple providers, less than half had received guideline recommended follow-up colonoscopy, and few had received assistance with lifestyle modification for themselves or family members [23]. This was echoed by a respondent:

"I have experience with cancer survivorship through the Healthy Living after Cancer program offered by Cancer Council SA. Many survivors participating in this program have found very little support after their cancer treatment has finished."(survey)

After treatment the physical and psychological changes and damage can have a massive impact on individuals and families, "people are surviving but they're not necessarily surviving well"(Int8). They may need psychological counselling, physiotherapy, prosthesis etc., but they may not be getting the support they need through the public sector, and these services are not currently covered by private health insurance(Int8).

Other interviewees were quick to point out there is a 'gap' in survivorship and that we need a health system which is all encompassing, for example, that addresses how people get back into work, how they have a productive, good quality life(Int 11, Int 12).

## Palliation

Palliative care is underutilised; patients are more likely to die in hospitals than at home, which would be their preference(Int 11), and clinicians can be slow to make referrals, despite the fact that home-based care has lower associated costs than hospital care[24] and the services often do a fantastic job of meeting patients' needs(Int2), with palliative care giving "...equal, if not better, health outcomes"(Int 10) than standard care.

"Late referrals, so 4 o'clock in the afternoon referrals on a Friday for an acutely ill metastatic cancer [patient] who is going to die in a week, that should just not be occurring."(Int3)

## Research

Treatment decisions are often based around whether a patient has access to a clinical trial, or not, and access to clinical trials is biased towards those who live in urban areas. This is a big concern for respondents:

"I think our access to clinical trials is patchy so in some places it is awesome and in other places it's very poor."(Int1)

"Their treating doctor may make decisions based around that so may not offer a clinical trial if they know that the clinical trial is only offered in Sydney or Melbourne, which means that you tend to have these poor recruiting rates in rural and regional areas for clinical trials."(Int6)

Enrolment on a clinical trial can be life changing for some participants. One interviewee talks about their luck at being placed on an international drug trial which prolonged their life, and vastly improved quality of life(Int7). For patients living somewhere remote, this might not have been an option.

## Policy

As mentioned previously, changes in Government and leadership can be difficult for health system management. There is also a feeling that politicians do not (and cannot) fully understand the pathway, and must look to advocacy groups for help, but this does not always result in good decisions, as they still need to balance things out and make trade-offs.

One interviewee talked about the Government's failure to look at the bigger picture, to take a holistic approach and to understand that granting a charity a significant amount of money for one project means sacrifices elsewhere(Int8). Another claimed they should increase tax on individuals and big business in order to change health behaviours, for example, a sugar tax(Int 11).

> *"...the politicians, the people who are signing the money away, need to make sure that they are getting the right advice from the right people who are actually looking after the patients"(Int3).*

Health insurance is a particularly contentious area, with two interviewees having lobbied to standardise medical insurance, so at gold/silver/bronze level the products for cancer care are the same across insurers(Int6, Int8).

# FUNDING (DESK-BASED RESEARCH)

## Cancer costs

**The cost of cancer to the Australian government from 2009 – 2013 was estimated to be $6.3 billion.**

This was the finding from a large-scale study (266,793 participants, with a distribution of cancer types that was similar to the population distribution), where costs were based on individuals' inpatient hospital episodes, emergency department (ED) presentations, subsidised prescription medicines captured in the PBS and MBS, then were matched with controls. The largest costs were associated with bowel cancer ($1.1 billion), breast cancer ($0.8 billion), lung cancer ($0.6 billion) and prostate cancer ($0.5 billion).[25]

Costs vary over the course of the cancer pathway. The first year post-diagnosis and the last year of life are most expensive, averaging $33,944 and $49,733 per case, respectively, although there is large variation between cancer types; Myeloma costs $5,372 per case, colorectal cancer and non-Hodgkin lymphoma exceed $40,000/case. Overall, the mean cost for the initial treatment phase is $28,719 per person. Inpatient hospital costs comprise 68% of the total for the first year post diagnosis, 18% are for other medical services subsidised by the Medicare Benefits Schedule (MBS), 13% are for prescription medicines and 1% for ED presentations.

The most expensive phase is the end of life, terminal phase. The final month of life averages $16,111 per case, with costs gradually increasing throughout the final year. During the final year, 40% of costs are for inpatient care, 35% for prescription medicines and 25% for other medical services covered by the MBS. During the terminal phase, 76% of costs are for inpatient care, 3% for ED presentations, 11% for prescription medicines and 10% for other medical services covered by the MBS. Leukaemia and head and neck cancers are the most expensive.

## Why are some cancer costs so high?

The following section explores three areas that can increase cancer costs. Some of the literature cited is from outside Australia (for example, North America) and although systems differ, learnings can be applied in Australia.

## Medicines

We know the cost of medicine development is high, and that prices are set by pharmaceutical companies and the Government, but it is important to consider the way medicines are used to treat cancer because prescription behaviours have a big impact on cost.

An American study looking at cancer medicine claims that when a treatment fails, patients may be treated with other medicines until they have been exhausted:

> "...patients are treated with each approved agent (sequentially or in combination), creating a virtual monopoly because the use of one drug does not automatically mean that the others are no longer needed. Third, even when the monopoly is broken with the arrival of "new and improved" versions of an approved drug, the older (and by now generic) drug tends to be viewed as substandard treatment, thereby perpetuating the situation. Fourth, the very nature of cancer, and the seriousness of the diagnosis, plays a role in that patients and physicians are often willing to pay the high price of treatment even for marginal improvements in outcome."[26]

There is evidence this is echoed in Australia. A Cancer Council and Clinical Oncology Society of Australia review of medicine regulation states 'off label prescribing' (whereby non-standard treatment, which is not recommended for the cancer type the clinician prescribes it for) is part of standard clinical practice, when standard treatment fails. The report suggests this "represents a disparity between evidence based clinical guidelines for anti-cancer therapy and product approval." This disparate approach is costly and raises clinical, safety and ethical issues.

However it often occurs because of issues within the regulatory and reimbursement system, which the authors suggest how to tackle, including: streamlining the process, improving flexibility within the system to accommodate developments in medicine, and working with similar jurisdictions in other countries[27].

## Oversurveillance

There has been a shift towards recognising that there is too much surveillance and intervention in the health system, as championed by the *Choose Wisely* movement (more detail on *Choose Wisely* below):

> "With the complexity of tests, treatments, and procedures available to modern medicine, the challenge is that not all add value. Some are rendered redundant as others take their place. Unnecessary practices are a diversion away from effective care. They often lead to more frequent and invasive investigations that can expose the consumer to undue risk of harm, emotional stress, or financial cost."[28]

This shift is international. An American academic commentary piece on cancer costs iterates the American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN) guidelines, which state:

> "...there is no benefit to surveillance testing with serum tumour markers or imaging for most cancers, including those of the pancreas, ovary, or lung, yet these tests are commonly used in many settings. In breast cancer, randomized studies showed that scheduled (not symptom-guided) imaging does not detect curable recurrences or alter survival... The common exception is colon cancer, for which some patients do benefit from scheduled carcinoembryonic antigen testing and computed tomography."[29]

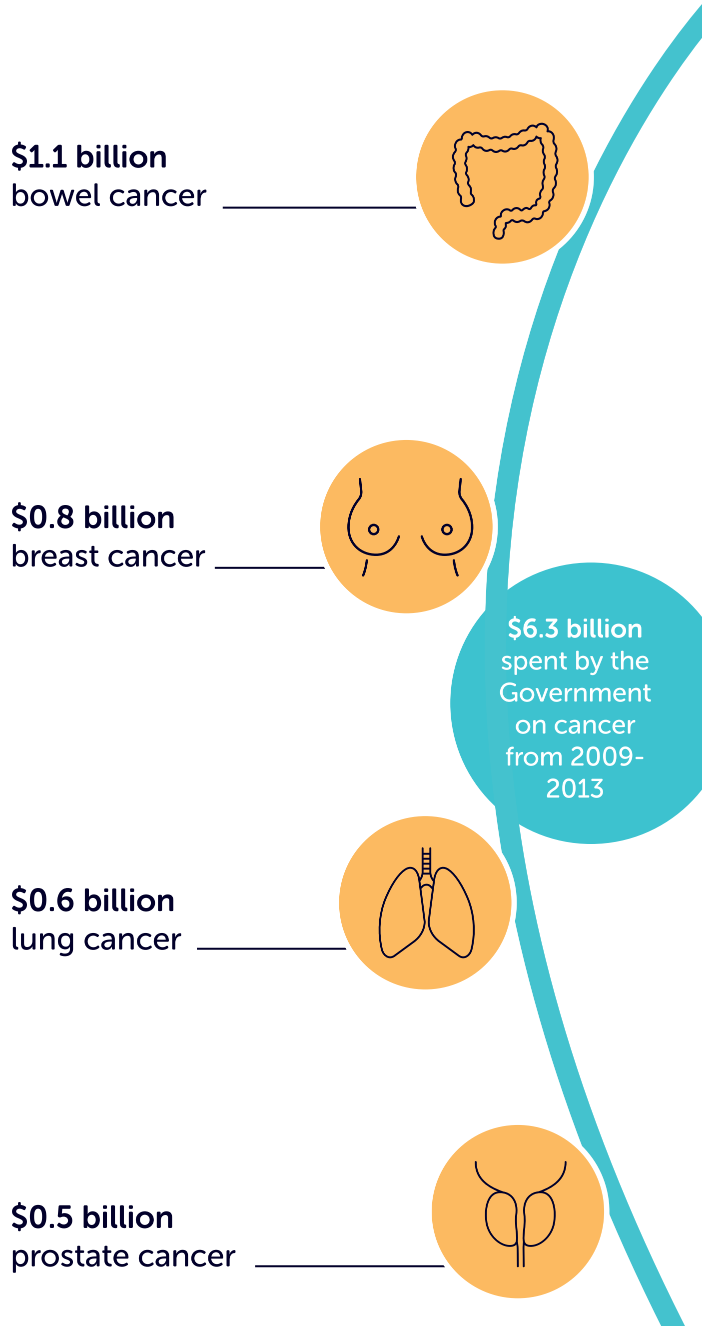
## Insufficient use of palliative care

**It is known that high volumes of expensive services do not equate with quality end-of-life care[30].**

There is research showing that, despite many patients stating they would prefer to die outside of the hospital setting, the majority of elderly Australian cancer patients still die in hospital[30] having had treatment within the last few weeks of life[31].

A systematic review of 78 studies, which examined end-of-life care in 3.7 million cancer decedents concluded there was prolific use of therapy in the end-of-life stage, with an extensive range of options available to patients. There were 15 studies using quality indicators, which demonstrated that over a third of patients receive chemotherapy or life-sustaining treatments in the last month of life and up to 66% do not receive hospice/palliative services.

This is a failing twice over; it means the patient is likely to have experienced poor quality of life in their final weeks and it generates unwarranted costs. One of the main reasons patients end up in this situation is the lack of timely conversations around death with their clinician or other health professionals[31]. Yet we know that persons who have end of life conversations experience less depression and anxiety, receive less aggressive end-of-life care, and rarely die in an intensive care unit or on a ventilator[29].



> The first year post-diagnosis and the last year of life are most expensive, averaging $33,944 and $49,733 per case. Overall, the mean cost for the initial treatment phase is $28,719 per person.

# HOW CAN WE REDUCE COSTS?

## Re-think medicines

- Consider the role of Precision Medicine for rare cancers (progressing to more common cancers), whereby the DNA of a cancer is sequenced, allowing clinicians to understand the underlying abnormalities in the tumour and potentially tailor treatment accordingly. This approach is currently used, albeit infrequently when other treatment options have been unsuccessful (therefore not cost effective at the moment) but the Government have given a $50 million grant to the Australian Genomic Cancer Medicine Program[32] and it could become a first line treatment. The evidence base needs to be grown, and it will be, the initial evidence is mixed but suggests it has a great deal of promise for selected patients[33].

- Better awareness from clinicians of the implications of QALYs and associated Incremental Cost-effectiveness Ratio (ICER) when considering new treatments[26].

- Collect 'real world evidence' on medicine effectiveness and patient quality of life (disease-specific PROMs) after a medicine is approved to allow for comparison between centres and informed decisions[26].

- Look at treatment costs in their entirety – what might be the impact of prescribing a drug on, for example, hospitalisation costs, surgeries and procedures, radiotherapy? Is it possible to provide clinicians with these comparisons and give guidelines?[26]

## Reduce surveillance

There is currently a call to clinicians from the National Prescribing Service MedicineWise (Government funded, not-for-profit organisation) to *Choose Wisely*.

They recognise the problems that come with oversurveillance and intervention across a wide range of diseases, including cancer and ask that health care providers start important conversations with patients about "improving the quality of health care by eliminating unnecessary and sometimes harmful tests, treatments, and procedures"[28].

They give guidelines, which are not prescriptive, but are intended to help start those conversations. Cancer guidelines (devised by the Royal College of Pathologists of Australasia) include:

01 Restrict the use of serum tumour marker tests to the monitoring of a cancer known to produce these markers, or where there is strong known underlying predisposition or suspicion.

02 Do not routinely test hyperlipidaemia in those with limited life expectancy.

03 Do not perform PSA testing for prostate cancer screening for men with no symptoms and whose life expectancy is less than 7 years.

## Make the commitment to good palliation real

Equipping clinicians with the tools to have important conversations with their patients about end of life care could have a large impact, particularly if combined with discussions on integrating palliative and usual care. These changes may well have an impact on cost efficiency and quality of care; there is plenty of evidence to support this, for example:

A study in South Australia with 461 patients (91% of whom had cancer) concluded that just one 'case conference' with a team of health professionals (for example, GPs, palliative care nurses, palliative care specialists, home nurses, social workers, nursing home representatives, occupational therapists) reduced hospitalisations by approximately 0.5 hospitalizations per patient.[34]

In a large American randomised trial with lung cancer patients, the combination of palliative care and usual oncologic care was associated with longer survival, plus significant improvements in mood and quality of life, when compared to usual care.[35]

A Canadian study with a sample size of nearly 55,000 patients who used home care nursing in the last 6 months of life, concluded those who received end of life nursing in any week had a 31% reduced ED rate in the subsequent week. In the last month of life, receiving end-of-life nursing of more than five hours per week was associated with a decreased ED rate of 41%, compared with one hour of standard nursing.[36]

The systematic review which examined end of life care in 3.7 million cancer decedents observed that palliative care and hospices are underutilized, but when used they are associated with reductions in health expenditure, compared with hospital-based pathways.[31]

# A cultural shift

In order to make long lasting, positive change we should consider rethinking our thinking about cancer.

All three of the areas suggested for change point towards having a transparent patient/clinician relationship and managing expectations (clinicians and patients alike) better. Cost savings would be a by-product of this. There is evidence that clinicians currently withhold prognosis information, but when given complete disclosure, patients and their carers can be truly active in the decision making process, which leads to better outcomes.[37]

There are tools to help clinicians provide truly informed consent, by sharing anticipated response rates, chances of cure, and side effects, which help patients and carers make informed decisions, and importantly were not found to increase decisional conflict or anxiety.[38] Should tools like these be better leveraged?

Creating a cultural shift is no easy task. *Choose Wisely* is a great example of a collaborative, health professional led campaign that is working hard to make change.[28] In 2017, membership was strong and growing (for example, 37 member colleges, societies and associations, including 80% of colleges; 12 health services representing five States), 77% of GPs had heard of the campaign, up from 4% in the previous year.

The evaluation captured changes in attitudes; in 2017 there was strong agreement GPs and specialists have a responsibility to help reduce the inappropriate use of tests, significantly more than the previous year (47% vs. 36%). There are also practical examples of implementation, for example, the Sir Charles Gairdner Osborne Park Health Care Group reduced repeat blood tests in inpatients by 30% across multiple departments; Royal Brisbane and Women's Hospital introduced 130 initiatives that address low-value approaches, including embedding Choosing Wisely into its performance framework.[39]

# SUGGESTIONS FOR CHANGE

## 1 A move towards value-based care

Value-based health care is a model for health services which aims to produce health outcomes that matter to patients relative to the resources or costs required.

This model shifts the focus to improving patient outcomes, and using these measured results to inform expenditure, clinical models and change the experience of receiving and giving care[40].

**52% of survey respondents favour a move towards value-based care** vs. 17.4% who do not. However a large proportion did not give a yes or no response (30%). It is clear there is a need for further education on value-based care and a need to expand the evidence base(Int4, Int5). Survey respondents talked a lot about measuring effectiveness and data sharing in positive terms, “we need an evidence base for primary care/prevention/early detection/community care”(survey); we need to “audit outcomes so that we actually know what we are achieving”(survey), but they may be unaware of how value-based care works.

A trial manager working on a value-based care trial observed that when presented with the model, clinicians are excited by it: “people are realising that they’re not really aware of whether they are doing things well or not, so I think, I think they’ve come to an understanding they need to better understand that they’re doing what they set out to do”(Int4).

Supporters of value-based care say, it’s the “best way to achieve better outcomes”(survey); “evidence from countries where this is used demonstrate more cost-effective care”(survey); “We need to ensure stewardship in health care spending that is patient centred”(survey); “concerns or issues can’t be identified until they are measured”(survey).

It is thought that Australia is moving towards this system; senior Government officials in state health department are reported to be considering it(Int1). “I certainly think the move is towards value-based health care and outcomes measurements, and there’s a lot of interest in patient reported outcomes, much more than there has been before”(Int4). One interviewee has a $9 million project in place with the aim of putting this model into practice across a range of cancer areas(Int5).

**There are, however, strong concerns over measurement**(Int1, Int3, Int 11, 12, survey); “the devil is in the detail’ how do you measure it?”(Int 11). One interviewee claimed “it will disadvantage doctors who choose to practise in difficult areas where your patients are unlikely to ever have a good outcome,”(Int6). The complex nature of cancer was also sighted as a problem when measuring outcomes(Int3), and the reality is that making the measurement work using existing systems, technology and data available(Int 12) is challenging.

“the biggest barriers we have at the moment that we are experiencing trying to put [VBC] into practice in our project that we are doing is around IT platforms, around you know the privacy questions, is around resourcing the ability to capture outcomes effectively and feed them back to services.”(Int5)

There was also a concern around cost. The needs of each patient are so different, to build care around them is expensive(Int 13).

> *“I think the Australian population is becoming more aware that there are other ways to, you know, live life and also support others who are coming to the end of their life. And stepping away from palliative care for a minute I mean I think there are a whole range of initiatives now about people being able to be supported in community more and in the home setting more. I think there’s a real distance if you like of a lot of patient groups to be defined by just treatments in hospitals and feeling like there’s nothing else going on in their life but that’s sort of health management.”* (Int9)

## 2 More cancer coordinators

### This is *the change* stakeholders think will make the biggest difference:

"...those who have a nominated nurse navigator/clinician at time of diagnosis have a much easier journey along the care continuum whether they have life limiting or curable disease."(survey)

"When we look after patients who come from the private system where [coordination] doesn't exist, it is acutely obvious, and those patients are usually much less informed...the care co-ordination is really essential, especially when there is increasing cancer"(Int3).

"Better patient experience is correlated with having a 'go to' person."(survey)

"Having someone who could manage the system would be useful."(Int 12)

"I know I keep whacking on about it, but... I think every single doctor that I have spoken to, or nurse that I have spoken to, or patient I have spoken to [the most important thing] really is that care coordination role."(Int 3)

Breast care nurses are heralded many times as a fantastic example of this, for example, McGrath Nurses. They help patients through the journey from diagnosis through to treatment, survivorship or palliation, "Breast Care Nurses make a big difference to people who are dealing with breast cancer diagnosis,"(Int6). They are actively involved in working with a patient, understanding their specific problems, and working out who they will need to see(Int2).

**We need this type of coordinator for other cancers**; particularly the complex ones, such as gynaecological and brain cancers. One interviewee notes it would not have to be expensive, it would not need to be trained nurses who do it, and it could be done remotely; it is about tailoring information for the individual, it is about ascertaining their level of knowledge and understanding and providing guidance(Int2).

Another way to tackle the navigation problem is to grow the number of cancer centres, where all services are under one roof, and the approach is patient centric (for example, The Lifehouse in NSW), but it should be noted the large monetary and resource implications that come with this.

## 3 Improve flow along the pathway

The flow of the health system itself could also be improved by implementing:

Faster referrals, for example, routine prompts to medical and radiation oncologists managing patients with advanced disease; an ED fast track system; a protocol for quicker referrals to Palliative care clinics/nurses or palliative care home-based services; rapid assessments for radiation oncology, which could see patients getting radiation in a matter of hours after the need for it has been detected(Int3).

A more consistent referral process, "I think the referral process remains a little bit random, it's not as good as it could be... sometimes patients don't even necessarily get referred to the right specialist,"(Int5).

Better use of the Optimal Care Pathways, that are endorsed by every State.

Improved data sharing, so the health system is better connected and easier for health professionals to navigate(survey).

More multidisciplinary meetings, "one thing where we do fall down on here, which we don't do well, is having multidisciplinary meetings before further treatment to decide the best treatment option"(Int5). Currently it is often the case that the surgeon makes a decision, treatment takes place, then multidisciplinary teams are consulted.

Getting the administration and low-tech aspects of the pathway right, "a lot of the blocks are there when people call up to make an appointment and they can't get someone to answer the phone, that sort of thing"(Int1).

## 4 Increase access to clinical trials

The geography of Australia makes research challenging. As does the mix of public and private health systems, because it is not as simple to get health professionals to collaborate as it is in smaller countries with entirely public systems.

However, there is momentum to overcome these barriers. Inclusivity would lead to stronger outcomes, and a move towards equality for those in rural and regional areas.

"I would like to see partnerships between city hospitals and country hospitals where in the country there's a very busy oncologist who does not really have time to do trials but they might have time just to monitor people who'd they be treating anyway, and I could maybe just help by telehealth once a month. I would like to have some resources and assistance to enable that, and the resources would be something like a clinical trials person sitting at the clinical trials hub maybe the Clinical Trials Centre at Sydney University to help facilitate that for rural patients, or something like that. I don't think it would be a very expensive thing."(Int1)

We need to be better at data sharing(Int5, Int7, survey). We need to enhance collaboration more than we do, and we need good registries, which document outcomes. We need to have better information available for research, "medical records are in silos…why that information isn't in a central database?"(Int7)

> Logistically and administratively this is challenging, but **researchers gaining ready but secure access to My Health Record or State and Federal health and related datasets would open an array of possibilities**.

There is positive work being done in this area; the Clinical Oncology Society of Australia (COSA) Teletrial model, outlines a "feasible and effective tele-health strategy to increase access to clinical trials closer to home"[41] which will hopefully improve access to clinical trials for patients living in regional or remote Australia, but also across the major metropolitan hubs in cases where recruitment is limited to only a small number of centres across the country.

## 5

## Optimise education

Information about cancer is widely available, and the information provided is of a high standard. However, that information needs to be packaged and disseminated better:

> “If they had a document that… all specialists just gave the patient… an initial… ‘what we’ve got going on’, ‘your surgeon will do these things’ you know? And then when they go back and they get the diagnosis of breast cancer that they are given an information pack that’s sensible that has good advice, local advice that they can take home and read through with their family and it will talk about everything from skin care to nutrition to surgical options. When they get to the point of radiation and chemotherapy then it is a different pack you know.”(Int2)

> “…education at the earliest level possible…I think people have this expectation that it’s all going to go ok, that the doctor is just going to fix it and I’ll be ok, and that is still an ongoing issue. And there’s a lot more to it, there’s a lot more choice that needs to be done about whether or not to have surgery or treatment, so to look at really fully informed decision making for patients and carers is really necessary”(Int3).

The Cancer Council is referred to multiple times as a source of good information; practical, psychological and financial advice(Int2, Int4). These materials need to be actively brought before the patient, with Clinicians (GPs, Surgeons) spending time talking to the patient about them(Int2).

## 6

## Better access to services in regional and rural areas

Interviewees want to see processes and options become uniform across the country (Int1, Int3). A valuable aspiration, but not an easy task. One interviewee claims there is a lot of “political power behind keeping the resources where they are” the primary reason being “because the central city hospitals and universities think they are better and they’ve maintained a ‘we’re better than them’ for such a long time that they don’t like the idea of resources being shifted from historically high you know high achieving institutions to new ones,” (Int1).

## 7 Better use of technology

Many interviewees discussed the **importance and power of technology for patients, health professionals and researchers,** and suggested that this is an area of untapped potential.

Apps and social media can be useful for patients for scheduling, tracking appointments, for putting them in contact with people who are going through similar things, and connecting patients with health professionals(Int1, Int2, Int3, Int6). There are clinical trials apps which received strong praise from an interviewee who had used one. They allow a search for specific cancers, with capability to check eligibility(Int7). Apps could be promoted to patients (or family members) more, especially less tech-savvy persons. Social media can be a valuable tool for gathering and disseminating educational information and can be useful for clinicians building health professional networks, for example, LinkedIn/Health Share(Int2).

Telehealth is moving in the right direction, one interviewee outlined the benefit of GPs conferencing in to multidisciplinary meetings from rural and remote areas, which has huge benefits(Int 13). However, it could be used more efficiently, for example, currently nurses must have a doctor present to use telehealth(Int3). Funding arrangements that support team-based access to telehealth could go some way to improving services for rural and regional patients.

There is also currently an issue with systems not talking to each other, meaning information sharing can be "painstakingly slow"(Int 13). Improved access to patient records, perhaps through an optimised My Health Record, could be a way to address this; for example, a pharmacist could have oversight of everything a patient is taking, which allows them to check their combination of drugs work okay together(Int3).

## 8 Treatment cost saving initiatives (as per funding section)

Rethink medicines

Reduce unnecessary surveillance

Make early access to palliative care a priority

Cultural shift – transparent, collaborative relationships between clinicians and patients

# CONCLUSION

## Weaknesses and inefficiencies

Cancer care in Australia is world-class, but the pathway is long, and there are strengths and weaknesses throughout. The factors influencing the pathway are numerous. They include: funding and policy, the geographic and socio-economic landscape and the culture of the community more broadly as well as the clinical community's, all of which in turn are influenced by a whole range of factors.

Treatment, screening and research are areas of strength, but there are inefficiencies which could be addressed, and savings redirected to areas of the pathway that need strengthening. Expensive treatments, or research into treatments, which benefit the few, need to be carefully considered. Screening programs are working well, but tailored screening may reduce costs.

The main weakness is system wide; the pieces of the pathway do not fit together well, and patients struggle to navigate their way through it, particularly those with low health literacy. There are also large inequalities within and between States, with those in rural and regional areas receiving lower standards of care, mostly as a result of limited access to cancer services. Looking at the individual stages, the weaknesses sit at either end of the journey; prevention, palliation and survivorship. Diagnosis and treatment are also problematic, with claims of too much diagnostic testing and intervention, particularly in the end of life phase.

### Strengths

- World-class care
- Treatment
- Screening
- Research

### Weaknesses

- The 'disjointed pathway'
- Social, cultural & geographical inequalities
- Over-surveillance and intervention
- Prevention
- Survivorship
- Palliation

> Funding cancer coordinators to help patients navigate the system would go a long way towards strengthening the pathway

## Implementing change for future

The health system itself would benefit from processes that make it more streamlined, for example, getting the administration and low-tech aspects of the pathway right, making referrals faster and encouraging multidisciplinary meetings.

Geographical inequalities could be addressed by striving to include rural and regional patients in clinical trials, which could be made easier with technology.

A cultural shift, whereby we move further towards a transparent clinician/patient relationship, giving patients all they need to make informed decisions on treatment and care, including the option not to have treatment, and getting a better understanding of palliative care would seem to be very worthwhile.

A move towards value-based care is largely supported and would lead to a better understanding of inefficiencies within the pathway; it places patients at the centre of the model, relative to the cost of care, and would provide a valuable evidence base for the redirecting of funds.

### Weaker pathway sectors could all benefit from more resource:

- Increasing funding into prevention should lower costs downstream
- Improve services to support survivors so they can lead fulfilling lives, especially as there is an increasing number of survivors
- Greater support for both specialist and community palliative care. This will help to even out existing services, which are viewed as currently patchy, and take the pressure off unnecessary and expensive hospital services

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