

The Rights and Roles of Australian Cancer Patients





About Rare Cancers Australia

Rare Cancers Australia Ltd (RCA) is a charity whose purpose is to improve the lives and health outcomes of Australians living with a rare or less common (RLC) cancer. RCA has a number of key areas of focus: strengthening the patient community, advocacy, patient support programs, fundraising, treatment and research, and early diagnosis.



About the National Oncology Alliance

The National Oncology Alliance (NOA) is an unincorporated not-for-profit alliance of cancer stakeholders founded by Rare Cancers Australia (RCA). NOA engages and consults with all members of the cancer community with the aim of developing consensus and innovation in Australia's cancer policy development and implementation. It aims to ensure Australians living with cancer get access to the best technology and treatments to improve their survival and quality of life. NOA has 400 registered members, including organisations and individuals. Members include people with a lived experience of cancer, patient organisations, clinicians, hospitals, supplier organisations (including radiation oncology providers), the pharmaceutical industry and technology companies.

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Foreword

It is almost 10 years since we formed Rare Cancers Australia. In that time, we have met, helped and learnt from many thousands of Australians living with cancer. Their lives and experiences, together with the collective experience of the National Oncology Alliance community, are both the inspiration for – and knowledge base of – this report.

Sadly, not every person that we have learnt from is still with us, but their lived experience is embodied here and helps shape the work of RCA and NOA now and into the future.

While the lived experience of Australian patients has deeply shaped our organisation, it is remarkable how little use is made of this precious resource across the cancer community. We glibly talk about quality-adjusted life-years, but do we really try to understand quality of life to an adequate level? And if we do, then how do we factor that into approval and funding discussions for new and expanded treatments? In Australia, once a treatment is approved for use and funding there is often no systematic follow up to measure the impact of the treatment either quantitatively or qualitatively.

With the emergence of personalised medicine this is an increasingly vexed issue and Australia needs to find new and innovative methods to measure the lived experience of those of us who live with cancer. While this is critical for our health system at large, it is also an ethical and moral imperative for our community as well. Life with cancer is never easy and if we ignore the experience and lessons of today's patients then we will lack the knowledge we need to improve our care for tomorrow's patients.

Caring for and working with cancer patients has also taught us that cancer patients are much more than their disease.

Increasingly, we are beginning to understand that the type of the person living with the disease is at least as important as the type of disease the person is living with. Building skilled holistic navigation pathways has always been the aim of our work, and the lessons of every organisation participating in this project – in combination with the research and lived experience that has fuelled this report – have hammered home the need for this non-clinical support and navigation function.

To all our patients and carers who have trusted us and relied on us over the past 10 years – this report is for you. We believe and hope it will provide a different and better lens through which we can see all the needs of Australians living with cancer. Together with our colleagues at all the other patient groups (See Acknowledgements), we will continue to work to support and advocate on your behalf.

Richard Vines
Founder, NOA
Chief Executive,
Rare Cancers Australia



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We would also like to extend our gratitude to the members of our Patient Advisory Board and the National Oncology Alliance Advisory Board for the time and energy put into developing this report.

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This report is the product of a great team effort over the past year and we would like to acknowledge all those who gave their time and intellect to its creation. For qualitative and quantitative research that informs the work we are grateful to Christine Cockburn and her extraordinary Patient Support Team, Emily Isham, Beth Abbey and Jaime Macedo. For the actual creation and validation of the finished report we are indebted to Dr Amanda Ruth and Victoria (Plum) Stone. For the organisation and co-ordination of workshops, speakers and topics, our thanks to Natalie Clancy, Nikki Kerr and Alexander Smith. And for their work in the final production of the report our thanks to James Mathews, Nikkie Beltran and Casey Virgin. Finally for making everything fit together and keeping all the bills paid our thanks to Jacqui Lidgard, Alicia Moses and Lydia Willoughby.

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Finally, as always, our thanks to Kate Vines for her continuing energy and inspiration.

Richard Vines
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Sponsors and partners

We would like to acknowledge all of the individuals and organisations that have helped support the National Oncology Alliance since it's foundation. Whether through financial support, written submissions, contributions through the workshop series or encouragement through this exercise.

We wish to emphasise that our acknowledgment does not imply that views expressed within the report are held by all who participated in the project. To the hundreds of contributors and supporters we simply wish to say **THANK YOU.**

abbvie

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AUSTRALASIAN
LEUKAEMIA & LYMPHOMA
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Health Alliance

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ANALYSTS**

ICON
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illumina

 **IPSEN**
Innovation for patient care

janssen

KYOWA KIRIN





Patients and their families need to be treated with dignity and respect. To be seen as active collaborators and decision makers in their journey. To be supported in efforts to research and access the most promising treatment options. To be fully informed regarding prognosis and treatment choices, and for this information to be delivered with empathy and compassion. This was certainly not our consistent experience of my husband's healthcare journey.

Research participant

We owe it to the cancer patients of today and tomorrow to act now. Their lives depend on it.



Executive summary

It is well established in the healthcare sector that patients and their caregivers should be central to their cancer treatment journey, as well as to the policy development that relates to the provision of treatment and care. However, we know from experience that too many Australians diagnosed with cancer do not have the right information, support or adequate communication from their health care teams to feel sufficiently empowered.

Disappointingly, most patients report feeling unsupported through part or all of their cancer journey, and don't feel engaged fully to embark on shared decision making. The preferences of cancer patients are not sufficiently integrated into the decision-making frameworks underpinning access to therapies and technologies, nor do they emanate through other parts of the health care experience.²

Patients, their families, and carers often need to self-advocate to receive the best available treatment options, find information, have their questions answered, and find appropriate supports. Every patient we have spoken to over the years reports periods of great uncertainty, confusion, and lack of confidence in the health providers and system to deliver continuity throughout the many twists and turns a cancer journey inevitably takes – especially in the cases of rare, less common, and complex cancers.

The challenges of rare, less common, and complex cancers

NOA and RCA maintain that in a highly functioning, person-centred model of cancer care, people should not need to be their own advocates, or appoint carers or family members to do this on their behalf. It is a sign that the system is failing.

All Australian cancer patients, regardless of the complexity of their diagnosis, age, location, socioeconomic status or education level, should have the right to expect the same high standard of care and ease of access to the most appropriate clinicians and treatments.

The aim of this report is to better understand the scale of the challenge we face in delivering the best person-centred care for Australian cancer patients. To explore how patients can be at the centre of their own care, well supported throughout their cancer journey, and have roles to inform healthcare decision making at the broader systems level. This will ensure that 'patient-centricity' or 'person-centred-care' is not just a catch phrase but a lived reality.

Methodology

NOA, together with RCA, engaged with more than one thousand patients and carers using a variety of qualitative and quantitative research activities in an effort to understand the real, lived experiences of Australian cancer patients and other stakeholder perspectives.

Key methods included:

- consultation (conducted April to May 2021) that called for submissions from people with a lived experience of cancer, families and carers on their own cancer experience.
- 25-item quantitative online survey regarding perspectives on the rights and responsibilities of people living with cancer, which received close to 700 responses.
- A series of four webinars, each exploring the rights and roles of Australian cancer patients, with panels representing four different stakeholder groups (patient organisations, clinicians, the pharmaceutical industry and patient advocates).

View Figure 3, page 33 for the full methodology.



Cancer is incredibly isolating. In a world where everyone's striving for the optimum – whether it be their own health or their kids' – to be willingly consenting to toxic treatments, dealing with end-of-life decisions, putting your child through pain, whilst feeling cut off from a normal social life or routine feels quite aberrant and alienating. That's why cancer families need support – people who, though not walking the same path, try to bridge the chasms and cushion the fall.

Research participant

Key findings

From the research patient and carers expressed frustration with a focus on the disease and not the person living with the disease, lack of continuity of care, lack of information or withholding, lack of consistent support and clarity of options, experiencing a disjointed health system and power imbalance with clinical teams, inability to access promising new treatments due to lack of funding, and significant financial burdens.

Participants were also asked about the system changes needed to improve their experiences. Respondents revealed three key areas in need of the greatest improvement:

- More information and better communication at the stage of diagnosis.
- Easier access to emerging treatments at an affordable price.
- Being recognised as a person at the centre of care, and as an advisor to the health system.

Another strong theme that emerged from the research was how the appointment of a 'dedicated navigator' to each patient would alleviate a lot of the logistical burdens and confusion associated with a cancer journey.

It is clear from our research this year that recognising a set of fundamental rights of cancer patients is key to realising person centricity in cancer care. Equally important is mapping the roles that patients can play in their individual cancer journeys, and in helping to influence the evolution of health systems.

To do this, we have proposed a framework for a person-centred cancer care system (*Figure 1, page 25*) that:

1. Ensures the fundamental rights of cancer patients are recognised and upheld, and;
2. Maps the roles that patients can play in the health system that draws on lived experiences through:
 - a. 'empowerment' – having the knowledge, information, continuity of care and support to manage their own health care and partner in decision making with clinical care teams
 - b. 'engagement' – informing system improvement and shaping health policy.

The following core themes were identified by those who took part in our research:



Challenges around diagnosis and treatment plan communication



Failure to deliver person-centred care



Lack of continuity with medical practitioners



Lack of communication between providers



Hospital and treatment access challenges



Financial impact of cancer and lack of available support



Survivorship support



Roles of the patient – the current state of play



How systems could be improved

Recommendations

Recommendations of this report are offered to the Australian Government for adoption and implementation as a matter of urgency. The experience of Australians living with cancer can be immediately improved if these recommendations are implemented, with a legacy that will transform the experience of the cancer patients of tomorrow.

1 Respecting the rights of patients

That the Australian Government and Cancer Australia develop an ‘Australian Charter of Patient Rights in Cancer Care’ as part of, or alongside, the Australian Cancer Plan.

The Charter should:

- be informed by the experiences of Australians living with cancer today, to ensure it is both meaningful and relevant.
- be fully embedded within our health system, with formal mechanisms in place to ensure that rights are being upheld. This must involve:
 - i. accountability among stakeholders, which could be achieved by capturing the lived experience of cancer patients through ongoing monitoring and transparent public reporting
 - ii. the appointment of a governance committee that consists of the full breadth of stakeholders across the sector, including patients, carers, and their families
- be considered when developing health policy and system reforms that are directly relevant to cancer patients.

2 Supporting the patient journey

That the Australian Government commit to funding and supporting a more holistic patient navigator scheme so that every patient with complex, rare, or less common cancer has access to a dedicated point of contact throughout their experience.

Our research has highlighted the complexities of navigating a cancer journey, and revealed overwhelming support for the appointment of dedicated navigators to walk alongside patients down an often complicated and uncertain road. This is especially critical as the treatment pathway becomes more complex and cancers become ‘rarer’ in their categorisation and presentation.

A navigator need not be a health professional – they could be a suitably qualified person who sits outside of the hospital or allied health setting.

Anecdotally, the potential benefits can include better outcomes through enhanced treatment opportunities, an increase in system efficiencies, and a reduction of costs through decreasing health resource utilisation and demands placed on hospital staff.

3 Recognising the roles of patients

That the Australian Government establish formal mechanisms that integrate Australian cancer patients as experts in our cancer system, and commit to listen and learn from their experiences.

This must include:

- Empowering patients to partner as equals in decision making with clinical care teams – from diagnosis through to survivorship – through the provision of information, support, and continuity of care.
- Addressing systemic inequities that impact participation in shared decision making – such as a patient’s education, race, rurality, social and economic status.
- Such inequities should be identified at diagnosis, with supports put in place immediately to assist the patient through the next steps in their journey.
- Evaluating and improving mechanisms for patient engagement to give patients varied and more prominent opportunities to shape system reforms and health policy changes.
- The meticulous capture of high-quality data on the lived experience of today’s cancer patients – including preferences, experiences, and outcomes. This should be utilised to its full extent to help the patients of tomorrow live longer and better lives.
- Identifying and removing historical barriers to patient engagement from health systems that were not inherently designed to be person-centred. For example, the inability for manufacturers to provide information about emerging therapies and data with patients.



Introduction



Introduction



It is estimated
150,782
Australians will be
diagnosed with cancer
this year.



One in every three of
these people will lose
their lives as a result
of the disease.¹



Over one third of these
cancers will be rare
or less common; this
proportion is much
greater if you account
for complex cancers.



The survival gains in
common cancers are as
high as 90%¹. For many
rare, complex, and
less common cancers,
progress in survival
gains remains far
too slow.

Cancer is Australia's most fatal group of diseases, indiscriminately affecting both adults and children alike.

Cancer has a profound impact on patients, families and society from a physical, emotional, financial and economic perspective, and remains one of Australia's most significant health challenges.

Every four minutes another person in this country is diagnosed with cancer. The random nature of a cancer diagnosis is hard to fathom. It's unfair, brutal, and terrifying for the person with the disease and for those who are close to them.

People living with cancer are everyday people before they become more commonly known as a 'cancer patient'. They are our friends, family members, colleagues, associates and sometimes even ourselves. Before living with cancer, people are seen to be active contributors to society, their communities, and the economy. Yet the fundamental rights people are entitled to in this first world country significantly diminish following a cancer diagnosis.



I've always had this saying that there's a person behind the disease, and that we were, and essentially still are, people. That never changed. But as soon as you enter the healthcare system, you become a patient.

Research participant

For people living with rare, less common, and now also 'complex cancers', the road ahead is not clear. Generally, there are few standard treatment options. This, together with a disjointed health system and commercially driven treatment development pathways – is resulting in morally reprehensible inequities in the lived experience among cancer patients. Some people are given potentially lifesaving treatment options at low cost (publicly subsidised) or no cost (clinical trials), while others who could potentially equally benefit from the same treatment options can't access them for a whole raft of reasons. This is denying people living with **complex cancers – that is, where the patient is beyond the routine of standard of care and is on a non-curative pathway – a chance to survive.** Are we willing to deny someone a treatment that may save their life because they don't fit the necessary criteria? Why is this acceptable? Is it because in our best efforts to balance value for money our system demands it?



What is the minimum standard of care, consultation, information and support that people living with cancer should expect to receive as they are thrust into the realms of the health system?

Rare Cancers Australia has supported thousands of patients and their families over the last ten years.

When contemplating person-centricity in the context of testimonies and feedback from hundreds of patients, it was clear that change should not be approached from a position of ‘fixing what is not working’. Rather, we should come back to agreeing on a set of moral and ethical principles on which to build better health systems, models of care and policy.

The complexity of cancer reveals itself in each person’s story that you encounter in this report. You will notice that the report starts and ends with personal accounts from cancer patients. If you read nothing else, within these pages the stories of the individual journeys speak volumes. Undoubtedly, patients have a lot of value, knowledge and insight garnered along their individual journeys. From each cancer diagnosis flows a wealth of ‘lived experiences’; of overcoming many difficulties and challenges that require swift and complicated decision making. Cancer patients very soon become experts in their own disease, and – disappointingly – the inadequacies of our health system. The lived experience is an asset that can be used to add to the longevity of the lives of future cancer patients, but also help shape system reforms to better serve the general community.

People with lived experience of cancer have a lot to contribute and a lot to say. Are we really listening and are we acting on their recommendations?



I think it is unfair to expect too much of patients. Cancer is hard enough without having to advocate for yourself and worry that you aren’t doing enough to be proactive in seeking out trials, support etc.

Research participant



Hosam's story

I am many things. I am a husband, a father of three beautiful children, a brother, a son, a friend and a rare cancer patient. I was diagnosed on Christmas eve in 2009 at the age of 25, a newly married man.

I started getting some headaches in the month or two before. They were getting progressively worse. Then, one morning I woke up with vertigo and I was vomiting. I was feeling quite unwell, so I decided to visit my GP. She was a bit concerned about what was happening, so she organised a scan of my head.

I can still vividly recall getting my MRI done and afterwards, the radiologist bringing me into their rear, dark rooms. He had a picture of someone there with an obvious, very large mass on their brain. He started talking to me and it didn't even click. I was just looking at this picture of this brain, and he was talking, and I remember interrupting him to ask, "wait, is this actually me?"

He sent me straight to the hospital after that. It was just around the corner and as I walked to my car, I remember looking up at the sky thinking "is this it?" I didn't know anything about brain tumours at all.

I ended up having the tumour surgically removed in January. Initially they thought it was benign, but when they looked at it under the microscope they found it was a very rare malignant cancer – anaplastic meningeal haemangiopericytomas. My surgeon who had 30 years of experience under his belt said he hadn't seen many of them in his whole career. He told me it was a malignant lesion, with a high risk of it coming back and a high risk of it spreading.

Getting a diagnosis of cancer is a very traumatic but hearing that you have cancer and there is not a lot known about it – that there's no rigid guidelines of how to manage it and that your doctors don't really know what's available for you – is another level of difficult.

Along the way, I've picked up a lot of important people who have helped me with my diagnosis and managing how things come along, like my Radiation Oncologist, my Oncology team and advocacy groups like RCA. When options are very limited, finding answers is not something you can do on your own.

After my second round of radiotherapy, my cancer did come back and it did spread to different parts of my body – into my shoulder, my lungs, and it came back in my brain.

I was fortunate to find a surgeon who was happy and able to take on further surgery that others had not wanted to do. In July 2017, I underwent my third craniotomy including the removal of a major sinus in my brain. It was a successful operation, but just like my last, it would come with bad news.

Five weeks after the surgery, I was diagnosed with Smart Syndrome, a stroke-like condition which left me significantly cognitively impaired. I lost vision in my right eye, I couldn't read, I couldn't speak, trying to solve very basic problems was extremely difficult. After a lot of determination and intensive rehabilitation, I learnt to talk, read and think all over again. But it has had long-term cognitive impacts on me. My ability to learn new things has been significantly affected. But I feel like there has been improvement, even though my specialists still tell me that they continue to see some deficits. Therefore I haven't been able to return back to work as a dentist. It's difficult, but if it wasn't for the surgery and radiotherapy, I wouldn't be here today.

Advances in treatments over the years has helped me to continue to improve. I still can't believe that when I was first diagnosed, we talked about options with my oncologist and there basically were none. It felt like we were left on our own, trying to piece together a plan. But now, as time has passed, other options have popped up and this has really made a big difference for me, such as the promising clinical trial that RCA found for my condition which involved genetic testing.

The stress before a clinical trial is the highest stress I've ever experienced in my life. There's no worse feeling than knowing there is something potentially available that could really help you, but you may not be able to access it because you don't meet certain criteria. Waiting for the response is horrible. There are no words to describe it.

That's the issue with me and my condition, and other patients who have rare cancers. Companies aren't making these drugs for people like us, they are making them for the more common cancers because that is a bigger patient pool for them to go out and support. That's why we rely on organisations to advocate for us to gain access, to make applications on our behalf.

I was eventually accepted into the trial and they took a bit of my cancer tissue that had been removed back in 2009, and tested it for any genetic abnormalities. This was a new concept for me, I hadn't heard of genetic testing before and I wouldn't have if RCA did not tell me about it.

The test found that my particular cancer had a genetic defect found in a type of skin cancer, the idea being that if I were to take that skin cancer drug that I could potentially get a response.

I continued on the trial for almost a year. The skin cancer treatment showed promise at the start, but my Oncologist wasn't happy with the way it was tracking so I stopped. It was difficult for me to unpack because the science was just so exciting.

Another immunotherapy-type drug became an option after this, which seemed promising. It would come at a huge financial cost for me and my family though, because the treatment was not funded for my cancer on the PBS. My parents sold their house, my wife returned to work when our youngest was just 14 weeks old, and my in-laws sacrificed superannuation to try to keep up with the high price associated with trying to keep me alive.

While we were busy generating the funds to pay for this option, I was fortunate enough to be accepted into an immunotherapy clinical trial. It was a godsend to be able to access that trial and not have to pay for it. This meant we didn't need to go ahead with the self-funded drug, so the money my family raised is now put aside to help pay for any treatment that I may need later on down the track. My parents say they have no regrets about what they did to try and support me, and I am really grateful to them.

Having a rare cancer is consuming – not just for the patient, but for everyone who loves and cares for them. I am so grateful to have such fantastic support around me, but it's hard to ignore the toll it takes sometimes.

I am still undergoing immunotherapy and I continue to try to fundraise to help with covering the still significant cost. We need a little more time to see whether this treatment is working well enough for me, but the longer I can stay on the trial the better.

However, if it doesn't work out, we'll see what else is available. I definitely feel buoyed by the fact that if I get bad news today, there are still options available, there's still hope, there are still people out there looking out for me – whether they are in the medical circle, the advocacy circle or the family circle.

It's not easy. Dealing with my kids and my current condition is one of the most difficult things I've had to do in my life, it's hard to know exactly what the right thing to do is. My oldest is nine and my youngest is three. They are acutely aware of what's going on, they know when dad is really upset, and they can see that dad looks a little bit different to some of the other dads – I've got a big scar on the back of my head, I have all these marks on my back and lots of incisions. It has been difficult to know how to balance keeping them informed and protected. But I try to be strong for my kids, I try to be strong for my wife, and I try to stay focused on the positive things in my life.



Tamlin's story

Most people want to hear the story about how you survived and how you overcame cancer.

They don't want to listen to the nitty gritty parts where you were lying in your bed at 12 o'clock in the morning, crying, thinking that you weren't going to wake up the next day. They don't want to hear about how you got stretch marks from putting on 40 plus kilograms from steroids and how you thought if you touched them, they would split.

They don't want to hear that. They want to see the story of you overcoming this challenge and believe that it's all there is to it, and that all that happens to you is that you lose your hair. But it's a lot more than that.

I lost myself when I had cancer. But let's start at the beginning.

I had this bruise-like lump on my leg that we called my 'Alien'. It had been growing for the past one to two years and nothing we did stopped it. Then, on a February afternoon, I landed on my Alien and it burst. This is what changed my life forever.

I went to hospital, they did tests and the results came back a few days later. At first, I was confused. Then I saw my mother's eyes, they were filled with sadness. I heard the words 'abnormal cells' and that's when I felt like my ears had stopped working. All I could hear was this buzzing sound that got louder and louder with each word that left her mouth.

They thought I had lymphoma, but after my Alien was surgically removed and further investigations occurred, they had a new diagnosis. It was blastic plasmacytoid dendritic cell neoplasm (BPDCN).

It was easily the worst day of my life. It was the day that I was diagnosed, the day that I was told by my doctors that my condition was so rare that they had no clue what it was. It was the day that I found out that I couldn't go out and see my friends, that I may never get to complete year 8, that I could never have my own biological kids, and that if I hesitated while in treatment I could quite possibly die.

One thing I've noticed from being a young person with cancer is that a lot of people will talk to the adult over you. It's really frustrating. People often just want to keep you happy because you have cancer, but we want the truth as well. We want to be included because it's our body.

I think being a teenager is hard, and then you add cancer on top of it. A lot of the time when you think 'childhood cancer' you think about the little kids, you don't realise that 'childhood cancer' also means adolescents. We're overlooked.

For me, this was made even more complex as my diagnosis of BPDCN is most commonly found in older men aged 60 and onwards. Even now, I'm on hormones to keep my levels stable and as they should be for a 17-year-old, but I'm still going through menopause. It sucks because you're no longer part of your age group. Instead of being in with the 12 to 30-year-olds, I'm a part of the 45 and older group. It's just one more thing that separates me from others.

Treatment was soul-wrenching and just all-out exhausting – emotionally and physically. Twice a week for weeks on end they would inject chemicals into my bloodstream or an area of my brain. Along with the chemotherapy were the bone marrow biopsies and lumbar punctures. They would lull me to sleep with gas while they told jokes and chattered away trying to distract me while I pleaded for them to stop the oncoming blackness. While I was in complete oblivion, they would drill into my hip for bone marrow and stick a needle into my spine to test my spinal fluid to see if the cancer had spread in the few days in between each torture session. The yellow chemotherapy would hang next to me in an IV drip while I dreamt about a normal life. They would then send me home with radiated chemotherapy tablets or injections filled with poison that I could touch, but others had to gear up to get near.

I had my bone marrow transplant (BMT) in July. By this time I had received about two years' worth of chemotherapy in less than five months. It went ahead despite the oncology team finding my cancer had spread because the risk of my death was rising.

Thanks to my brother who donated his bone marrow, and with the help of a brigade of doctors and an artillery of nurses as well as cocktails of disgusting medication, we started to rebuild my immune system, bit by bit, cell by cell. The days were long and cruel, but we managed.

Most of the time it was hard to be positive. If I went online, I could see all these joyous things other people were doing, and if I looked outside my window I could see the exact same thing plus the reflection of my encasing room. It's hard to be happy when you're stuck in what feels like a prison cell.

When the nurses disconnected me from my IV machine for the last time, it was like I was being released from jail for a crime I didn't commit. I felt such immense happiness that I danced, if you can call it that. I just danced.

Then I got home and realised things were different.



“

I want to celebrate my double freedom. I'm excited to have my life back.

Cancer really affects your brain and your mind. I had severe memory problems, I had severe concentration problems, I was extremely tired all the time because I just had cancer treatment, I just finished fighting for my life.

It broke my heart when I went back to school and failed my first exam – I've never failed in my life. And I thought I was a failure. But the truth was, I'm not a failure. I just had difficulties. I have disabilities now. Not because I'm a failure but because something happened to me, something so severe, two years' worth of chemotherapy and six rounds of radiation.

I still find it extremely hard to register that because I went back to school and no one knew what to say, they didn't say anything; it wasn't talked about.

I feel like fighting cancer can be the easy part. The hard part can be going back to normal life. I felt very isolated, I felt very alone. I felt like I missed out on a lot of opportunities, and I got to the point where I tried to kill myself.

I guess I never thought that I'd fight for my life so hard, and then two years later I'd be trying to end it. It's PTSD. A lot of people don't realise that. Cancer gives you PTSD.

I remember one day, my system was so messed up, and I told my mum 'I didn't want to do this anymore' and my mum did the hardest thing that a parent ever has to do. She said, "Ok, it's your life." As soon as she gave me that permission to take control of my life, I started to fight more, I started to fight harder because I was no longer fighting out of obligation, I was fighting for me.

Last month was my fourth year cancer free. There's a rule for kids with cancer, it's called the five-year rule because it's after this milestone that the chance of the cancer returning is significantly reduced. Next year, I'm having a massive party because I will be five years and I'm turning 18 as well – I'm calling it my 5-18th. I want to celebrate my double freedom. I'm excited to have my life back.

Megan's story

I found out I had thymic cancer in July 2019 by accident.

Like many people living with thymic cancer, I didn't have any symptoms directly caused by the tumour, but I knew something wasn't right.

I couldn't project my normally loud voice, I was easily short of breath and I choked regularly. Chewing and brushing my teeth were tiring. I live and work in the Northern Territory; my job involves a lot of outdoor work in the heat, mostly with cattle. I'm pretty used to the extreme climate, but I found that I couldn't cope anymore – my clothes would be completely saturated, my arms and legs would start to shake and then I would collapse with pretty minimal exertion.

I didn't know at the time that these were all symptoms related to myasthenia gravis (MG); a chronic autoimmune, neuromuscular disease that causes weakness in the skeletal muscles. It's a condition that is strongly correlated with thymic cancer.

I went to my GP and said there was something really odd going on. He put it down to menopause, suggested that maybe I was 'a bit out of shape', not as strong as I used to be, and showing signs of heat stress. I was confident what was happening wasn't normal, and pretty shocked that menopause could be that brutal. But I trusted his judgement, started some medication and just tried to manage the collapsing and extreme fatigue for the next 18 months without telling anyone, because I was really quite embarrassed about my 'snowflake' tendencies.

In the meantime, I had a cardiac ablation to address a heart rhythm disturbance. There were complications, and because of excruciating post-operative pain, I had a CT scan to investigate. They said my heart was normal, sent me home with pain relief and said to see the cardiologist for a check-up in six weeks.

At this follow-up, the cardiologist told me my heart was fixed, and then asked what I was doing about my thymic cancer. I was stunned. When I asked him what he was talking about, he said, "Oh, we didn't tell you? Yes, you have a large tumour in your thymus, you need to see a cardiothoracic surgeon, I'll send a letter to your GP."

I felt like I was given a huge bomb and just left with it.

My GP read the letter and told me that thymic cancers are not a big deal; I should get an opinion, but not worry about it. I couldn't get an appointment to see a cardiothoracic surgeon locally for another nine months, but I just accepted my GP's advice once again and put it out of my mind.

By the time the appointment came around in April 2020, COVID had hit and there were restrictions on medical consultations, so it was done over the phone. A very blunt cardiothoracic surgeon told me that I had a large tumour in my thymus that needed removal. He said I would need a full sternotomy (super scary), but because of COVID restrictions I would not be on a surgery list for another six to seven months, and asked did I have any questions?

It was a brutal way to deliver such sensitive news over the phone to a person they'd never met. I remember saying I'm sure I've got lots of questions, but you've just really thrown me and I can't think of what they are right now. I was given the number of a nurse to contact, but told that the surgeon would only speak to me again closer to the time of surgery.

I hung up and remember feeling completely dismissed. He had just told me I had cancer, needed a big operation, and then put me on the backburner. I didn't want to sit there for months thinking about it, I wanted it out.

I rang a few cancer charities for guidance and found RCA. They told me about the support available and took the time to ask me what I wanted and needed. It was a massive relief to talk to someone who was speaking the same language.

They helped me find cardiothoracic surgeons with an interest in thymic malignancy in Melbourne, where my extended family live. I found one with availability and organised a video appointment.

This surgeon was lovely. Finally, I felt like someone had their finger on the pulse – he looked at my scans and told me this wasn't optional surgery, the tumour had been there too long already. When could I come to Melbourne?

He was kind and compassionate and took the time to answer all the questions I had racing through my head. But more importantly, he went a step further and asked me some screening questions about MG. I told him I had read about my symptoms and thought I might have it, but my GP had not thought my problems warranted investigation. The surgeon referred me to a neurologist for assessment before he would operate. When it was confirmed – as hard as it was to hear – it was a relief to know that I wasn't imagining the difficulties; my experience was validated. I'm so grateful to that surgeon, because he put me on the right path to diagnosis.

Travelling so far from home for treatment was hard for my family. I was away for two months; I couldn't go back and forth as it is a full day of flying and driving to cover the 3000km from my home in Katherine to Melbourne. We live on a big rural property and my husband was taking care of our three children while working full time, and I wasn't there to help. It put huge pressure on all of them. COVID restrictions meant they couldn't come to Melbourne to visit me.

Financially, going from two incomes down to one was also a huge change. The initial estimate from the surgeon was that I would need four to six weeks off work, but it ended up being 14 months until I was back at work full time. While I wasn't earning, I was spending an enormous amount of money on specialists, scans, tests, treatments – it was extremely expensive. That said – I don't regret going through the private system, I'm just grateful that we could manage it.

The surgery in Melbourne to remove my tumour went well initially. The surgeon said he thought they got it in time, and there was a good chance that my cancer journey would end there. I was discharged and kept improving for another two weeks. I was ready to go home and celebrate!

Unfortunately, two weeks after discharge, my left lung collapsed spontaneously, and my left phrenic nerve stopped working, so I had a paralysed diaphragm. It's a well-known risk of thymic surgery but it usually happens immediately after the operation. At two weeks post-op we thought I was safe, so it came as a big shock. Around the same time, and then progressively over the next three months, my MG symptoms went from mild to moderately severe. I couldn't stay awake for long or get out of a chair by myself. I definitely couldn't go to work. I struggled to lift my arms above my waist so washing my hair, brushing my teeth, even holding a coffee cup was exhausting. Then I had a horrible reaction to some medication, which left me further incapacitated.

The disappointment around this level of debilitation was crushing after the high of the successful surgery. Any choice and control over my life seemed gone. The overlay of COVID added another layer of complexity to everything with restrictions in the hospital, and then the need to isolate in quarantine for two weeks when I finally returned home. I could not have gotten through all this without the practical and emotional support of family and friends.

Despite the difficulties, finding my treating team in Melbourne that I really trust, who are thorough and optimistic about my long-term outcomes, is an absolute godsend. The specialists work closely together; it was and is a team-based approach to treatment. I felt included in the decision-making and well informed. I'm so grateful for their expert care.

Although I don't like it, I have accepted that I have a chronic illness that will continue to wax and wane. Treatment keeps me as stable as possible and mostly keeps me out of hospital. My lung hasn't re-inflated and my diaphragm is still paralysed, but fortunately there was no evidence of the cancer recurring at my one year post-operation scan. I feel like I'm coping well with it, although MG continues to present unexpected challenges.



When I look back on it all, what helped the most were the people who believed me when I had concerns, and my 'village' who encouraged and motivated me through the worst times, including the RCA Thymoma Support Group. I am very grateful for the people who said "OK, how about I do this to help you?" And those who said "I know it feels awful, but we'll get through it." And we have.



Person centricity

- the opportunity



Person centricity - the opportunity

Patient-centred care and patient-centred health policy has been embraced in Australia as well as internationally for over a decade. Yet the lived experience of patients, their families and their carers is far removed from this notional ideal. Do all people diagnosed with cancer have enough of the right information to be put in the centre of their own care? Is everyone supported to understand the medical nuances of their diagnosis and treatment options? Do people feel heard and have the autonomy to make informed decisions in reality? And are the preferences of cancer patients sufficiently integrated into the decision-making frameworks underpinning access to therapies and technologies?²

The answer to these questions from patients, families and carers is consistently and undeniably 'no'. We know from our work with patients and their families that there are significant disparities in the delivery of cancer care among cancer patients.

What does person-centricity mean?

Patient centricity – or person-centricity, as we prefer to term it – is defined in many ways within the literature. While a number of similar definitions of person-centred care exist, the comprehensive definition endorsed by the Institute of Medicine^{3,4} (IOM) is the most frequently used internationally.

Categorised into six domains, IOM defines person-centred care as:

1. Responsive to patient needs, values, and preference
2. Integrated and coordinated
3. Relieves physical discomfort
4. Provides emotional support
5. Allows for the involvement of family and friends
6. Supports the provision of information, communication, and education to enable patients to understand and make informed decisions about their care.

The key principles of person-centred care include respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of carers and family, and access to care.⁵

Person-centred care supports people to develop the knowledge, skills and confidence they need to effectively manage and make informed decisions about their own health and health care.⁶ It is widely recognised as a foundation of safe, high-quality health care.

The person-centred approach to health care treats each person respectfully as an individual human being, and not just as a condition to be treated.⁷ Person-centred care involves seeking out and understanding what is important to the patient, fostering trust, establishing mutual respect, and working together to share decisions and plan care.⁵ This might seem a common sense vision for any form of health care, but too frequently it is not the experience of people diagnosed with cancer.⁶ In too many cases care is conducted 'to' or 'for' people rather than 'with' them, and it is therefore difficult for people to feel involved in decisions about their care.⁶

For person centred care to truly become part of the lived experience of cancer patients, NOA with RCA maintain that it must be considered holistically in the direct cancer care experience of the individual, as well as in designing our health systems and health policy (see Figure 1).

Person-centred care should be considered in:

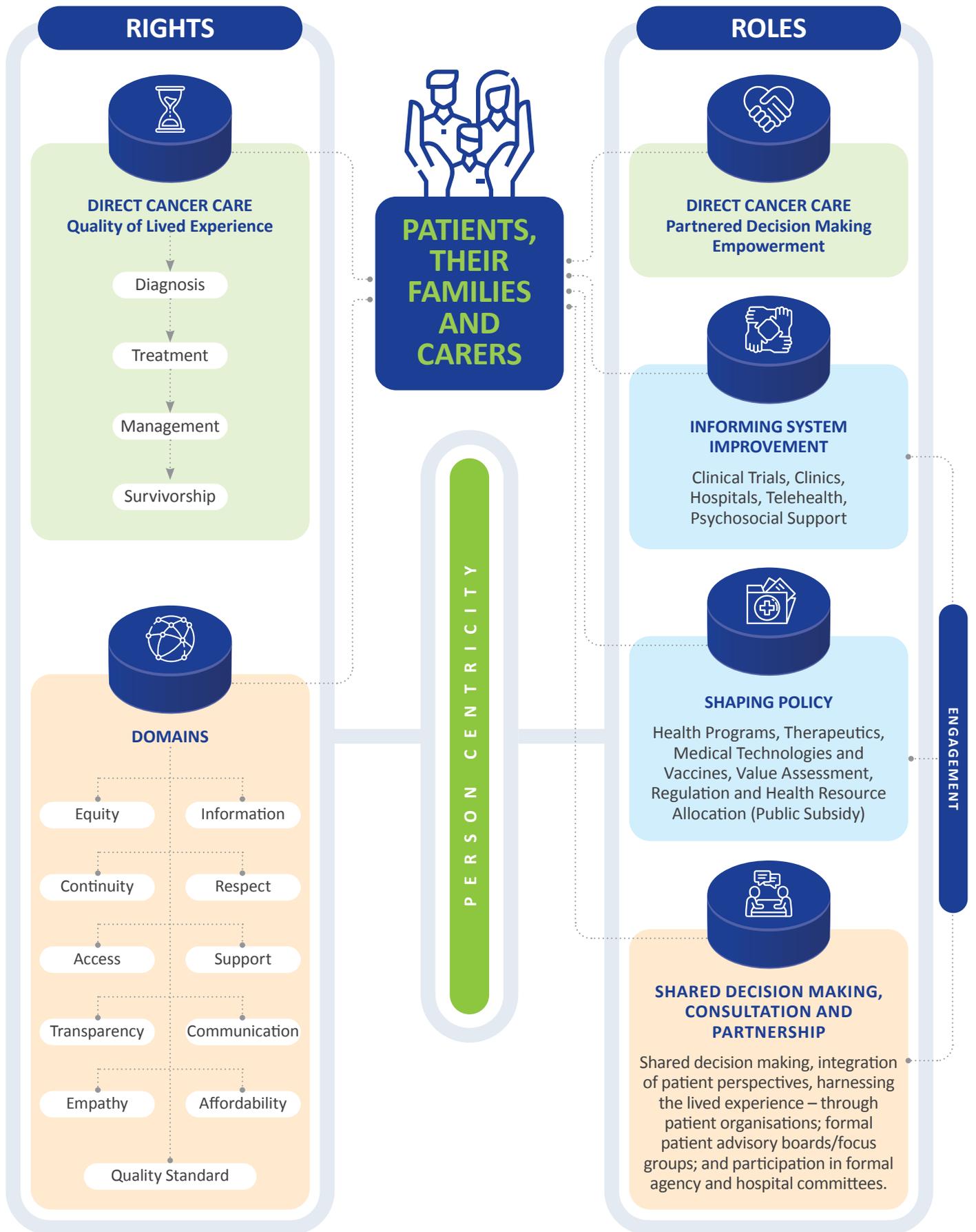
1 The direct care experience of the person living with cancer, where decisions are based upon patient preferences together with clinical judgment. This experience also extends to carers and family members.

2 Informing systems and how they operate. This includes patient input into the governance of clinical trials, hospital visits, clinics, telehealth consults and the provision of psychosocial support.

3 Policy as it relates to all aspects of the cancer continuum, including health programs, therapeutics, medical technologies and vaccines, value assessment, regulation and health resource allocation and financial investment.

FIGURE 1

Framework for person-centred cancer care, system improvement and health policy



Barriers to equal participation

Patients and their carers are often self-educated in the cancer world and frequently have no choice but to invest time in learning how to obtain the best care and best treatment teams to increase their chances of survival.² Is this right? Why should they have to resort to these extreme measures?

This requirement alone, demands a lot of patient's families and carers, such as advocacy skills, reliance, determination, resourcefulness, time, together with health and computer literacy. Equity in the receipt of high-quality cancer care is highly dependent on what is known as the social determinants of health. These include the conditions in the environments where people are born, live, learn, work, play, age, cultural diversity.

Despite the recognition of the importance of person-centred care the social determinants of health – people's individual circumstances, such as economic stability, health literacy, education, geography and social supports- determine how well people can advocate for themselves or a loved one living with cancer. When a health system relies on individual advocacy too heavily it creates huge inequities among cancer patients and the opportunities, they may encounter on their treatment journey.

NOA and RCA maintain that in a highly functioning, person-centred model of cancer care, people should not need to be their own advocates, or appoint carers or family members to do this on their behalf. It is a sign that the system is failing.

Jelena Magic is an experienced patient advocate and contributes to many boards and committees including the NOA Advisory Board. Jelena's first and most important role as a cancer advocate has been for her own little boy Marko, now four years old, who was diagnosed with a rare neuroblastoma. Jelena's direct experiences looking after Marko and actively pursuing the best possible options for him have made her an expert in what needs to change to create a truly person-centred health system.

Nick Kelly is a member of RCA's Patient Advisory Board. Nick became an expert patient advocate when he supported his late wife Nicole, who developed salivary gland cancer. Nicole sadly passed away last year, but before being a cancer patient Nicole worked as an occupational therapist within the public health system. Nicole had great knowledge and experience of how the health system operates. Nick told us that having the insider knowledge of the workings of health system gave his family a great advantage that others are not so fortunate to tap into when making decisions. He also explained that for a person to feel that they are 'central' to the cancer journey, the approach to cancer treatment needs to shift as clinical teams are so focused on the disease itself that the 'person' with the disease is overlooked.



In order to navigate the system, a patient is required to have a really high level of medical, organisational and information management skills. And at the same time to enable that shared decision-making and then to be an equal partner, patients and families and carers are supposed to be rational when their logical thinking may be impaired due to all the stress associated with diagnosis and everything else that follows.

That is one of the major issues right now. Everything is so fragmented, and every speciality and every department and every stakeholder, they seem to be working in silos. And then you have these patients who are in the centre and everything is supposed to be about them, but they seem to not have the information to understand what's happening and how decisions are being made.

The Australian system is very good at marketing. Before you enter the system you kind of expect that it's going to be the best system there is because that is the perception. But then once you start learning about it, and especially if you are dealing with something that's not a common disease, you will start to see those gaps.

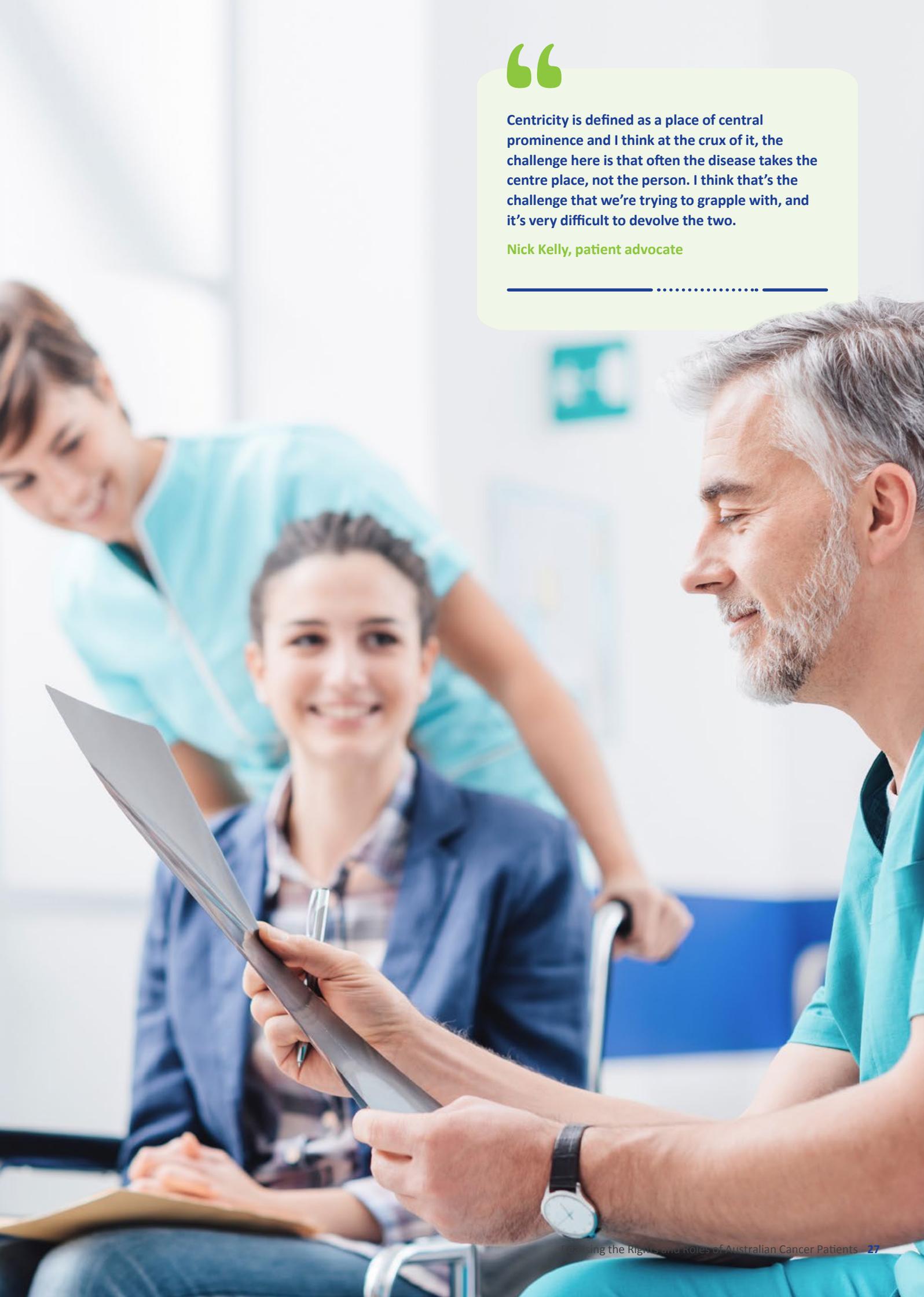
Until we have patients seen as a person that has health needs, but also has social needs, has mental health needs, has financial needs, and that all those parts have to work together in alignment to deliver that person-centred care, until the system is redesigned in such a way (to recognise this), we are always going to feel like something is missing and that we are not being fully informed.

**Jelena Magic
Cancer Advocate and Carer**

“

Centricity is defined as a place of central prominence and I think at the crux of it, the challenge here is that often the disease takes the centre place, not the person. I think that's the challenge that we're trying to grapple with, and it's very difficult to devolve the two.

Nick Kelly, patient advocate



The opportunity

Building on Vision 20-30

Over the past 20 years we have seen significant improvements in our knowledge and treatment of cancer, which have brought great hope to patients and their families.

The rapid acceleration of our understanding of the biology of cancer and its detection and treatment has resulted in radical improvements in outcomes for many Australians.⁸ As science and technology have gathered pace we have seen the development of new targeted therapies, immunology treatments, genomic science, technology improving surgery and radiation targeting.¹ The ability to understand the molecular characteristics of cancer through genomic screening, identify common elements between cancers emerging from different parts of the body, and the consequent design and development of therapies that target cancer at its cause, is a game-changing development.¹

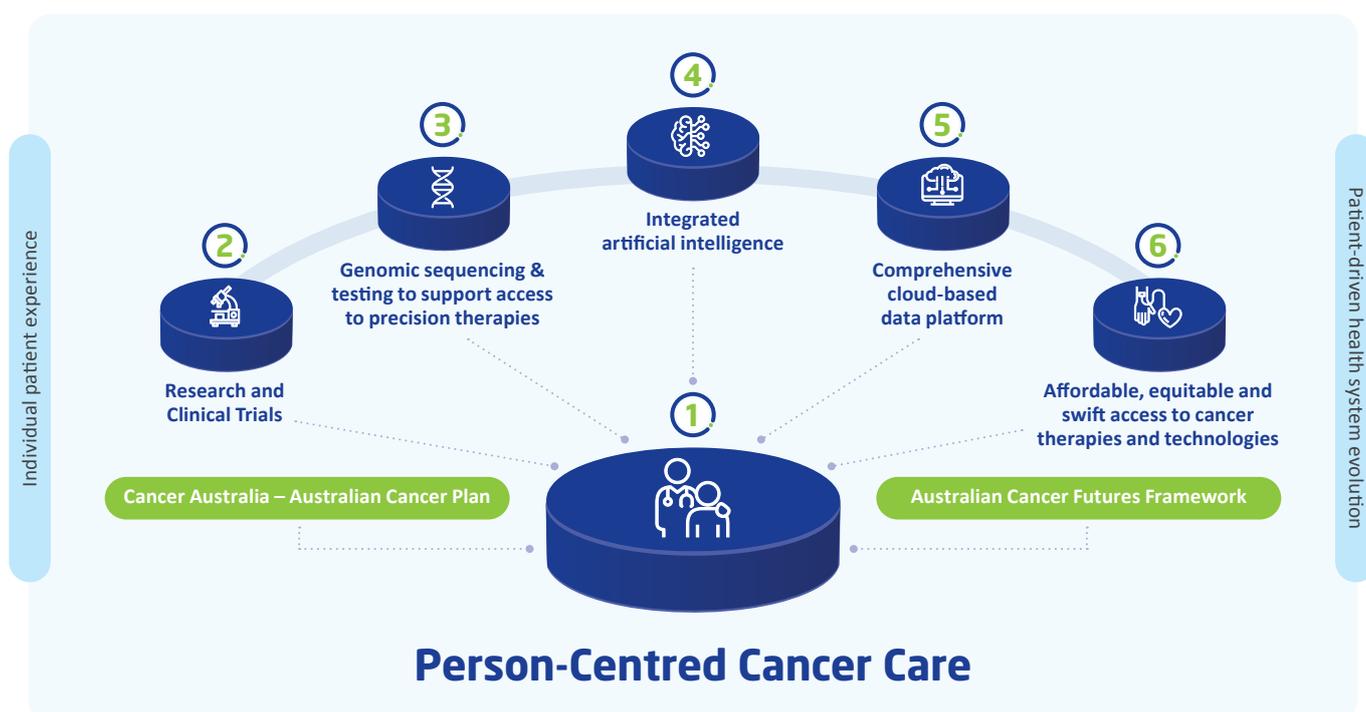
Despite the promising advances, not all people living with cancer have equal access to these promising new therapies and medical technologies. There are also added complexities in the provision of treatment modalities that intersect causing inherent system failures and the denial of treatment, or delays.

No other disease area has seen the scientific and medical advances and progress in personalised treatment as cancer. With the view of wanting to harness the opportunity these advances could bring patients for longer and better lives, NOA together with Minderoo Foundation launched the Vision 20-30 Report in 2020 as an aspirational view of what could be achieved in cancer care over the next decade if the stakeholders across the cancer community committed to planning for the future.

The report presented an **Australian Cancer Futures Framework** (the Framework) that could be built on to deliver the desired outcomes from Vision 20-30.² The Framework aims to increase the utility and availability of cancer treatments and technologies in the interest of saving lives and optimising the health system (*Figure 2*).

FIGURE 2

The Australian Cancer Futures Framework⁶



Within the Vision 20-30 report, the first pillar of the Australian Cancer Futures Framework intersects the other five pillars, focusing on person-centred care.

- 1. Person-centred cancer care** – cancer patients are engaged and ‘central’ to all aspects of their journey. Cancer patients have equity of access to understandable information to empower decision-making, as well as to the best medical teams and the support they need. Patient preferences are captured formally in evaluation frameworks that lead to improved decision-making on resource allocation. Preferences can be embedded through rigorous modelling and patient reported outcomes.
- 2. Research and clinical trials** – these build on the recent expansion of access to digital, telehealth and tele trials to ensure equity of access for patients regardless of disease type or geographical location. In particular, tele trials are used to expand access to clinical trials for patients outside major metropolitan areas.
- 3. Genomic sequencing and testing to support access to precision therapies** – provide genomic sequencing for cancer patients on non-curative pathways who are likely to benefit from analysis to inform optimum treatment, and link to clinical trial therapies where no funded therapies are available. Determine how to offer funded access to NGS, which will be needed as companion testing for emerging tumour-agnostic therapies. Explore the feasibility of establishing a national co-ordinated genomic centre of excellence.
- 4. Integrated artificial intelligence** – develop capacity for the use of AI across the cancer continuum and more broadly within the health system. Understand the breadth of its utility and current application. Develop frameworks for policy, governance, ethics and infrastructure.
- 5. Comprehensive cloud-based data platform** – an Australian cloud-based data platform that collects and houses comprehensive data that includes access to care, trends in survival, variation in practice and genomic data. This would allow stakeholders to store, share, access and apply AI to digital data and objects across the cancer care continuum.
- 6. Affordable, equitable and swift access to cancer therapies and technologies** – a fast-track provisional reimbursement pathway (akin to Therapeutic Goods Administration [TGA] priority and provisional fast track pathways) with a risk-share funding mechanism for cancers with high clinical need. Streamlined reimbursement pathways for multi-indication targeted therapies. Comprehensive evaluation and funding pathways that are designed to meaningfully measure the value for money of newer therapies and technologies over the long term.

This report focuses on building upon pillar one – person centred cancer care. A fully integrated model of person-centricity in cancer care ensures all patients have the right to receive the best possible care, no matter their cancer diagnosis, age, location, education level, socioeconomic status, or ethnicity. Person-centricity also gives patients the opportunity to lead, partner and shape health systems and policy.



A person’s care experience is influenced by the way they are treated as a person, and by the way they are treated for their condition. The ultimate goal of our health system is to deliver high-quality care that is safe, of value and to provide an ideal experience for patients, their carers and family.

Australian Commission on Safety and Quality in Health Care⁵

The Vision 20-30 Report was the catalyst for the development of an Australian Cancer Plan, under the direction of Cancer Australia. The Australian Cancer Plan is due for completion in 2023. It presents an opportunity to fully integrate person-centred care across all cancer types, regardless of rarity.

It is intended that the Plan will build on current achievements, investments, capabilities and evidence, but will focus on the future of person-centred cancer care, and cancer care minority populations for whom there are inequities in cancer outcomes such as for Aboriginal and Torres Strait Islander people.⁹ The Plan is intended to provide an overarching national approach to cancer control though building on optimal care pathways that meet the needs of all Australians, now and in the future.¹⁰

In looking to truly realise person-centricity, NOA and RCA sought to complement the work being undertaken by Cancer Australia and build on Pillar 1 of the Vision 20-30 Report – to explore the fundamental human values and ultimately rights of patients, carers, and their families. The roles patients can play in shaping system improvements and health policy become abundantly clear when we agree on the minimum standard of cancer care we are willing to accept. This standard of excellence can be delivered by upholding the rights of cancer patients which serves as moral and ethical framework. Furthermore, outlining the central roles patients can take to shape and inform these processes ensures that the health system continually evolves to benefit the very people it is intended to serve – equitably.



The current reality

- patient experiences



The current reality - patient experiences

Methodology

Recognising that person-centred care is far from the lived reality for most cancer patients, their carers and families, NOA and RCA embarked on several consultation initiatives. The design and delivery of these initiatives was informed by the Patient Advisory Board (PAB) of RCA before being taken out to the broader community.

Submissions

Through social media and Rare Cancers Australia patient community and the PAB, we called for submissions from patients in relation to patient rights and roles based on direct or indirect experience. The consultation received 18 patients and six industry responses, and we are extremely grateful to all the patients, their families and loved ones who responded. To inform this report, and to ensure our approach is truly person-centred, we asked for views on the following areas:

- Your patient journey from diagnosis, treatment, and management.
- What you believe are the rights and roles of patients in their healthcare journey – including whether you think these are currently being realised or need further integration.
- Your experience of the current Australian healthcare system.
- How you think the system can be improved to better ensure patients remain at the centre of care and decision-making.

Patient Focus Group Research and questionnaire

RCA's Patient Advisory Board tested several domains on patient rights and explored the roles of patients, their carers and families. The feedback from the PAB directly informed the 25-item quantitative online survey. 24 of the 25 items were categorical variables, with one open text field asking participants to add their thoughts on patients' rights at diagnosis. This open text response was analysed qualitatively by an expert research agency, CaPPRe, using specialist software called NVivo. The survey received an overwhelming response, with close to 700 completed questionnaires.

Stakeholder Perspectives Webinars

In July and August 2021 NOA hosted a series of four webinars, each exploring the rights and roles of Australian cancer patients. The panels represented four different stakeholder groups: patient organisations and not-for profits, clinicians, the pharmaceutical industry, and patients. The goals of the webinars were to understand the perspectives of different stakeholders on truly delivering and recognising patient rights; the value of more meaningful patient engagement in delivering person-centred health systems; and policies that enhance the lived experience of patients.

The first webinar was led by representatives from Australian patient organisations who all spoke passionately about the rights and roles of cancer patients, and how they can be defined in Australia. The panellists who took part in the clinician panel discussion were also passionate about doing their best for their patients and were incredibly humble when it came to the role they play in treating cancers. Some even reflected upon their self-perceived 'failings' in achieving the lofty standards they set for themselves in saving lives. The third panel, which consisted of pharmaceutical industry representatives, shared their views based on the experiences they have had working in industry markets overseas and within our region. While coming from very different backgrounds, the panel agreed that it is time to ensure that the patient voice is embedded within key decision-making in Australia. Our final webinar was led by a panel of patient advocates and was attended by a record audience of more than 160 patients, carers, family members, clinicians, and representatives from government, the health system and industry. We are grateful for the time that all our participants gave to the series and are reminded of how powerful the voice and views of people with lived experience can be.

Horizon scan and learning from other work-streams

The aim of this horizon scan was to examine the patient-centred cancer care environment in a select group of countries (Australia, USA, Canada, UK, and New Zealand); document the approaches taken by relevant entities within these countries; and report observations.

An initial desktop review of 26 entities within Australia was conducted in March and April 2021. A supplementary review of 23 entities across the USA, Canada, UK and New Zealand was conducted in May 2021.

In conducting the review, the websites of each entity, as well as any relevant publicly available strategic documents (such as strategic plans, annual reports, consumer resources, clinical guidance) were analysed to gather information about the following topics:

- Definition of patient-centred care – Does the entity define patient-centred cancer care? If so, how?
- Vision and/or approach to patient-centred care – Does the entity outline a vision for patient-centred cancer care and/or its current approach? What are the core elements or defining features?
- Implementation of patient-centred care – Does the entity provide information on specific activities that are being undertaken/could be undertaken to inform or deliver patient-centred cancer care?

FIGURE 3

Methodology – planned activities & research



Communication challenges

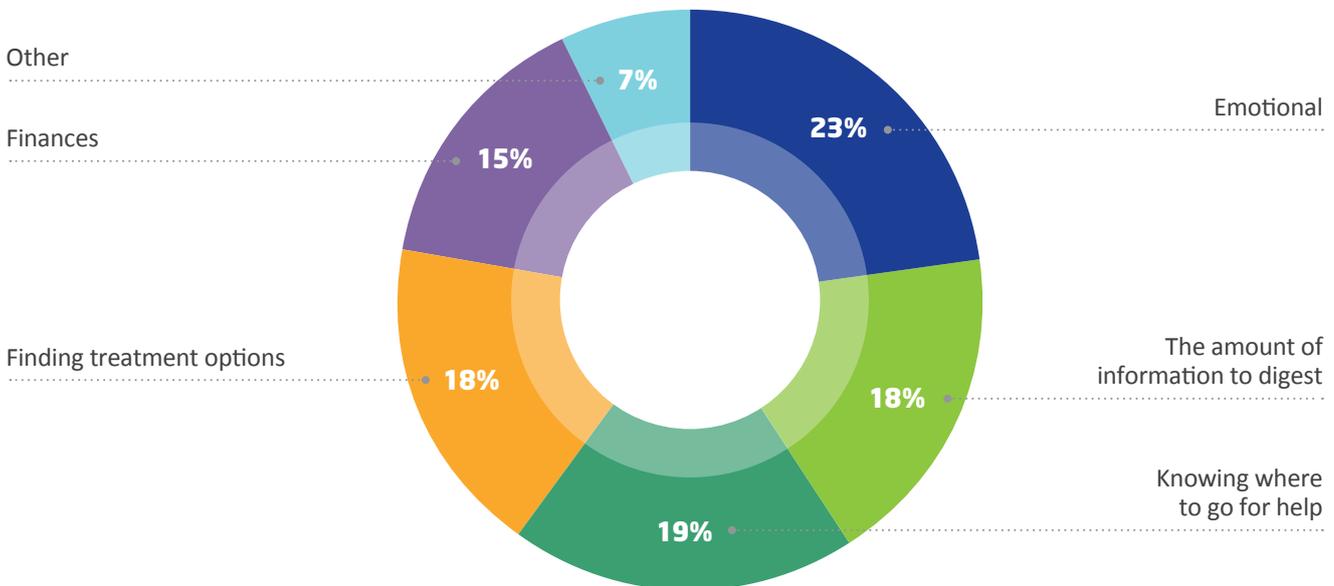
Challenges associated with communication of a cancer diagnosis

Communication between clinicians and patients following a cancer diagnosis is often difficult, especially as cancer care is typified by emotional and physical challenges.

Recognising that all patients have a different experience following a cancer diagnosis is key to being able to effectively tailor care that focuses directly on individuals. When asked to rank the most significant challenges patients experienced following a cancer diagnosis, the most common answer was the emotional impact (Figure 4).

FIGURE 4

The most significant challenge associated with a cancer diagnosis



At a time when you are feeling very overwhelmed it is still important to be told everything both verbally and in written form, so you and your support group can all be on the same page and get correct information.

Research participant

Accurate information at diagnosis

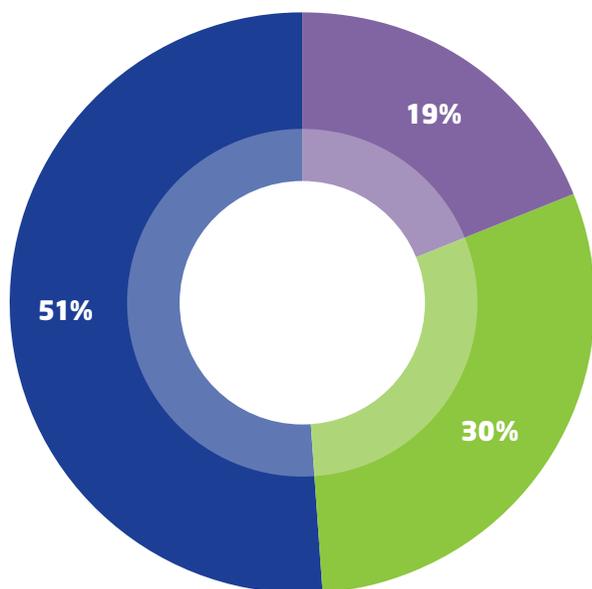
Cancer patients and their families often spend time becoming self-educated in oncology, and undertake research on how to obtain the best care and find the right treatment teams themselves.

Thirty per cent of survey respondents felt that they had received clear, thorough, and honest information at diagnosis. The remaining 70% of respondents felt that the information they received was completely lacking (19%), or that it left them needing to conduct additional research (51%) (see Figure 5).

FIGURE 5

Do you feel you received clear, thorough and honest information upon diagnosis?

- Yes I was told everything I felt I needed to know
- Yes but I still had to do my own research
- No, I was left with little information



Despite only 30% of respondents feeling that they had received adequate information, 95% felt that it was ‘very important’ to be given thorough information at diagnosis, while almost all (99%) agreed that good information is needed to help patients and families make important and sometimes complex decisions.



I was diagnosed with MGUS in 2015. I was not overly worried because the conversation was always that this could turn into Multiple Myeloma but it could just stay where it is for years and years – funny thing is I didn’t realise what I already had, was a blood cancer. About 18 months later, the pp went to 34 and I was sent for a bone marrow biopsy. At my next appointment I was told that I now have smoldering myeloma. She then told me that we were moving towards MM and I would then need to have a stem cell transplant. I could have two stem cell transplants, but only two. I was also given a prognosis of 7 to 10 years. I noticed the difference with her telling me this, as I remember the doctors asked my mother whether she wanted to know her prognosis or not. I think I should have been asked if I wanted this prognosis, as it came as quite a shock to both of us and my husband broke down in the doctors office. I had a stem cell transplant in Nov 19 and it was successful, and the good news is that I can access lenalidomide now in Australia for maintenance.

I think we have the right to be informed as much as possible in regard to options for treatments, especially with my cancer which is ongoing and incurable. I think we should also have the right to decided when we do not want to take certain medications.

Donna, patient

Managing expectations when diagnosed

Patients with cancer face a monumentally difficult task: navigating a path while confronting an often terrifying disease.¹³ At the same time, oncologists also face a monumentally difficult task: to guide patients on what may be the scariest and most unpleasant journey of their lives. They must preserve their patients' hope, manage expectations and provide them with accurate information.¹³

Almost all (99%) survey respondents agree or strongly agreed, that it was important to know what to expect when first diagnosed, demonstrating the need for clinicians to be open and honest with patients from the beginning.

Unfortunately, communication with patients is not always ideal, and patients frequently leave medical visits overwhelmed, with unmet expectations and confusion around treatment plans.¹⁵ People responding to our consultation spoke of their own experiences and the challenges they faced when discussing treatment plans with their clinicians.



I formed the opinion that the only viable treatment option for him was CAR T-cell therapy. When I attempted to present this to the treating specialist, the idea was immediately dismissed.

Research participant



Patients should have to be informed about trials that they qualify for. My husband (a doctor) and I specifically asked my oncologist about immune therapy trials for triple negative breast cancer. We were very keen to try it. Despite an hour-long discussion about it with the doctor and her nurse assuring us that they were on top of trials and there were none that I could join, my husband and I learned about a trial that was exactly on point for me. By the time we learned of it, it was too late as I'd undergone treatment. When asked about it, my doctor admitted that she knew about it but made an excuse why she thought I wouldn't like the trial. It was my decision to make. I should have been informed. It was disempowering to have her withhold such important information.

Research participant

Power imbalances

The power imbalance across the health system emerged as a strong theme in our webinar with a panel of leaders from Australian patient organisations, and directly from patients themselves. In the absence of full disclosure of all possible and even more difficult-to-access treatment options, patients feel that they are not equal partners in shared treatment decision making.

Health professionals were said to often make assumptions or judgements and withhold information from patients' families or carers as a duty of care. Yet most patients and carers said that they found this approach to be limiting in a way that could prevent fully realising the potential options they could possibly pursue outside of the standard pathways, such as clinical trials and non-funded therapies.

It shouldn't be a presumption and a patriarchy which says 'you'll do what I say because you're my patient and I know best'. It's got to be a conversation and a more engaged view. It's changing but it's really hard to get health professionals to understand the innate power imbalance between you as a patient and them as a specialist. That desk across which you are sitting is a major power barrier and we have to find ways to break that down.

Richard Vines, CEO at Rare Cancers Australia

I think all possible treatment options should be laid on the table. For example, Drs often assume that drug costs will deter patients – but that is our choice to make... Rather than a 'not one size fits all approach' at diagnosis, the patient should be treated as an individual, not as a disease. Tumour genetic testing should be offered... ALL potential clinical trials MUST be made available. A patient deserves transparency, balanced with hope. All options put on the table, and the patient connected with ALL experts in the field. Drs need to put their ego aside, and do what is best for the patient... especially with rare cancers.

Research participant

Despite the perceived power imbalances, the clinicians who spoke at the webinar were clearly passionate about doing their best for their patients, and were humble when it came to the role they play in treating cancer patients. Some even reflected upon their self-perceived 'failings' in achieving the high standards they set for themselves in saving lives. When considering person-centred care, shared treatment and management decisions are clearly an important part of patient consults for all. The need for clear communication and time spent with people to uncover the needs of each individual patient, as well as gauging patients' depth of clinical understanding of their cancer and options, was clearly conveyed.

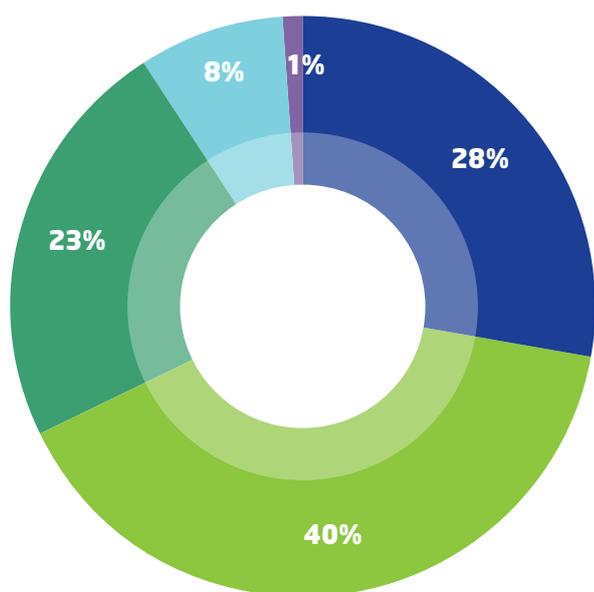
Shared decision-making treatment and management decisions

The uniqueness of each person, their cancer and prognosis mean that it is important for them to be at the centre of the decision-making when it comes to treatments. Nearly all (96%) respondents agreed that patients and their personal preferences should be considered in decisions about their treatments. For this to happen, clinicians need to discuss with patients all the options available, and their impact, and understand what is important to them as an individual. Almost all (99%) survey respondents agreed that being heard and having their preferences respected is a patient’s right; however, our survey also showed that this is not always the case (Figure 6).

FIGURE 6

Personal preferences were heard and respected in treatment decisions

Always Sometimes Never
Usually Rarely



I would stress the importance of shared decision-making in this process. We’ve got so many challenges as our cancer treatment world becomes more sophisticated and difficult, providing the information is more challenging, and the health literacy of our patients is crucial. Adequate assessment yields appropriate care. As an individual, dealing with an individual patient, you need to get to know them more.

Dr Christopher Steer, Medical Oncologist
Albury Wodonga Regional Cancer Centre

Genuine empathy around prognosis’

Further to the communication issues described regarding treatment options, many consultation respondents raised concerns about what they perceived to be a lack of empathy in their treatment. What may seem to clinicians and staff to be a minor detail can constitute a powerful stimulus to patients,¹² and it is imperative that medical professionals understand the wants and needs of the person they are treating, especially when it comes to discussions of prognosis.

My husband’s Haematology Oncologist sent to him an article which detailed a single case study of a doctor diagnosed with relapsed NHL [non-Hodgkin lymphoma] who obtained remission on this treatment but ceased due to the unbearable side effects. He felt his doctor had a complete disconnect from his patients’ experience and it left him feeling despair, helplessness and anger.

Research participant

The registrar called us in, there was also a nurse specialist and the registrar explained she would call the medical oncologist in when we were ready. She then proceeded to outline the palliative chemotherapy treatment Kevin would be starting...a couple of weeks ago we were at the surgeon’s discussing surgery and now you are sitting here saying he is not curable, that the treatment he will receive will be palliative. It might have been nice to lead into that since we did not know.

Research participant

My cancer was discovered during tests to find out why I was unable to get pregnant. I had spent the last five years on a journey with my fertility. This was and still is the most upsetting part of my cancer to me. When I saw a psychologist on a few occasions she was very unsympathetic around this. Using comments like, “Think of the money you will save not having a child, there are too many children in this world anyway”. This made me feel that my feelings for a child were not valid and it affected me seeking further advice on pregnancy with cancer. And still, now nearly two years on, when I discuss the possibility of pregnancy, I feel like I am wasting the oncologist’s time and my wants are not worthy.

I was given a prognosis of 7 to 10 years. I noticed the difference with her telling me this, as I remember the doctors asked my mother whether she wanted to know her prognosis or not. I think I should have been asked if I wanted this prognosis, as it came as quite a shock to both of us and my husband broke down in the doctor’s office.

Research participant

Almost all (99%) survey respondents agreed, or strongly agreed, that expected treatment outcomes should be fully explained to patients so that they can make informed decisions. Some 98% of respondents also agreed or strongly agreed that patients should be involved in shared decision-making with their healthcare providers if they wanted to be.

Feeling heard by the treatment team and being involved in decision-making was also important, with many participants mentioning the 'patient voice'.



Patients want choice and options. It's the specialist's responsibility to know the various options available to patients. Empowered consumers are no longer willing to take "doctors" orders.

Patient advocate

The survey responses demonstrated that full disclosure and information can empower patient decision-making, but it is most effective when delivered sensitively and with appropriate emotional and process support. Accounting for individual differences in preferences for timeliness, context and method of information delivery should be considered as part of routine, person-centred care.¹¹

Understanding information

Ensuring that communication is tailored to meet the needs of patients and their families is a core consideration for improving shared decision making. This includes ensuring that patients and their families understand the information delivered to them. Some 97% of survey respondents agreed or strongly agreed that receiving information in a culturally appropriate way and in plain language is important for patients.

Support options

Many survey respondents discussed support, with some specific mentions of where this support should come from (healthcare support, for personal reasons at diagnostic appointments). Having questions answered and a place to seek help in navigating the system were frequently mentioned as necessary support, in addition to being offered emotional or mental support.¹¹



Information about not only diagnosis but also about the available support network should be provided to the patient at diagnosis.

Research participant

Some 95% of respondents agreed or strongly agreed that having a dedicated person to help navigate a cancer journey would also make things easier and more equitable.

Experiences with clinical teams

The research showed that patients often had to see different oncologists, specialists, and clinical care teams. This led to patients feeling overlooked and that no one was ultimately accountable for their care.

It was discussed that good relationships and communication between patients and their care providers are an essential component of a person-centred care model. Strong relationships between patient, carers and the clinical teams cannot develop when patients may not always see the same clinicians or nurses.



I see whoever is assigned at my appointment – currently I have been seen by six different doctors/registrars over the course of eight oncologist appointments. Whilst all doctors have been pleasant and helpful, the lack of consistency has resulted in several problems and caused some angst. For example, certain test results were emailed to one particular doctor and were not available to the next doctor I saw. Chasing up these results required several phone calls and another two oncologist visits.

Research participant



Treatment within a public hospital has not been smooth sailing with regards to consistency and organisation. In my personal experience, in multiple instances various aspects of my care (results, tests and appointments) have been overlooked, incorrectly scheduled or mismanaged, costing me time and the hospital money for unnecessary appointments/tests/rescheduling. I genuinely worry about patients who have limited knowledge of medicine or English and the effects such mismanagement could have on their treatment.

Research participant



Questions and second opinions

A common experience of treatment consults discussed and reported in the research was patients feeling rushed and not having enough time to ask all their questions. Almost all (99%) survey respondents agreed, or strongly agreed, that patients should be given time and feel comfortable to ask questions in order to understand their options.

Survey participants also felt that seeking a second opinion should be encouraged, rather than considered an offence, to their treating physician, whether it be GP or specialist.

Sharing information

A key theme that emerged through the research was lack of data connectivity and sharing of clinical results and information between health care providers. Issues around the lack of communication between them was seen to be burdensome for patients and their families. Many patients also noted that systems within hospitals and primary care are not always connected, which means patients must spend time, effort, energy, and money, going between providers rather than providers connecting directly with each other.

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A patient has the right to ask as many questions that he/she wants and be given the time by clinicians to answer these questions... A patient has the right to seeking second (or third) opinions and for doctors not to feel threatened by this.

Research participant

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The medical system should be able to ensure that ALL medical files be shared with ALL people who are involved with the patient's journey, regardless of their status in the medical field. Also, that the patient can easily have copies of their file and related information without the endless paperwork to sign for approval and authorisation from medical personnel. After all, it is about me.

Research participant

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I had for a time received CT scans through the public system because they would use my port, unlike our Qld Xray. I found it infuriating that my doctor couldn't see my scans though because private and public use different systems. In order for me to get the scans on a disc for my doctor to see I would be sitting on the phone for hours.

Research participant

Treatment access

Equal opportunities

When exploring access to novel treatments and technologies,¹ the vast majority of survey respondents (93%) agreed that all patients should have the same treatment opportunities, no matter what cancer they have. The regulatory authority (Therapeutic Goods Administration – TGA) and reimbursement schemes (namely, Pharmaceutical Benefits Scheme – PBS, and Medical Benefits Scheme – MBS) add a significant layer of complexity. Many patients find themselves in situations where they are forced to self-fund new treatments and tests at huge personal expense, as described by respondents to our consultation.



There are no drugs and treatment available to me because it is so rare. I have no treatment options. I have literally been told there are no treatments available to me because it is not profitable for businesses and the government to develop any. I am now 29 years old and have to manage the unknown of my disease, and an unknown life expectancy.

Research participant



I believe all cancer patients should have the right to free health care and free medication. The burden of a cancer diagnosis is enough without the financial burden to add to this. Not all the lines of treatment for GIST are paid for by the government. This is a massive worry for me for the future. Medication can be 1,000s dollars a month, I don't know how I will pay for this. Are we really at the place in Australia where your financial position decides if you live or die?

Research participant

The immune-oncology treatment my oncologist prescribed was government funded for melanoma or lung cancer patients. Even though I had secondary cancer in my lungs, the funding did not extend to my primary cancer of thymic carcinoma. There is quite a growing number of successes being seen using this treatment from other patients (with the same type of cancer), but obviously not the numbers that the Australian government wanted to see.

Research participant

Access to care for cancer patients in Tasmania is mixed. I have witnessed very sick patients going to Melbourne to access their care. I cannot imagine how much difficulty this brings to an already tragic set of circumstances. All my treatment required daily travel, and only by luck of having a decent boss did my husband manage to take time off to be my driver and support. As part of the arrangement, it took two years for him to regain access to his holiday leave. I would have missed a significant amount of treatments if he was not my driver. There was no overnight stay options linked to the major hospitals or cancer treatment support services.

Research participant

At the end of the day patients are taxpayers, patients are constituents, and it's a patient's right to be able to have broad access [to treatment] in under 100 days from registration. We see it happening in other countries. There's no reason why it shouldn't be happening in Australia.

Michael Azrak, Former VP and Managing Director, Australia and New Zealand, Merck Sharp and Dohme (Australia)

The science, which is our underlying core competency as a company, is moving faster than it's ever moved in the past. If the system doesn't change then not only will you see inequitable access, you won't see access at all to some of the true latest innovations. It's changing into maintenance therapy, or in some cases into cure therapy. If we truly want to put the rights of Australian patients at the heart of this discussion, we have to continue to follow the science. We have to continue to make an investment window available where Australian patients can receive the best healthcare possible. There is a risk that if we don't change, then the reality of science will change faster, and then as such we will fall further behind.

Neil MacGregor, Managing Director, Australia & New Zealand at Bristol-Myers Squibb



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I strongly believe that the fundamental rights of cancer patients should be equity in access and treatment for all patients. I believe that everyone should have access to treatment and medication for their cancer, no matter the type of cancer, no matter how 'common' or 'rare' that cancer may be, and no matter the bottom line and most profitable for pharmaceutical companies, and for the government.

Research participant

Clinical trials for children

Access to tailored paediatric treatments is a significant issue for childhood cancer patients and their families. Since 1980, fewer than 10 drugs have been specifically developed to treat cancer in children (compared to the many 100s developed for adults). All childhood cancers are rare, and most treatments options are accessed through participation in a clinical trial.

Children are still growing and developing, and potentially have many, many more years ahead of them. Children respond to and tolerate treatments differently to adults, and there are different considerations to weigh up with regards to treatment risks that are not relevant for adults. RCA has seen many families travel overseas repeatedly while the child is very sick to participate in a clinical trial. Not only is it challenging to be involved in a trial under usual circumstances, but the burden of being in a foreign country, paying for accommodation, temporarily relocating siblings and so on is a logistical and financial nightmare. A clear theme emerging from the research was the need for local treatment opportunities tailored to children, and more investment in clinical trials.



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Ned was enrolled in a few (clinical trials) at various times, two of them particularly significant in his treatment: blinatumamab, an immunotherapy drug running on continuous infusion from a backpack he had to carry around and sleep with 24/7. And CAR-T, the trial we went to Seattle for, in which Ned’s T cells were extracted, modified to identify and kill his leukaemic cells, and re-infused into him. Though nothing worked in saving his life, and they both brought considerable burdens in the decision-making process given there was no evidence/expertise to guide us, they bought us time and we are ever grateful Ned had access to them.

**Dr Emily Isham, Advocate,
Carer and Mother**

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One of the most important roles patients can play is helping us to really understand the value in the medicines we develop. This is the idea that we design clinical trials but they don’t always recognise what patients see as great breakthroughs or great progress when it comes to their treatment. I think we have to be listening better to make sure that yes, our clinical trials meet the end points that they’re designed to meet to get us to a regulatory and reimbursement process, but as regulators and payers get better to listening to patients too, hopefully this will mean that we will develop medicines that more holistically address the concerns of patients as they’re fighting diseases that we are all dedicated to addressing. I think there’s a lot more room for improvement, we’ve come a long way, and there’s a lot still to do.

**Jaime McCoy, General Manager at
Gilead Sciences**

Financial burdens

Cost of care and treatment

Australian cancer patients and their families who are forced to self-fund cancer treatments that are not covered by the PBS also incur other substantial out-of-pocket expenses.

The costs involved in paying for diagnostic tests (e.g., PET scans), for example, can rapidly accumulate and cause enormous stress to patients and families, especially when people are unable to work due to illness and ongoing treatments, as respondents to our consultation discussed.



As a mother of five young children it was a massive strain on our household to pay \$60,000 to receive treatment. My parents also helped pay some of the costs. My husband is a small business owner, so not only did our family budget suffer, he was also not able to expand his business because we used the money he had set aside for that purpose.

Research participant

I should be able to concentrate on getting well or, in my case, enjoying the time I have left, rather than having to work full time for financial stability. Under the current Centrelink rules, I would most likely still have to keep working or applying for jobs regularly because outwardly I am healthy, although I do have memory and concentration problems and limited energy as a result of my medication.

Research participant

Over time the cost of having cancer has significantly disrupted my finances. Years and years of paying for specialist appointments and diagnostics has impacted every part of my family and myself. The need to keep an income flowing is mandatory for us to maintain a home and “food on the table”. I also found it incredibly painful to witness how my family had to miss out on milestones because we couldn’t afford it due to my poor health and loss of income. This forced me back into the workplace too soon after my treatment. I do not qualify for any Centrelink support, and with no concessions I pay full price for everything. A temporary healthcare card would have been so supportive. Due to these ongoing costs, I need to work full time, when really my health needs dictate I need to work part time, so as to meet appointments and stay well.

Research participant

We both have insurance in case we can’t work due to illness or accident. A huge flaw in this is that we cannot access this when our children are sick. As a mum, I had to leave my position and take two years off to care for my very sick child.

Carer and mother of a child living with cancer

Unsubsidised or overseas treatments

Given the often-significant cost involved when patients have to self-fund treatments not available on the PBS, there may be an ethical or moral dilemma for the treating clinician. Do clinicians tell a patient there is a medicine available that they know the patient cannot afford, or only discuss treatments that are readily available and fully funded? Some 78% of survey respondents disagreed or strongly disagreed with healthcare providers making their own judgement on whether patients could afford certain treatment options. In addition, 92% of agreed that patients should be told about treatment options, regardless of location or cost.

When the webinar discussion with Australian clinicians shifted to all cancer patients getting equal access to potentially lifesaving new treatments, there was clear recognition of the current financial constraints and system-level failings. Professor Grant McArthur spoke about the rationing that occurs within the health system that increases the access divide.



The health budget is not infinite. So, there is rationing. Sadly, we have some rationing because we cannot have every innovation that comes through available to everyone because of budgetary constraints - that's the harsh reality. Does that mean some patients are missing out? Unfortunately, yes.

Prof Grant McArthur, Executive Director of the Victorian Comprehensive Cancer Centre

Members of the clinician panel agreed that change is needed to deliver better experiences and outcomes for patients, as the current approaches are antiquated and no longer delivering the same results. The magnitude of this issue in Australia is obvious when considered in a global context, and it was noted that Australia continues to fall behind in the speed and availability of new treatments and technologies compared to other countries.

We need to continue to think and reform the reimbursement and the support for drugs, new medicines and other innovations in Australia to ensure that patients get rapid access. If you are looking at the countries that we are comparing to – we are comparing to France, we are comparing to the UK, we are comparing to Germany, we are comparing to Switzerland – we are comparing to countries that we like to think that we have an equivalent standard of life to, an equivalent society. Yet here they are, we are 40 countries down the track and the drug is not available. And it is available in other places. And there are innumerable examples, not one or two. It doesn't matter what persuasion the government is, the fact is we are Western Society, in a developed country, with a high GDP per patient, and we shouldn't have to ration drugs like we do.

Health is a right, not a privilege.

Professor John Zalberg, Professor of Cancer Research at Monash University

We are living in the last century. There is a lot of work to be done so that we can get evidence together and to also change the way patients are viewed. We can make a difference, and we have to.

Prof Clare Scott, Professor of Gynaecological Cancer at the University of Melbourne

The webinar panel of pharmaceutical industry representatives discussed the different ways in which changes to access can be manifested, with panel members recognising the significant interest in clinical trials. They highlighted the importance of ensuring that sustainable long-term change remains the focus by looking at reforms that enable faster access to treatment for patients, as opposed to relying on mature clinical trial evidence that may never become available.



Survivorship support

In the coming years, there may be more Australians surviving cancer than ever before given the significant leaps forward in the understanding of cancers and tailored treatments. These gains rely on system wide reform to keep pace with the evolving treatment landscape. In this setting, survivorship considerations become very important. Survivorship challenges are incredibly common, yet most patients report a complete lack of support during this phase of the journey.

For many, the side effects from cancer and aggressive treatment methods may continue to interfere with quality of life. Patients need to know about the potential longer-term issues arising post-treatment and receive ongoing support.



When finishing chemo, patients should be given information about their immune system such as how long their recovery will probably take and things they can do to improve it/help themselves get well. Information and resources should be provided. My oncologist provided none of this. I felt dumped off at the end of my treatment.

Research participant



I am witnessing a post-treatment phase that is missing the same level of medical support I had during treatment. During treatment the support from the breast cancer area was exemplary... However, post treatment it becomes clear there are “PTSD” style issues. The life-long anxiety of the cancer’s return is now my domain to manage on my own. Unless I wish to pay for support, as I witness small businesses created to address this gap.

Research participant

Survivorship issues may include stress and anxiety about recurrence, ongoing screening, abandonment, and grief when appointments end, survivor guilt, concerns around returning to work, and PTSD. With Australian cancer diagnoses projected to increase by 38% between 2015 and 2025, and a growing number of people living longer with cancer and other chronic diseases, there is more need than ever to address the long-term health and wellbeing of people affected by cancer.¹⁷ As more lives are saved, further support frameworks will be needed to improve survivorship.²

Valuing patients

The research sought to understand what roles patients, carers and family members believe they should play in improving the cancer care system in Australia. Most survey respondents (80%) agreed or strongly agreed that patients should have a great influence on designing optimal cancer service delivery; informing value-based access decisions; inputting into health system design; and playing a role in key decision-making relating to aspects of the health system.

The patients who responded to our consultation universally agreed that as recipients of care and treatment, they know first-hand where system improvements should occur.



I think it's that concept of perception versus reality. So, we are essentially the players on the field, we're the ones seeing it, we're the ones hearing it, we're the ones living it, and that is such a unique lens that you just can't find in any other area. You don't know what you don't know, right? And at the end of the day, everyone is passionate and working hard in the area and industry that they're in. They think they are doing their best job and that's their best. But I think it's up to us to be helping to drive that change, and to be helping to identify those gaps within these organisations and within the system that we're actually involved in, to ensure we can keep moving forward and not backwards.

Lisa Briggs, rare cancer advocate

Patients and family members also provided their thoughts on how they would like to be treated and the roles they can play in their own direct cancer journeys.

To be treated with dignity and respect. To be seen as active collaborators and decision makers in their journey. To be supported in efforts to research and access the most promising treatment options. To be fully informed regarding prognosis and treatment choices, and for this information to be delivered with empathy and compassion. This was certainly not our consistent experience of my husband's healthcare journey.

Research participant

You have to be on top of everything. Make sure you ask all the questions you have and have clear answers. Try and find people who have the same cancer as you, I know this is hard with rare cancer but so important for knowledge and understanding.

Research participant

Patients (and carers) can have a very important role in the health system, being advocates or even by sharing their stories so that others can see what makes a cancer 'journey' easier or harder. [They] also need to speak out to their health team if they aren't sure what is going on; ask questions.

Research participant

Being your own advocate. Since discovering my diagnosis and lack of treatment, I am an advocate for myself. Make sure you speak up if something isn't right... but we need the right people to hear and listen to us, who have the power to make the change.

Research participant

System improvements

While most of the research focused on patient rights – leading to inherent inequities being highlighted – participants were also asked about system changes that were needed to improve their experiences. Respondents revealed two areas in need of the greatest system improvement: more information and better communication at the stage of diagnosis. Being recognised as a person at the centre of care and as an advisor to the health system were also highlighted as key improvements.

Here are some examples of the direct recommendations commonly expressed by research respondents.



Better communication by the hospital with regards to what resources are available. At no time have any resources relating to [the] navigation of my cancer experience (for example financial considerations, emotional or physical support) been even mentioned by anyone at my treating hospital, let alone offered. Similarly, I have not been told who to contact (patient navigator, receptionist, etc.) for help regarding various aspects of my care, nor has access to a nurse consultant been mentioned/offered. An information pack issued by the hospital at the first visit would be a valuable resource to patients and would save the hospital time answering questions from people to whom no information has been provided. I am not sure how widespread this problem [is] re: lack of information with regards to resources and appropriate support (whether it is specific to this large, very well renowned hospital or whether it is common to many hospitals).

Research participant



There are many areas that could be improved upon: individualising patients, their treatments and their lives is one. A person can expect or accept a terminal diagnosis without the need to reinforce it every minute of every day, and often that allows for a greater quality of life.

Research participant



Governments – I think more support needs to be provided from governments to big pharmaceutical companies to encourage them to SUPPORT and RESEARCH and DEVELOP treatments for RARE cancers. At the moment, it is only the ‘common’ cancers that are ‘winning’ the race and get the funding for research and development. I think governments should offer more incentives for big pharmaceutical companies to develop treatments for rare cancers. That ‘rare’ cancer may not be ‘rare’ in the future. It is an investment in somebody’s life, in many people’s lives. Cancer doesn’t just affect the patient.

Research participant

Patients strongly voiced that they would greatly value the availability of a 'navigator' for the course of their cancer journey.



Navigation support

A strong theme that emerged from the research was how the appointment of a 'dedicated navigator' to each patient would alleviate a lot of the logistical burdens and confusion associated with a cancer journey.

Some 95% of survey respondents agreed that having a dedicated person to help navigate a cancer journey would make things easier and more equitable.

The webinar discussion with Australian patient organisation representatives and not for profits touched on how some hospitals offer all cancer patients a navigator, regardless of cancer diagnosis, whereas others may only have specialist navigators available for the most common cancer patients. This type of navigation was said to only be available while the patient was an admitted patient.

Patients strongly voiced that they would greatly value the availability of a 'navigator' for the course of their cancer journey.





Recognising the rights of cancer patients

Recognising the rights of cancer patients

When trying to navigate a very complex cancer journey, patients can lose sight of their fundamental rights. Most patients and their families understand that health care teams are working to do their very best for them, yet often these efforts fall short because of the complexities that are entrenched within the health system.



Delivering truly person-centred care as a right for all Australian cancer patients

Defining patient rights - a human rights approach

In looking to outline a universal and undeniable set of rights that must be applied to cancer patients without distinction within Australia, we are setting a moral compass from which to navigate all aspects of the cancer journey. The outcome of embedding these rights then is an agreed quality standard of experience that all invested stakeholders must work in collaboration to achieve.

NOA and RCA maintain that human rights must be equally applied to all patients with cancer, regardless of the rarity or type of cancer they have, their ethnicity, rurality, social or economic situations.

The literature suggests taking a human rights based approach to health care involves identifying a set of benchmarks or expectations about the standards of service provision that we all can, and should, receive as standard.²⁸ Human rights principles that apply to patient care include the right to the highest attainable standard of health and focus attention on the right of socially excluded groups to be free from discrimination when receiving health care.²⁶

Australia already has a charter of rights that apply directly to patients, 'The Australian Charter of Healthcare Rights' (the Charter). It outlines seven themes: Access, Safety, Respect, Partnership, Information, Privacy and Give Feedback. These themes apply to everyone who is a recipient of healthcare and as such, the themes are very broad.

Cancer, as a collective, has had the greatest investment in research and development over the last decade, more than any other therapeutic area. The advances in science and genomic screening have meant that we have a better understanding of these diseases and can target them more specifically with treatment tailored to individual cancer presentations. The health system that patients are navigating today was not designed to manage the complexities of the new technologies and treatments that are emerging. The equity in the system is diminishing at a rapid rate and Australian cancer patients are finding it more difficult to have their needs met optimally. To consistently deliver an agreed standard of excellence in cancer care we need to develop a patient rights charter designed to meet their complex needs.

In addition to the lack of granularity of the domains, most cancer patients are unaware of its existence (some 70% of respondents to our survey had no knowledge of the Charter). Furthermore, there is no governance of the Charter or reporting mechanism for patients or their families to ensure that their rights are being upheld.

If we refer to this broad Charter, our research shows the fundamental rights of cancer patients are not being upheld with any continuity within our health system today, as articulated through the personal experiences that were shared.



The Australian Charter of Healthcare Rights (the Charter) defines the rights of Australian patients based on seven key themes³⁰ that aim to ensure all Australians have a right to:

- 1 Access healthcare services and treatment that meets their needs (ACCESS).
- 2 Receive safe and high-quality health care that meets national standards and be cared for in an environment that makes you feel safe (SAFETY).
- 3 Be treated as an individual, and with dignity and respect, and have your culture, identity, beliefs, and choices recognised and respected (RESPECT).
- 4 Ask questions and be involved in open and honest communication, make decisions with your healthcare provider, to the extent that you choose and are able, and include the people that you want in planning and decision-making (PARTNERSHIP).
- 5 Clear information about your condition, including the possible benefits and risks of different tests and treatments, so that you can give your informed consent. To receive information about services, waiting times and costs. To be given assistance, when you need it, to help you to understand and use health information. To access your health information and be told if something has gone wrong during your health care, how it happened, how it may affect you and what is being done to make care safe (INFORMATION).
- 6 Have your personal privacy respected and have information about you and your health kept secure and confidential (PRIVACY).
- 7 Provide feedback or make a complaint without it affecting the way you are treated. To have your concerns addressed in a transparent and timely way and to share your experience and participate to improve the quality of care and health services (GIVE FEEDBACK).

If we look to overseas examples, many countries define the rights of all patients, but a few go further and define the distinct rights of cancer patients.

One example from which a future 'Australian Charter of Patient Rights in Cancer Care' could draw is the European Code of Cancer Practice (the European Code). The European Code is a citizen and patient-centred accessible, widely disseminated statement of the core requirements for good clinical cancer practice that aims to improve outcomes for all of Europe's cancer patients.³¹ It was co produced by a team of cancer professionals, cancer patients and patient advocates,³² and has its origins in the European Cancer Patient's Bill of Rights, which was launched at the European Parliament on World Cancer Day 2014.

The European Code sets out a series of 10 key overarching rights (*Figure 7*), and in particular, signposts what people should expect from their health system in order for them to achieve the best possible outcomes.⁸ The rights highlight the importance of equal access to affordable and optimal cancer care, as well as good-quality information about an individual patient's disease and treatment and about the quality and outcomes of the cancer services they will use.⁸ Specialised multidisciplinary cancer care teams, shared decision making, research and innovation, a focus on quality of life, and the integration of supportive and palliative care within oncology are all emphasised.⁸ It is intended as an empowerment tool and a resource to ensure the best available care is delivered for European citizens and patients.^{8, 32}

FIGURE 7

Cancer patient rights as defined by the European Code of Cancer Practice

YOU HAVE THE RIGHT TO:



1. EQUAL ACCESS

Equal access to affordable and optimal cancer care, including the right to a second opinion.



2. INFORMATION

Information about your disease and treatment from your medical team and other reliable sources, including patient and professional organisations.



3. QUALITY, EXPERTISE AND OUTCOMES

Information about the quality and safety of care, the level of expertise and the outcomes achieved for your type of cancer in the centre where you are being treated.



4. SPECIALISED MULTIDISCIPLINARY CARE

Receive care from a specialised multidisciplinary team, ideally as part of a cancer care network.



5. SHARED DECISION-MAKING

Participate in shared decision-making with your healthcare team about all aspects of your treatment and care.



6. RESEARCH AND INNOVATION

Be informed about ongoing research relevant to you, and your ability and eligibility to participate in research.



7. QUALITY OF LIFE

Discuss with your healthcare team your priorities and preferences to achieve the best possible quality of life.



8. INTEGRATED SUPPORTIVE AND PALLIATIVE CARE

Receive optimal supportive and palliative care, as relevant, during any part of your cancer journey.



9. SURVIVORSHIP AND REHABILITATION

Receive and discuss with your care team a clear, managed and achievable plan for your survivorship and rehabilitation.



10. REINTEGRATION

Be fully reintegrated into society and protected from cancer-related stigma and discrimination, so that, in so far as is possible, you can return to a normal life.



www.europeancancer.org/code
info@europeancancer.org

Adapted from the European Cancer Organisation³²

The key themes relating to rights that our patient research revealed include equity, communication, information, continuity, access, respect, empathy, support, transparency, affordability, and an agreed quality standard of excellence. These are related to all parts of the cancer journey, from diagnosis to survivorship.

There is much to build on to develop an Australian cancer-specific Charter of Patient Rights, starting with the key themes that have been highlighted through the lived experience of today's cancer patients. To fully embed a such a Charter within our health system, accountability amongst stakeholders and governance to ensure the rights are being upheld would be required. This could be achieved by capturing the lived experience of cancer patients through ongoing monitoring and transparent public reporting. Further, a governance committee could be appointed that comprises of the full breadth of stakeholders across the sector, including patients, carers, and their families.

Recognising and upholding the rights of patients within the health system is fundamental in realising person centricity in cancer care. To consistently deliver an agreed standard of excellence in cancer care, a patient rights charter that addresses their specific and complex needs must be developed.

THE ASK —...

That the Australian Government and Cancer Australia develop an 'Australian Charter of Patient Rights in Cancer Care' as part of, or alongside, the Australian Cancer Plan.

The Charter should:

- *be informed by the experiences of Australians living with cancer today, to ensure it is both meaningful and relevant.*
- *be fully embedded within our health system, with formal mechanisms in place to ensure that rights are being upheld. This must involve:*
 - accountability among stakeholders, which could be achieved by capturing the lived experience of cancer patients through ongoing monitoring and transparent public reporting*
 - the appointment of a governance committee that consists of the full breadth of stakeholders across the sector, including patients, carers, and their families*
- *be considered when developing health policy and system reforms that are directly relevant to cancer patients.*



A woman with grey hair, wearing a blue and white patterned hospital gown, is sitting at a desk. She is giving a thumbs up gesture with her right hand. On the desk in front of her is a white computer mouse on a wooden mousepad and a portion of a white keyboard. A desk lamp with a copper-colored base and a white shade is lit, casting a warm glow. The background is slightly blurred, showing what appears to be a clinical or office setting. The overall mood is positive and hopeful.

Supporting the patient journey

**- maintaining continuity
and high standards in
cancer care**

Supporting the patient journey - maintaining continuity and high standards in cancer care

A navigator is a consistent point of contact available to the patient who becomes familiar with a patient's personal circumstances and cancer journey.

Ideally a navigator works closely with the patient and family to optimise the interactions with the health care system. Navigators help to ensure that patients receive appropriate information, psychosocial support, treatment opportunities and care when they need it. Ultimately the benefits of cancer navigation are in the provision of continuity of care across settings, ensuring that people don't become lost in the system and can stay on top of their cancer, various appointments, and understand what to do next to achieve the best outcomes while maintaining the best possible quality of life for them and their families.

Navigation in cancer care is not a new concept and different models have been adopted across the world. In Australia, cancer navigators are available for some common cancers and through specialist treatment centres like Peter MacCallum Cancer Centre in Melbourne, Victoria. Some major hospitals and private health insurance providers offer patients cancer navigators, and many patients with common cancers (such as breast, prostate, and lung) also have access to specialist cancer nurses. The definition of the role and access to navigators varies considerably: some may be specialist nurses while others may help with routine needs, such as appointment and transport coordination.

Currently, not all cancer patients who need a navigator can access one or know it is even an option. There is a growing consensus within the cancer community that as treatments and technologies become more expensive and complicated but more promising, a patient will need at least one person who is dedicated to help them navigate the course of their cancer experience, from the psycho-social impact of diagnosis, through to survivorship. Navigators are often appropriately qualified allied health professionals. For navigators to be high performing they need not be experts in all cancers but are focused on the person living with the disease, their immediate family members, and the added complexities that the disease brings to their life.

Anecdotally, navigation has profound benefits for people living with cancer, particularly those with complex cases or rare or less common cancers, where the journey is less chartered.

A strong theme that emerged from the research undertaken to inform this report was how the appointment of a 'dedicated navigator' to each patient would alleviate a lot of the logistical burdens and confusion associated with a cancer journey.

Some 95% of survey respondents agreed that having a dedicated person to help navigate a cancer journey would make things easier and more equitable. The need for patient navigators also arose independently in most webinars, submissions, and consultation with the RCA Patient Advisory Board.

Patients, their families, and carers want the ongoing help of a trusted and dedicated person who could assist them to navigate their experience and other aspects of their lives affected by cancer, such as financial insecurity and social supports. Navigation helps deliver person-centred care by supporting patients and families to be informed and taking the time to fully discuss the nuances of the options available to them before going back to their clinical team or doctor. This has been shown to enhance the patient's ability to take part confidently and meaningfully in partnered decision making with their doctors.



Having one (or two) central care coordinators that can inform me of what resources (covering all aspects of my health and day to day living) are available and how to access these resources would be exceptionally helpful (i.e. help navigating life with cancer).

Research participant



A strong theme that emerged from the research undertaken to inform this report was how the appointment of a 'dedicated navigator' to each patient would alleviate a lot of the logistical burdens and confusion associated with a cancer journey.

THE ASK —...

That the Australian Government commit to funding and supporting a more holistic patient navigator scheme so that every patient with complex, rare, or less common cancer has access to a dedicated point of contact throughout their experience.

Our research has highlighted the complexities of navigating a cancer journey, and revealed overwhelming support for the appointment of dedicated navigators to walk alongside patients down an often complicated and uncertain road. This is especially critical as the treatment pathway becomes more complex and cancers become 'rarer' in their categorisation and presentation.

A navigator need not be a health professional – they could be a suitably qualified person who sits outside of the hospital or allied health setting.



Recognising the roles of cancer patients



Shared decision making

The consultation RCA and NOA undertook with the cancer community this year has highlighted why it is important for patients and carers to be involved in partnered decision making when it comes to direct cancer care.

Realising patient centred health care in a tangible way – that is, a model that embraces shared decision-making – is clearly desired by both patients and their health care teams.

Shared decision-making means patient preferences can be taken together with clinical judgement and evidence to shape treatment and management plans that suit the individual person.

It is also clear that to have a truly person-centric health system, patients need to play a role in shaping the health system and health policy in a meaningful way. Without the integration of patient preferences and perspectives, valuable insights will be forever lost that could have benefitted future cancer patients. The lived experiences of patients should be captured as they become experts on what works and what needs to change. Furthermore, having patients actively involved in system improvement and health policy works to ensure that patient rights are upheld.

Our work suggests that the mechanism for patient empowerment is through consultation, involvement, and partnership with other stakeholders. Not all patients expressed the desire to participate actively in informing system improvement and shaping policy. Yet others are extremely passionate about advocacy and should be given the opportunity to contribute their knowledge.

The patient ‘voice’ or ‘perspective’ can be represented by patient organisations; part of formal patient advisory boards/focus groups; and heard through participation in formal agency and hospital committees.

In addition to these active roles, patients can also inform and help shape the health system indirectly through sharing their data to help benefit future patients living with cancer.

Data captured from the lived experience could include patient demographics, treatment, outcomes, adverse events, and granular quality of life measures.

The quote, “Experience arrives just after you need it” is true for today’s cancer patients, but their experience can help inform the treatment and outcomes of the patients who follow similar journeys in the future, provided the data is captured and utilised optimally.

Roles-shared decision making in direct cancer care

With growing emphasis on person-centred care, enhancing opportunities for partnered decision-making can better align clinical decisions with the person’s preferences for care.¹⁸ Empowered and informed patients can make a substantial contribution to ensure good practice and quality assurance.⁸ Partnered decision making affords people and their families the autonomy to make difficult decisions after receiving comprehensive information about medical facts and treatment options, and should be seen as an opportunity to collaborate in all aspects of clinical care.^{19,20} For shared decision making to be optimised, the relationship between patient and medical professional must be participatory, collaborative, open and respectful.²¹

The key objectives of partnered decision making between patients and their clinical team are achieved when:

1. People are fully informed of the treatment options and the trade-offs between risks and benefits.

2. A person’s values and preferences are incorporated into treatment decisions.^{22,23}

First, it is the ethical responsibility of clinicians to facilitate patient participation in decision-making because patients and their families are ultimately subjected to the outcomes of these decisions.²² Second, there is strong evidence that more engaged patients are more informed, are more likely to fully consider the risk/benefit trade-offs of the different treatment options, and are more satisfied with the clinical encounter.²² There is also evidence that more informed and involved patients have better psychosocial, and in some cases physical, outcomes.²⁴

Ensuring that all Australian cancer patients are supported to actively participate in decisions relating to their treatment and care is essential, especially for delivering person-centred care. For some people this will be easy, but for others there are many barriers that must be overcome.

Barriers to person-centred care and partnered decision-making

Social inequality in cancer can occur for many reasons including, but not limited to, a person's socioeconomic status (SES), education level, ethnicity, religious and cultural beliefs/practices, sex, disability, sexuality, geographical location, and even type of cancer.^{28, 39} Marked, persistent social inequalities occur across the cancer continuum and remain a crucial public health issue. These affect everyone, but hit the most disadvantaged individuals particularly hard.³⁹

Social inequalities can have a significant impact on a person's treatment journey and outcomes. They can also significantly impact the role a person plays in their own cancer care, including their capacity for taking part in partnered decision-making.

Geographic location - Regional versus metropolitan Australia

About one third of Australia's population resides in regional and remote areas. The geography of Australia, with its highly concentrated populations and large land mass, raises particular problems for both the government in providing, and the regional population in accessing, the full range of healthcare services.¹²

A noteworthy difference between Aboriginal and Torres Strait Islander and non-Indigenous Australians is the high proportion of Aboriginal and Torres Strait Islander people who live in regional and remote Australia.⁴² In a 2019 paper it was noted that the disparities in cancer care and outcomes stem from the disadvantaged social and economic conditions experienced by Aboriginal and Torres Strait Islander people and that understanding both the historic and present-day contexts for these groups is fundamental to addressing the gap in cancer care and outcomes.⁴²

A recent review by the Cancer Council found that Aboriginal and Torres Strait Islander people, as well as those living in the most disadvantaged areas, are 39% and 33% more likely to die from cancer, respectively. The disparity in cancer mortality among Aboriginal and Torres Strait Islander people has widened by 82 deaths per 100,000 since 1998.^{43, 44}

Cancer screening rates in rural Australia have improved in recent years; however, they remain poor among remote and Aboriginal and Torres Strait Islander communities, especially for cervical screening, despite these groups experiencing substantially higher cervical cancer incidence and mortality.⁴¹

Ideally, all cancer patients should have access to uniformly high standards of care with health professionals in the community, regardless of their location. However, living in regional and remote Australia is often found to be associated with social and economic disadvantages, leading to the lack of optimum outcomes for cancer patients.¹² Traveling to major cities for cancer care also imposes an economic burden on rural patients who often have to self-fund transportation and accommodation.²⁵

Culturally and linguistically diverse communities

People from culturally and linguistically diverse populations in multi-ethnic societies such as Australia, tend to have poorer outcomes for some cancer types when compared with the general population.⁴⁶ The causes of these inequalities in cancer outcomes are complex and often poorly understood. For example, the potential role of health literacy (*page 64*) on symptomatic presentation and diagnostic interval (the period between first primary care consultation and definitive diagnosis of cancer) by ethnicity is unknown.⁴⁶ Given the increasing need for partnered decision making and patient involvement in the diagnostic process, understanding the potential impact of the differences in health literacy may help redress inequalities in cancer outcomes.⁴⁶

Effective person-centred communication and a positive patient-provider relationship have been associated with improved treatment adherence, survival and health-related quality of life among cancer patients.²³ Patients from culturally and linguistically diverse groups are at higher risk than other patients of poor communication and a strained patient-provider relationship, which in turn can lead to delayed or non-standard care.²³ Incorporating culturally appropriate and individual patient preferences into cancer treatment planning through partnered decision making may improve adherence to treatment recommendations and reduce delays in care.²³

Socioeconomic status

For most cancer types, the trends of past decades have been more favourable for groups with higher socioeconomic status (SES), who have apparently benefited more from advances in the prevention and treatment of cancer.³⁹

People from higher SES groups are usually in a better position to benefit from health improvements as they have greater access to an array of resources, greater health literacy (see next section), and fewer financial barriers to health care. This suggests that redistributing specific risk factors for cancer is not enough to eliminate inequalities in cancer, and that policies should also tackle the underlying inequality in social and economic resources.³⁹

Education and health literacy

Health literacy refers to a set of cognitive and social skills required to understand, access and use information in ways that promote and maintain good health.⁴⁶ Education level directly affects health literacy; therefore, providing disease-matching health education is crucial for patients with lower education levels to enhance their health literacy.⁴⁸ Health literacy also directly affects partnered decision making. Health professionals, therefore, need to understand the health literacy levels of their patients and ensure more active assistance in achieving patient health literacy and partnered decision making.⁴⁸

In a 2016 study of the impact of health literacy on decision-making preferences conducted in the USA, patients with adequate health literacy were almost two times more likely than those with limited health literacy to prefer partnered decision making.¹⁸ The study concluded that patients with limited health literacy may have difficulty understanding medical information and lack the self-efficacy to be actively involved in their care. Due to the stigma of low health literacy, some patients may also experience feelings of shame, thereby not admitting their difficulties or seeking assistance when needed.¹⁸

The study also found that patients with limited health literacy may be unaware of their options to participate in decision-making, instead assuming that clinicians know the best course of action.¹⁸ However, particularly in cases where no clear solution exists, the engagement of patients and the consideration of their values is important. Clinicians should, therefore, clearly provide contextual information and available options, as improved communication can facilitate patients informed decision-making preferences. While some patients may ultimately prefer to leave decisions to their clinicians, they may want to be engaged in the process. This suggests that a broader definition of partnered decision making should be considered, and that physicians should recognise patients' expressed preferences regarding their decision-making role.¹⁸

Since health literacy is a dynamic between the individual's capabilities and the demands of a healthcare system, interventions are likely needed both to assist patients with limited health literacy to participate in decision-making, as well as to support clinicians in engaging with patients.¹⁸ Given the increasing need for partnered decision making and patient involvement in the diagnostic process, understanding the potential impact of ethnic differences in health literacy is important.⁴⁶

Childhood cancers

With reference to childhood cancers, the management of partnered decision making must be handled in a highly sensitive way and recognise the cognitive awareness appropriate for the age of the child. Parents, and their children when old enough, face the unenviable challenge of having to make difficult decisions about care, while weighing the quality-of-life impacts on everyday childhood activities. As with adult patients, parents carry an enormous burden of personal research and navigation, and so a child's cancer experience may be further impacted by their parent's own health literacy (see left).



Informing system improvement

There is significant value that can be derived from learning from the lived experience of cancer patients and applying these learnings to system and organisation improvements. Patients have first-hand experience of the intricacies of what works and what is lacking with regards to the care received throughout a cancer journey – both through various phases, and across in multiple settings. These settings include but are not limited to, hospitals, telehealth consults, MDT experiences, clinical trials, and clinical consult visits. The research undertaken to inform this report suggests that patient advisors as well as analysing data captured from the lived experience would be of great value in improving both the efficiencies of these systems and the quality of the experience for patients themselves.

Shaping policy

Patient engagement should occur more readily and holistically so that the patient voice is more prominent in shaping relevant health policy. For example, policy that directly affects patients should be shaped around patient needs and preferences to deliver a truly person-centred health system from conception onward.

While further work is needed to determine the best way to engage patients, there are many clear opportunities emerging. Several significant reforms and policy reviews are underway that present an important opportunity for extensive patient engagement:

- The review of the National Medicines Policy (2021)
- Development of The Australian Cancer Plan (2021-2023)
- The work flowing on from the five-year Strategic Agreement between Medicines Australia and the Federal Government (2022-2027)

Also of note is the House of Representatives Standing Committee on Health, Aged Care and Sport, which commenced an inquiry into approval processes for new drugs and novel medical technologies in Australia in August 2020. The Chair of the Committee, Mr Trent Zimmerman MP²⁵ said:

The Committee looks forward to receiving information on how Australia can continue to be well positioned to access new drugs and novel medical technologies, with a particular focus on access to the treatment of rare diseases and conditions where there is high and unmet clinical need.

Over 200 submissions were received by the inquiry from patients and patient organisations, clinical groups, and industry, and we look forward to the report of that inquiry being published and working with government on the next phase.

The recent emphasis on patient centricity throughout the sector suggests that the culture is starting to shift toward one that embraces patient engagement but there is more work to be done to ensure that the ‘patient voice and perspective’ is both tangible and prominent within the system.



THE ASK —...

That the Australian Government establish formal mechanisms that integrate Australian cancer patients as experts in our cancer system, and commit to listen and learn from their experiences.

This must include:

- *Empowering patients to partner as equals in decision making with clinical care teams – from diagnosis through to survivorship – through the provision of information, support, and continuity of care.*
- *Addressing systemic inequities that impact participation in shared decision making– such as a patient’s education, race, rurality, social and economic status.*
- *Such inequities should be identified at diagnosis, with supports put in place immediately to assist the patient through the next steps in their journey.*
- *Evaluating and improving mechanisms for patient engagement to give patients varied and more prominent opportunities to shape system reforms and health policy changes.*
- *The meticulous capture of high-quality data on the lived experience of today’s cancer patients – including preferences, experiences, and outcomes. This should be utilised to its full extent to help the patients of tomorrow live longer and better lives.*
- *Identifying and removing historical barriers to patient engagement from health systems that were not inherently designed to be person-centred. For example, the inability for manufacturers to provide information about emerging therapies and data with patients.*

Sarah's story

I discovered I had gastrointestinal stromal tumours [GIST] when I was 18. At the time I had over 50 seedings of tumours in my small bowel. They told me I had a prognosis of 12 months, with no treatment options and no cure. They sent me home and said I should sit back and wait for medical research to provide me with some options. I was completely shocked and felt incredibly fearful, confused and alone. That was the beginning of my race against time.

For the next 15 years we managed to hold the progression of the disease through clinical trials, surgery, and emerging treatments. I wasn't eligible for any of the support programs at the time, so it was extremely isolating. It wasn't until 20 years after my diagnosis that I actually met another person face to face with the same disease.

A few years later at CanForum I met a young woman in her 20s who had just been diagnosed with GIST. She was overwhelmed and terrified. It took me straight back to how I felt when I was first diagnosed at 18; I could see her grappling with the same stress and uncertainty. I ended up meeting six other GIST patients that day who were all at the beginning of their journeys too. For me it was a pivotal moment – I wanted to support them in any way I could and make sure they didn't feel the same helplessness and isolation that I had.

The first thing I did after the forum was make medical folders for each of them, to help them manage their appointments and feel a little bit more empowered within the medical system. There was a place for different paperwork, and suggested questions to ask their oncologists. It was something tangible and practical I could do to help them feel a little bit more confident and less isolated. We stayed connected online where I ended up building personal connections with more and more patients. I think I ended up sending around 50 folders out to new patients across the country.

My advocacy work really started from there. I was growing increasingly frustrated at the challenges and inequities that rare cancer patients faced regarding support and access to affordable treatment. It had been 10 years since the GIST community had a treatment approved. There are effective treatments out there, but because of the nature of them being rare, it's nearly impossible to get them funded.

I had to crowdfund \$100,000 for my next treatment and would need to worry about doing this every time my disease progressed. I decided I had to try and change the system so that my family and other GIST families didn't have to sit around their dining tables in despair, worrying how they could possibly raise this huge amount of money year after year just to stay alive.

I'm a primary school teacher, so I'm much more comfortable standing in front of a kindergarten class than trying to lobby the government for treatments. I had absolutely no idea how the medical system worked beyond my experience as a patient, and no idea how the drug approval system worked. But I had my experience as a patient and sheer determination to improve access to treatments and to make life easier for newly diagnosed patients.

I joined the Rare Cancers Australia (RCA) GIST Support Group, where we really started to unite as a group behind these issues. Our next treatment failed to make it onto the PBS again; a disappointment we'd experienced a few times now in the last 10 years. At that point I leaned on the support and guidance of RCA to come up with a plan to finally get this treatment funded.

First, I reached out to all the patients I had met over the last eight years and asked them if they'd be comfortable writing a submission to the PBAC for the approval of our treatment, Qinlock. Within 72 hours I had a significant number of patients pour their heart out; sharing their GIST story, their fear of running out of treatment, and the pain of living with a rare cancer with limited treatment options. Collectively we had about 10,000 words and 26 patient submissions to put to the Pharmaceutical Benefits Advisory Committee (PBAC).

Next, we asked patients, their families and friends to write to Members of Parliament (MPs) from all parties at all levels – whoever would listen. We met with over 20 MPs to discuss the inequities we face, and I managed to get a meeting with the Shadow Health Minister. Then one small media interview led to a national interview, and the momentum just grew from there.

We discovered that together we could do so much, and with a united plan our voices could be heard. Even though we were all individuals with a rare cancer, collectively we were a force to be reckoned with. This is such a contrast to how most people initially feel with a rare cancer. You start out feeling so isolated, helpless and confused, but then when you come together you feel supported and united; you are no longer alone.



“

The patient voice matters... they can and should be heard, and they should keep talking until someone listens.

With the backing and guidance of RCA we were able to advocate for change. The drug that we were told would cost \$10,000 - \$15,000 per month indefinitely, is now listed on the PBS and costs \$41.05 per month. There are six patients in Australia who are currently taking it, so they got to move to their next treatment rather than to palliative care. This isn't something that has an impact in a generation's time; it had an impact on people's lives the very next day. These people are not well enough to fight, they are in absolute survival mode and need all the help and support they can get. Knowing it made a difference to their lives instantly made all the hard work worthwhile.

I am determined to keep fighting until there is equal access to treatments for all rare cancer patients. So we don't have to fundraise and stress about whether we can pay for our next treatment. So if you're diagnosed with a rare cancer there doesn't have to be a discussion about if you can afford the treatment; it's a discussion about the side effects of the treatment. So patients can focus on their own health and not be fearful of their finances while they're dealing with a new disease.

Something else very important to me is supporting new GIST patients so they understand more about the medical system, including clinical trials and medical research. I try to help them understand that although they may feel desperately helpless at first, they are not powerless in the system. They have a voice, they can and should be heard, and they should keep talking until someone listens. Eventually people will listen, and your sense of control and quality of care will improve because you can be more of an equal partner in the conversation. You can take an active role rather than a passive role in your own health, and in your own experience with the disease.

On a personal level, once I realised I had a voice in meetings with my oncologists and that I was being heard, I felt so much more empowered and in control of my disease. That sense of control helped me fight the disease physically, and it's had a profound impact on my ability to cope with the disease emotionally. As a patient, being at the centre of decision making has been essential and empowering. It has had a profoundly positive impact on living with a rare cancer for 25 years.

If this experience has taught me anything, it's that with determination, support and a clear sense of purpose, patients can unite to affect real change at all levels. I am one person with one voice, who didn't know anything about the medical system when I was first diagnosed. This month, I presented at a Global GIST Conference to patients from over 65 countries about our Australian success story of Qinlock's funding approval. The patient voice matters.

Conclusion

In defining the rights and consequent roles of Australian cancer patients, questions emerge around the moral, ethical and societal obligations owed to them (the 'why'), and how these obligations should be met (the 'what' and 'how').

Despite the best intentions of all those who work within the health system, it has been made abundantly clear from our consultation that patients and their families are being failed in significant areas.

For too long, 'patient-centricity' and 'person centred care' have merely been notional concepts that have not been reflected in the reality of patients' lived experience. By continually hiding behind these terms and the illusion of action they provide, we will continue to overlook the human beings behind the label of 'patients'; the very people our health system exists to serve.

Now is the time to act; to face these moral and ethical questions and start answering them. To decide what cancer patients, deserve from our health system; from all of us as a society. What role they should – and are entitled to – take in their own care. And what needs to change to start truly valuing their lived experience in a real and tangible way.

We owe it to each Australian living with cancer to genuinely value, respect and learn from their experience. We must listen to what they have learned, and meticulously capture data around their inimitable lived experience. We must make the commitment to actively capture and learn from patients – through real world data, patient reported outcomes, and experiences leading to real world evidence – to not only honour what they have endured, but to benefit those will have cancer in the future.

We must set a new standard through a Charter for the Rights of Patients Living with Cancer and integrate this into the health system. We must support patients with continuity, information, and communication through a dedicated point of contact – a navigator who can walk the journey with them. We must elevate the roles of patients and recognise their expertise in shaping system improvements in areas like clinical trials, hospital clinics, and clinical consults. And we must provide a variety of mechanisms to engage with patients in shaping health policy.

We owe it to the cancer patients of today and tomorrow to act now. Their lives depend on it.



We owe it to the cancer patients of today and tomorrow to act now. Their lives depend on it.

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If you would like to speak with us about joining NOA or to discuss the content of the report or the proposed *Australian Cancer Futures Framework*, please contact:

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