Cancer, COVID-19 + You.

Experiences of cancer care during the pandemic.

2022 Report

Cancer Council
Victoria

Cover photo: Shireen, diagnosed with ovarian cancer, regional Victoria.

Cancer Council Victoria. Cancer, COVID-19 and You - 2022 Report. (2022)

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Thank you to the people affected by cancer who completed the survey and participated in interviews. We also are grateful for our Advisory Group, our Clinical Network and Community Advisory Network who provided input into this research.

Acknowledgement of Country
Cancer Council Victoria acknowledges the Traditional Custodians of the land and water ways on which we work and live. We pay our respects to the Elders past and present and those emerging, and extend that respect to all other Aboriginal and Torres Strait Islander Peoples.

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About Cancer Council Victoria

Cancer Council Victoria (Cancer Council) is a non-profit cancer organisation dedicated to world-leading cancer research, prevention, and support. We play a leading role in reducing the impact of all cancers on all people. Our mission is to prevent cancer, empower people and save lives.

Established in 1936, we are independent of government and rely on the generous support from the community to carry out our work. Our singularity of purpose, a cancer-free future, drives us and will always be balanced by our deep connection with the experience of people with cancer and their families.

Message from our CEO

Cancer Council Victoria's mission to 'empower people' focuses our work and by listening to the lived experiences of people affected by cancer, we place them at the centre of everything we do. We help all Victorians with all types of cancers to navigate the healthcare system and empower them in their decision making through evidence-based and trusted information and support. As cancer affects the entire family and network of carers, we are also here for those who play a vital role in providing care and support to the person with the disease.

Over the last three years, we responded to around 30,000 enquiries through our 13 11 20 information and support service, staffed by qualified cancer nurses. Hearing directly from a wide variety of people and health professionals from across the state allowed us to identify and respond to unmet needs. With the support of the Victorian Government, we increased resourcing on our support line as well as our emotional and financial counselling services. Much progress has been made to date, but more work needs to be done.

This report captures the lived experiences of people affected by cancer during the pandemic and we're grateful to everyone who contributed to this work. While COVID-19 undoubtably presented unique challenges, it also presented opportunities to improve the way we supported cancer patients, their families, and carers.

As a result, we are well placed to ensure our health system delivers for people with cancer and supports them navigating a complex and ever-changing healthcare system. A shared approach to planning not only makes sense, but there is also an expectation from the public that we do so. The effectiveness of cross-sector collaboration was evident through the Victorian COVID-19 Cancer Network (VCCN) that was set up to manage cancer care during the pandemic. However, there were key issues that we could not influence, such as the distressing impact of blanket visitor restrictions.

We stand ready to continue to collaborate with government, health care services, people with a lived experience, and other cancer support agencies to address the challenges identified in this report and make cancer care better for everyone affected by cancer.

Executive summary

Cancer is hard, and COVID-19 made it even harder. The disruption caused by the global pandemic presented unique challenges for people affected by cancer and the healthcare sector. It required many changes to the way cancer care was delivered, making it even harder for people to navigate treatment, support, finances, and physical and emotional well-being.

Between May and August 2022, we heard from more than 300 Victorians affected by cancer to understand how the pandemic affected their cancer care and experience. Results highlighted the impact of disruptions and changes to medical appointments, telehealth, cancer treatment, screening services, supportive care, and palliative care.

The pandemic has exposed and deepened existing gaps in cancer care, particularly for those already experiencing disadvantage. Regional Victorians travelling for treatment as well as migrants and refugees who struggled to access interpreters were particularly at a disadvantage and without the support they needed.

Hospital visitor restrictions meant people with cancer were often alone during distressing and stressful times. Classifying carers as 'visitors' and restricting their access, greatly undervalued the important role that they play in providing care and support. It caused communication issues for people with cognitive, verbal or language barriers and most distressing was the experiences of those at the end of life, which will leave a legacy of trauma for years to come.

Lockdowns and fears of contracting COVID-19 exacerbated anxiety and isolation. Increased demand for emotional and mental health support services, combined with a shortage of healthcare practitioners and backlog of appointments, meant wait times blew out to weeks and even months.

With increased telehealth and less face-to-face contact with health professionals during treatment and care, information was harder to come by and it became more difficult for people to navigate to support. The economic impact of the pandemic added further financial pressures to families affected by cancer who were unable to work or needed to work at reduced capacity.

The Victorian Government has played a critical leadership role during the COVID-19 pandemic. As we emerge from this phase of the crisis, we now look to the government to lead necessary reforms and invest in the sector to implement the recommendations for improvement based on the learnings in this report.

We're seeking investment in emotional and mental health supports and to upskill health professionals to build capacity in the sector. People need improved mental health screening, navigation, and support, not just at the beginning but right throughout their cancer experience and the vital role of carers needs to be acknowledged and embedded into future disaster planning.

Improving access to supportive care needs to be approached through initiatives that reach both health professionals and people affected by cancer. Investment is needed in public campaigns so that people are made aware that cancer information and support is available to all Victorians and carers with all types of cancers regardless of where they live or where they are treated. With barriers to equitable access to supportive care impacting on people's ability to get the support they need, we cannot rely on self-referral alone. Cancer support referrals from health professionals need to be embedded into standard care throughout the cancer experience to help people as their needs change.

COVID-19 has fundamentally changed the cancer experience in Victoria. Cancer Council is ready to work with the Victorian Government, health services and cancer organisations to shape cancer support services to meet current and future demand.

Working together to improve cancer outcomes

Introduction

A cancer diagnosis can be scary, overwhelming, and complex and is the start of a long and complicated journey through the health care system. People need to take in complex health information and make quick decisions about treatment, whilst their emotions are heightened. Cancer affects not only the individual's health but can also significantly affect their family's emotional and financial wellbeing.

While most cancer treatments were deemed essential during the COVID-19 pandemic, some screening and in particular cancer support services were deprioritised as staff were redeployed to aid pandemic efforts. The rapid implementation of public health measures, hospital visitor restriction policies, vaccinations, alternative ways of delivering care, the use of telehealth, and lockdowns that restricted movement, have greatly affected the cancer experience.

The pandemic also affected incidence of cancer screening and assessment, resulting in a growing burden of undiagnosed cancers across the globe. In 2020, the Victorian Cancer Registry recorded 2,420 fewer individual cancer diagnoses in Victoria, a decline of 7 per cent.(1) New data in 2021 shows that diagnoses declined again by 4.3%, or 1,485 fewer individual diagnoses. In total it is estimated that there were more than 3,800 fewer diagnoses than expected over 2020 and 2021.(2)

These undiagnosed cancers may mean people will present very late or with more complex conditions that could make their care more complicated or result in poorer outcomes. Combined with increasing diagnoses, the need for supportive care in the years ahead will be greater than ever.

In this report we feature the voices of people with cancer, and carers, who received treatment or provided care during this time. Many people wanted to tell us their stories, and we use these to humanise the impact of the public health response and to present tangible solutions so that cancer care can be better for everyone.

Cancer in Victoria

Cancer is the leading cause of disease burden in Victoria, with

36,974

Victorians diagnosed in 2021 and 11,581 deaths.

That's an average of

101 **new diagnoses every day,**

or 1 new cancer every 14 minutes.

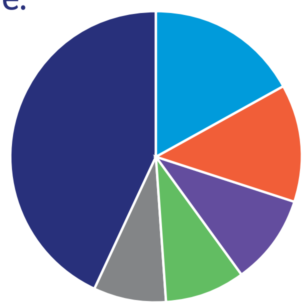
Cancer diagnoses in Victoria are projected to increase 43% over the next 15 years.

By 2036, the number of new cancer diagnoses is expected to be more than

51,000

The five most common cancers diagnosed in Victoria in 2021 were:

prostate (17%)
breast (13%)
bowel (10%)
lung (9%)
melanoma (8%)



Together, they account for 56% of all new cancers.

Victorian Cancer Registry (2022), Cancer in Victoria 2021, Cancer Council Victoria.

COVID-19 in Victoria

By the end of 2022, there had been more than

2.8 million

COVID-19 cases in Victoria.(3)

98%

of Victorians aged 16 and above received a first dose of the COVID-19 vaccine.(4)

Melbourne had **262 days** of stay-at-home orders beginning April 2020 to October 2021.(5)

During the pandemic, our **13 11 20** cancer information and support service responded to around

30,000

enquiries from people affected by cancer.

In 2021 at the peak of the Victorian lockdown, **50% of requests were related to COVID-19 and length of calls increased by 19%.**

30% of enquiries identified **psychological and emotional support needs** as the main reason for getting in touch in 2021.

Priorities for action

	Impacts of COVID-19	Recommendations
1	Treatment and care were impacted	Bolster disaster preparedness to reduce future impact to treatment and care
2	Emotional and mental health supports were lacking	Increase emotional and mental health supports
3	Navigating the cancer system was hard	Boost public awareness of navigation support
4	Visitor restrictions saw people go through difficult times alone	Elevate the role of carers in cancer care
5	The pandemic compounded financial distress	Ease the financial burden

	Impacts of COVID-19	Recommendations
6	Telehealth is efficient, but isn’t always suitable	Ensure telehealth is fit for purpose
7	Cancer information and communication was inadequate	Bridge the cancer information gap
8	Most people unaware of clinical trials	Invest in clinical trials education
9	Regional Victorians struggled with costs and navigation	Improve travel support for regional Victorians
10	Migrants and refugees lacked culturally responsive care	Develop language and mental health supports for migrants and refugees

About this research

To deliver this research, Cancer Council has worked with The Daffodil Centre, a joint venture between Cancer Council New South Wales and the University of Sydney and a leading research centre on cancer control and policy.

The aim of this research was to capture the experiences of people affected by cancer during the COVID-19 pandemic in relation to their cancer treatment and support services.

The two-part research project involved a state-wide cross-sectional survey, followed by qualitative interviews with regional Victorians and migrants and refugees living in Victoria.

We aimed to understand how Victoria's COVID-19 response affected:

- cancer care,
- access to treatment and support,
- access to formal emotional and mental health support,
- the cost of cancer, and
- access to clinical trials.

About the people we heard from

272 surveys

43 interviews with **28** regional Victorians and **15** migrants and refugees

272 Victorians were surveyed between May and June 2022 and an additional 43 people were interviewed between July and August 2022.

In this report, we reflect the cancer experience of people who:

- were diagnosed with cancer, received treatment, or follow-up care in a Victorian health service, or
- cared for someone with cancer.

We wanted to hear from a diverse range of Victorians and were able to give a voice to:

- 221 people with cancer and 51 carers through online and hard copy surveys.
- 28 regional Victorians (20 people with cancer and 8 carers) through semi-structured interviews by video conference.
- 15 migrants and refugees from Arabic, Cantonese, Karen, Portuguese, and Vietnamese communities via semi-structured interviews by video conference (8 people with cancer, 6 carers and 1 person with cancer who was also a carer).

People we spoke to had a mean age of 61 years, identified as predominately female (78%), and were mostly Australian born (77.9%). Our research findings are likely to be more representative of the cancer experience of older people living with some cancer types who were born in Australia.

How we recruited people

We sought to reflect a diverse range of cancer experiences from across Victoria by promoting the opportunity through Cancer Council networks, social media, community groups, interpreters, and bicultural workers.

We actively sought recruitment from underserved groups by partnering with cohealth and Bendigo Community Health Service, who hold strong relationships with Victorian migrants, refugees, regional residents, and people living in areas of significant socioeconomic disadvantage.

Recognising that some people have low levels of digital literacy, we distributed hard copies of the survey. We actively promoted interviews to people living in regional areas, and people who spoke a language other than English.

Research limitations

Despite best efforts, we were unable to recruit a large enough sample size for the survey results to be representative of all Victorians affected by cancer. Men were underrepresented, making up only 21% of the sample, while people with breast cancer were overrepresented (44%) compared to people with other cancer types. Young adults were also underrepresented.

We did not actively recruit Aboriginal and/or Torres Strait Islander people for the current project, rather we are supporting the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) as it undertakes research into the cancer experience.

The survey length may have contributed to the lower sample size. The survey did not specifically ask about pathways to diagnosis and experiences of end-of-life care, and these are areas warranting further exploration.

Through interviews, a wide variety of cultural perspectives are reflected in the sample, and because of this diversity, the interviews may not have allowed for thematic saturation to be reached. We see a need for further engagement with migrant and refugee groups to better support health service planning.

A note on terminology

Throughout this report we use the following terms.

- *Telehealth* - refers to a consultation with a health professional by phone or video call.(6)
- *Plain language* - is clear, concise, well-organised and straightforward writing that uses only as many words as are necessary.(7)
- *Supportive care* - in cancer refers to the physical, psychological, social, information and spiritual needs of those affected by cancer.(8)
- *Migrants and refugees* - is an all-encompassing term to describe people who were born outside of Australia, people who speak a language other than English at home, culturally and linguistically diverse people.
- *Regional Victorians* - is an all-encompassing term used throughout this report to describe people from rural and regional areas in Victoria, classified using the Accessibility/Remoteness Index of Australia (ARIA+).(9)

Summary of findings

1. Treatment and care were impacted

People with cancer (22.6%) and carers (21.6%) reported that the pandemic and associated restrictions continue to affect their cancer care. Most people reported changes to health and support appointments such as psychology, physiotherapy and social work being delayed, rescheduled, cancelled, or changed to telehealth (64%). More than a quarter (26%) of people with cancer surveyed told us that their cancer treatment was delayed, rescheduled, or cancelled.

2. Emotional and mental health supports were lacking

A substantial proportion of people with cancer (26%) and carers (20%) said they did not have enough formal emotional and mental health support. People told us that treatment teams often didn't tell them that support was available, or did not offer referrals for psychological support, especially for caregivers.

3. Navigating the cancer system was hard

People were often left feeling lost within the cancer care system and found it difficult to navigate information, treatment and support. Just under half (44%) of people with cancer and 63% of carers, reported they were not given enough information about support services.

4. Visitor restrictions saw people go through difficult times alone

Visitor restrictions profoundly affected the cancer experience, with people receiving life-changing information, treatment, and palliative care, without the support of family and friends. We heard that people were denied their wish to be with their support people of choice as they reached the end of their life.

5. The pandemic compounded financial distress

COVID-19 placed financial stress on many Australians who were already doing it tough. Out-of-pocket costs were a significant problem at a time when people were already struggling. Almost half (47%) said their out-of-pocket costs were different to what they expected, with most people reporting higher costs. People did not know what financial and legal supports were available.

6. Telehealth is efficient, but isn't always suitable

More than half (59%) of people with cancer surveyed said medical appointments had been conducted via telehealth. Many people (54% of people with cancer and 43% of carers) identified positive aspects of receiving care via telehealth, especially when it came to its convenience. However telehealth was not always suitable with some people concerned about missing a physical examination and others experiencing difficulties building rapport with health professionals.

7. Cancer information and communication was inadequate

People needed better health information from cancer experts to understand their cancer, treatment, and care, and available services and supports. Some migrants and refugees reported they wanted more information about cancer, treatment, and care.

8. Most people unaware of clinical trials

Most people with cancer and carers, were not involved with clinical trials during their cancer care. Almost all (99%) of these respondents reported they had not been made aware by their healthcare team of any clinical trials that might be relevant to them.

9. Regional Victorians struggled with costs and navigation

Regional Victorians reported costs when travelling to treatment and some were not aware of financial help. Care was not coordinated and they felt lost in the system. Visitor restrictions meant carers often had to wait in the car, or outside the hospital or not attend at all.

10. Migrants and refugees lacked culturally responsive care

The pandemic exacerbated existing problems for migrants and refugees. Language, cultural barriers and stigma deterred some migrants and refugees from receiving mental health support. Certified interpreters were in short supply and visitor restrictions meant that people could not attend appointments to provide translation for the person that they supported.

Recommendations

Bolster disaster preparedness to reduce future impact to treatment and care

1. Now is the time to bring together government, cancer organisations, health services and people with lived experiences to ensure we draw on the learnings from the past few years and improve the system for all those who need it.

Increase emotional and mental health supports

2. Cancer Council is seeking an investment of $1 million over four years from the Victorian Government to:
    - fund an integrated Nurse Counsellor telephone service to deliver up to 2,500 counselling sessions a year for Victorians affected by cancer.
    - fund four scholarships for health professionals in rural and regional Victoria, including nurses with a primary role in supporting people with cancer, to upskill them in mental health support and build workforce capacity to address unmet needs.
3. Increase mental health assessment and screening of people with cancer and their carers over several key periods during the cancer experience. Hospitals, health services and professionals can be supported to do this by automatically referring people to Cancer Council's 13 11 20 information and support line.

Boost public awareness of navigation support

4. With expert knowledge of the cancer sector from experienced cancer nurses, as well as access to a directory of more than 450 support services across the state, Cancer Council is well-placed to provide navigation support to all people affected by all cancers. We are seeking an investment of $4 million over 4 years (2023-27) from the Victorian Government for a public education campaign to improve awareness of our 13 11 20 cancer information and support services.

Elevate the role of carers in cancer care

5. Carers provide vital support to people with cancer, and in the future there needs to be continued involvement of carers, even in the event of visitor restrictions. Hospitals and health care services must:
    - improve communication about restrictions with visitors and meet their differing levels of health literacy, language, and accessibility needs.
    - ensure that people affected by cancer get the logistical, emotional and communication support that they need.
    - recognise the fundamental importance of visitors during end-of life-care so that people with cancer can be accompanied by their visitors of choice.
    - make exceptions to visitor restrictions more transparent, so that the choices of the person with cancer are respected and their family and friends get fair and equitable access to the person they care for.

Ease the financial burden

6. Cancer Council recommends action by government and health services to reduce financial distress, by:
    - improving transparency of costs including out-of-pocket costs, differences between public and private pathways and the financial impact of different treatment options.
    - enabling people to be informed and find the information needed. The health system can help prevent financial distress by embedding early and routine assessment and referral to 13 11 20.
    - making improvements to income support systems to include clearer eligibility criteria. There is opportunity to improve awareness and understanding of these supports, particularly for migrants, refugees, and people from regional areas.

Ensure telehealth is fit for purpose

7. To maximise benefits of telehealth, patient-centred guidelines are needed to support equitable access to high-quality telehealth across all Victorian health services. Cultural change within health services is required to ensure people are empowered to have a say in how they get healthcare, whether it's in-person appointments or via telehealth.

Bridge the cancer information gap

8. The Victorian Government has a pivotal role to play in improving access to cancer information by establishing a communication skills standard for clinicians and investing in cancer organisations and health services to deliver:
    - plain language, health literacy, and communications skills training for health care professionals so that they can explain complex information simply.
    - cancer information in bi-lingual and plain language using a co-design approach with multicultural organisations and communities.

Invest in clinical trials education

9. Investment in information and education is needed to improve clinician and patient awareness of clinical trials , including in regional areas, and encourage clinicians to discuss clinical trials with patients as a standard part of their care.

Improve travel support for regional Victorians

10. Urgently review the Victorian Patient Transport Assistance Scheme (VPTAS), so that regional Victorians can get upfront reimbursement and can access the scheme if they need to travel for clinical trials.

11. Investment is needed for an awareness campaign so that VPTAS is more accessible and transparent, and so that those who need it, know about it.

Develop language and mental health supports for migrants and refugees

12. Investment in partnerships between the cancer sector and multicultural organisations is needed to develop culturally responsive, targeted and sustainable mental health support.

13. Expand the capacity and capability of the interpreter workforce so that a certified , professionally trained interpreter is available for those who need one.

What people told us

1. Treatment and care were impacted

People with cancer (22.6%) and carers (21.6%) reported that the pandemic, and associated restrictions, negatively affected their cancer care.

About 40% of people surveyed said that they, or someone in their household, had tested positive with COVID-19. More than half of people with cancer said that their COVID-19 infection affected their cancer care, and more than a quarter of carers said it affected their ability to give care.

Several Victorians from regional areas believed that cancer treatment and support services may have been delivered differently if they were diagnosed with cancer prior to the pandemic.

Fear of getting COVID-19

People affected by cancer lived in constant fear of getting a COVID-19 infection.

Just under half of people with cancer worried that they may be immunocompromised and more susceptible to infection due to their cancer diagnosis. Carers faced an additional burden, with nearly 70% worried about this risk, and about infecting the person they cared for. People told us that they changed their actions and behaviours to ensure they were keeping themselves, and others, as safe as possible.

> ***"When you hear you have a disease and the disease is called cancer, which until not too long ago was a death sentence, [but now means] you're immunocompromised and then there's a virus out there that is killing people by the thousands…you just feel very vulnerable…I was here [at home] most of the time by myself and I didn't want to go out. I didn't want to see anyone. I was terrified".***
>
> Migrant or refugee with cancer.

Changes to treatment and care

Most people with cancer reported changes to cancer care and services, including changes to delivery of medical appointments via telehealth (59%). This disruption was even greater for other health and support appointments such as psychology, physiotherapy, and social work (64%).

35% of people with cancer reported being worried that their treatment might be delayed, and that these delays would lead to their cancer spreading. More than a quarter (26%) of people with cancer did experience a change to their cancer care (treatment and surgical procedures) however cancellations were uncommon (2%).

> ***"There's a lot of support services for people with cancer but some of the programs didn't run because of COVID. So I think in that way, I was probably disadvantaged rather than if I'd got [cancer] before COVID. My [local cancer wellness centre] offered a range of programs, like there's massage, there's groups and whether it was postponed or whether I didn't feel comfortable going to group sessions during COVID, that was part and parcel."***
>
> Person with cancer from regional Victoria.

People with cancer reported major delays in receiving pathology results or other test results, resulting in people repeating tests or delaying treatment.

Recommendations

Bolster disaster preparedness to reduce future impact to treatment and care

Now is the time to bring together government, cancer organisations, health services and people with lived experiences to ensure we draw on the learnings from the past few years and improve the system for all those who need it.

2. Emotional and mental health supports were lacking

During the pandemic, people with cancer reported emotional distress, with the highest distress levels reported during lockdowns.
Most people with cancer reported moderate to severe emotional distress (90% during lockdowns, and 70% prior to completing the survey).

A substantial proportion of people with cancer (26%) and carers (20%) reported that they did not currently have enough emotional and mental health support. Of those people, 25% did not know what formal emotional and mental health support (such as psychology, counselling, and support groups) was available to them.

While most people interviewed were aware of the formal emotional and mental health support that was available to them, many told us that they had not used these services. They were uncertain about the practical benefits and told us that the waitlists were too long.

> ***"I have sourced my own 12 step program; very difficult to have regional access to mental health care."***
>
> Person with cancer.

Feelings of loneliness and isolation

In December 2021, Mental Health Victoria reported that Victoria was experiencing a mental health crisis due to the pandemic.(10) This crisis stemmed from the necessary physical isolation and change in routine.

People told us that they experienced severe and continuous feelings of loneliness and isolation, as a result of isolating to reduce their chances of getting COVID-19.

Mandated lockdowns made it difficult for people to get psychological support. One person said that pre-pandemic, they were able to talk to psychologists, and that its closure during lockdown greatly affected their mental health.

> ***"I think if not [in] lockdown, I can get services [formal psychological support] anytime. The [local counselling centre], because of the lockdown, was closed. I can't access the psychologist in there. At the beginning, when I first got diagnosed, they gave me a lot of support, but once lockdown, closed everything, I have no one to go to. I feel like I have no one to talk to. I go to chemo and then when I came home, I put myself [took some] medication to put myself to sleep, and then it might be 15 hours sleep, because I can't eat, I can't swallow. Yeah, so I just put myself to sleep, that's all. The only thing I can help myself is put myself to sleep, take the pill."***
>
> Person with cancer.

Carers need targeted support

Carers recommended that health professionals automatically refer to psychological services and follow up on their mental health. This would help them cope with competing priorities, which they told us generated emotional and mental distress. Several carers recommended a specific support line for carers to have an outlet to discuss their stressors and seek support.

> ***"From a carer's perspective, I would need more mental support just like I would like to have someone to talk to me because taking care of someone with cancer, the patient may become very ill-tempered, and during the emotional outbreak in the patient, I would be the one receiving all the negative emotions from the patient and that will make me feel upset or down for the whole day. And if someone can talk me through that, then that would be very good."***
>
> Carer.

Limited mental health supports for regional Victorians

When we interviewed regional Victorians, we found that most people with cancer needed more support immediately after treatment than at any other stage of their cancer journey. Some also noted that they could not take part in local support groups because of pandemic restrictions. They also told us that in-person psychological, or counselling services were not always available in their area.

> ***"I didn't feel I needed anything [formal emotional or mental support] during treatment, but at the end of treatment, something about a month, two months later, it [emotional distress] suddenly hits you and that's when I was talking to one of the doctors and they said, "Well, why don't we refer you over to somebody [psychological counselling service]?"***
>
> Person with cancer.

Migrants and refugees need emotional and mental health support

Our research showed that migrants and refugees faced key challenges in getting formal mental health support. Culturally responsive support should be developed to address migrants' and refugees' understanding of mental health. This will allow health professionals to take a culturally sensitive approach when addressing emotional and mental health.

Further information and recommendations can be found on page 34 under 'Migrants and refugees lacked culturally responsive care'.

Suggestions for improvement from patients and carers

We asked people what solutions they thought could improve the use of formal mental health supports. Across all parts of our research, people reflected on the importance of automatic referrals to psychological services, or mental health checks as part of routine care. One person noted that surveys/questionnaires were not an appropriate way of assessing wellbeing.

> ***"Surveys were sent from hospital that asked about wellbeing on a 1 to 10 scale which just didn't get to the heart of how hard it was and how much we were struggling. I also thought the nurses brushed off our concerns."***
>
> Carer.

Recommendations

Increase emotional and mental health supports

At present, there is not enough mental health professionals to support people affected by cancer. By investing in Cancer Council support services, the Victorian Government will be reducing the mental health burden that comes with a cancer diagnosis.

1. Cancer Council is seeking an investment of $1 million over four years from the Victorian Government to:
    - fund an integrated Nurse Counsellor telephone service to deliver up to 2,500 counselling sessions a year for Victorians affected by cancer.
    - fund four scholarships for health professionals in rural and regional Victoria, including nurses with a primary role in supporting people with cancer, to upskill them in mental health support and build workforce capacity to address unmet needs.
2. Increase mental health assessment and screening of people with cancer and their carers over several key periods during the cancer experience. Hospitals, health services and professionals can be supported to do this by automatically referring people to Cancer Council's 13 11 20 information and support line.

3. Navigating the cancer system was hard

People told us they found it hard to find their way around Victoria's cancer care system, which they viewed as fragmented, and uncoordinated. They often felt lost and wanted someone to help them navigate to other information, treatment and support. They needed support that extended beyond medical care.

People need help from cancer experts to understand their cancer, treatment, care, and any available services and supports. Of the people we surveyed, 44% of people with cancer and 63% of carers, did not think that they were given enough information about support services such as websites, support groups or Cancer Council's Information and Support Line.

Cancer comes with many other challenges, and people need someone who can help them find the right support, at the right time.

> ***"Finding information can be difficult nothing is clear cut, especially when it comes to finance, Centrelink, super or insurances they screw with your mind and feelings. I was very lucky and had the right support people to steer me in the right direction. A lot of people don't."***
>
> Person with cancer.

Regional Victorians routinely said that their care was fragmented, and they felt lost within the cancer care system, particularly without someone to help them navigate during the pandemic.

Carers unaware of available supports

Our research shows that a higher proportion of carers (63%) were unaware of available support services during COVID-related disruptions compared to people with cancer (44%). There is a clear information gap about support services available for carers.

More carers used Cancer Council services (31%) than people with cancer (22%), indicating Cancer Council is helping to meet some of this expressed need from carers.

> ***"If there is good communication with family and carers about how they are going it might stimulate the conversation and I'd probably try to seek support. Not knowing about the cancer and learning on the go, left me feeling isolated, my husband had been going through his treatment and I'm not part of the team, I didn't have anyone to ask questions and seek support, I had to learn from what I'm experiencing with my husband as he went through the treatment and side effects."***
>
> Carer.

Recommendations

Boost public awareness of navigation support

With expert knowledge of the cancer sector from experienced cancer nurses, as well as access to a directory of more than 450 support services across the state, Cancer Council is well-placed to provide navigation support to people affected by all cancers.

- We are seeking an investment of $4 million over 4 years (2023-27) from the Victorian Government for a public education campaign to improve awareness of our 13 11 20 cancer information and support services.

Dr Amrooha Hussain, General Practitioner,
Airport West, Victoria.

4. Visitor restrictions saw people go through difficult times alone

> ***"No one should ever go through a cancer diagnosis and treatment on their own... it was absolutely disgusting that I wasn't allowed to have my husband present."***
>
> Person with cancer.

Visitors play an integral role in a person's cancer journey by providing logistical, emotional, and physical support during appointments, treatment, and care. They are an indispensable part of a person's support system and should not be stopped from giving support. During the pandemic, visitors were unable to give this much-needed support, leaving people with cancer to go through difficult times alone.

Of the people we surveyed, those with cancer (61%), and carers (61%), reported they were stopped from taking, or accompanying, a person to appointments because of visitor restrictions. Our research shows that visitor restrictions profoundly affected the cancer experience.

Alone while getting life-changing news

During the pandemic, people with cancer sat opposite health professionals, without a support person, and were confronted with life-changing news. Carers were particularly distressed with not being able to provide support, because they were unable to help their person manage the physical and emotional challenges of cancer treatment.

> ***"I was scared, I didn't know what was happening. I had a mastectomy and that's not something I've ever been through. In my first operation, I actually had a complication ...and my husband was on the phone because he wasn't allowed in. I'd happen to ring him just to say I was in the ward and waking up, and then the complication came something about finding METS [metastasis] and I couldn't have him there to support me and he found it horrible to listen to over the phone and not being able to be there for me."***
>
> Person with cancer.

Help needed to understand complex health information

People told us that, without a support person, they struggled to understand the complex information that was given to them. Fatigue, mental and physical exhaustion is a commonly reported side-effect of cancer and its treatment. Visitors play an important role in helping with decision making and understanding of treatment plans, serving as another 'pair of ears' to help people with cancer understand complex information from doctors.

Visiting restrictions were especially difficult for people with English language barriers and has been explored further with recommendations on page 34 under 'Migrants and refugees lacked culturally responsive care'.

> ***"It is almost impossible to understand a doctor in a mask on a mobile phone where reception poor (most hospitals), and even harder when in a public ward with all the noise therein. Abrupt cancellations of access for carers to medical appointments, without any prior communication, was also extremely distressing. This was particular(ly) so as chemo brain is a real thing - the patient often doesn't hear all the detail being described, and then forgets it all within 15 minutes. This makes it even harder for carers to provide necessary or recommended support."***
>
> Carer.

Physical help needed during treatment

Cancer treatment can make people physically unwell, making it difficult for them to do tasks without help from a support person. Visitor restrictions meant that people with cancer were unable to get the physical help that they needed from their support person.

> ***"After I finished the chemo treatment, my son come and pick me up. And then after that, in March, my son is not allowed to come and pick me up. Even the radiation are finished, I have to walk."***
> Person with cancer, migrant or refugee.

Regional Victorians needed support getting to appointments

Visitor and travel restrictions presented another set of challenges for regional Victorians. They told us that typically, a support person accompanied them on the journey to the cancer care centre and helped with driving when they were fatigued after receiving treatment.

However, due to the visitor restrictions, their carer or support person would have to wait in the car or outside the centre for long periods of time. Other people receiving treatment opted not to bring their support person or carer at all because of the restrictions.

> ***"It [visitor restrictions] meant that I had to obtain my treatments on my own. I can't take my wife with me, so I have to drive about – it's a two-and-a-half hour, one-way trip for me to have the chemo, so it's a five-hour trip, round trip, when I have it. And chemo makes you tired."***
> Person with cancer.

Great distress for people at the end of life

People told us that visitors were restricted for people who were actively dying. It was distressing, not only for the person dying, but for their family and friends. We heard that they did not receive clear communication about when visitors were allowed to visit. One person told us that they were only able to visit the person they cared for once they had reached end-of-life care to say their goodbyes.

These experiences profoundly affected the lives of both the person with cancer, and their support networks. Cancer Council calls for future planning to ensure the choices of the person who is actively dying are respected, and they can be accompanied by their visitors of choice.

We cannot see a repeat of this situation in future disasters.

> ***"My dad was not offered a wheelchair when he went for his blood tests. They did not let me escort him either. He was made to waddle his way through a multiple level hospital. He received a blood test appointment letter for a future date 3 days after he passed away. His FOI reports arrived a couple days later. We were not allowed to spend the entire time he was in palliative with him. We were given the last hours after which he was already on the drug. I never got to say a proper goodbye."***
> Carer.

Recommendations

Elevate the role of carers in cancer care

Carers provide vital support to people with cancer, and in the future there needs to be continued involvement of carers, even in the event of visitor restrictions. Hospitals and health care services must:

- improve communication about restrictions with visitors and meet their differing levels of health literacy, language, and accessibility needs.
- ensure that people affected by cancer get the logistical, emotional and communication support that they need.
- recognise the fundamental importance of visitors during end-of life-care so that those who are actively dying can be accompanied by their visitors of choice.
- make exceptions to visitor restrictions more transparent, so that the choices of the person with cancer are respected, and their family and friends get fair and equitable access to the person they care for.

5. The pandemic compounded financial distress

COVID-19 placed financial stress on many Australians who were already doing it tough. People lost income because they were infected with COVID-19, lost their jobs, and because of pandemic measures such as lockdowns and forced isolation. At the same time, the Victorian and Australian government introduced a suite of temporary economic policies that sought to alleviate financial stress for people.

We found that 36% of people with cancer, and 29% of carers, reported that their income changed during the pandemic. Of these, 13% reported reduced pay/ income and/or work hours, while on the other hand 11% reported an increase in wages because of the federal government support programs implemented during the pandemic, such as Jobkeeper and Jobseeker.

However, Jobkeeper and Jobseeker did not meet everyone's needs. People who lost their jobs told us that the pandemic compounded the financial hardship they were experiencing during their cancer journey.

> ***"I was unemployed for 5 months during the worst of husband's treatment. I now work part time to manage everything, but it means our finances are suffering. We can pay the mortgage, but our food and bills are tricky. There is no buffer."***
> Carer.

Financial distress was highest during lockdowns

We asked people to rate their level of financial distress during the COVID-19 lockdowns and at other times during the pandemic. We found that financial distress was highest during the COVID-19 lockdowns, compared to the time out of lockdown or in the two weeks prior to survey completion.

Out of pocket costs continued to be a burden

People affected by cancer experienced high out of pocket costs before the pandemic. Our research showed that this financial burden continued to be a significant problem at a time when people were already struggling. They continued to experience many other unexpected direct costs at all stages of our research, such as for medical tests, appointments, procedures; and indirect costs, such as for parking, accommodation, or transport. Almost half (47%) said their out-of-pocket costs were different to what they expected, with most people reporting higher costs.

It is common for people to stop work during cancer treatment, significantly and unexpectedly affecting their financial status.

> ***"I was unable to work and had to use savings to cover cost of living, feel like lost wages has had a financial impact however grateful my husband's job is secure and stable; appointments that are not bulk billed add up significantly (thousands of dollars over 2 years of treatments) along with allied health support (physio, massage, osteo, GP, counselling and mental health support)."***
> Person with cancer.

We asked people to what extent they found it difficult to pay for things that were directly or indirectly related to their cancer care. A third of people with cancer surveyed reported some difficulty paying for the cost of prescription and over-the-counter medication, services to help them manage the symptoms and side effects of cancer and treatment, the cost of transport for medical appointments and other essential goods and services. Around 12% of people with cancer reported not being able to access cancer treatment or medicines because of cost.

> ***"I couldn't afford my prescriptions. I don't qualify for DSP [disability support payments] as my incurable terminal cancer, I have no 'due death date.... seriously."***
> Person with cancer.

Private health and out-of-pocket costs continued to take a toll

People who received care from a private health service told us of the substantial direct out-of-pocket costs, and how they affected their cancer care. Some people with private health insurance went without necessities, such as heating, because of high out-of-pocket costs.

> ***"What happens is that there's less money to spend on other things. And so you have to cut down on regular things, because I see a specialist at least once a month and so there's a big amount of out of pockets that private health insurance doesn't pay… What I started doing was, I am very mindful of times when electricity and gas are more expensive. So, I would turn off the heating during the day a little bit because it's cold. Otherwise, the bills are gonna go through the roof. I only buy the things that you can afford at the supermarket, so I buy the cheaper version and things like that."***
>
> Person with cancer.

Additional costs for regional residents, migrants, and refugees

For several of the regional residents that we spoke to, access to public or subsidised treatment often came with other costs, requiring them to travel to major cities or specialist centres away from home. Costs related to travel (transport and accommodation) and hospital parking were significant. Lifestyle changes, including changes to diet, also contributed to the indirect costs experienced by regional residents, migrants, and refugees.

People did not know what financial and practical support was available

Migrant and refugee carers told us how cultural attitudes and expectations affected their financial status. They had a strong sense of familial duty of care, and it was commonly observed that financial burden experienced by people with cancer was extended to the carers and/or the wider family. Migrants, refugees and regional residents were not always aware of available financial support, or if they were eligible to receive it. This was echoed in the comments of the carers we surveyed.

> ***"[I've] heard about it [Centrelink], but am I eligible for that? If [as a carer] I have to be there 100%, only have the job of looking after her [person with cancer] then I can't do it [apply for carer support] because I have a small child, I can't say I commit 100%."***
>
> Carer.

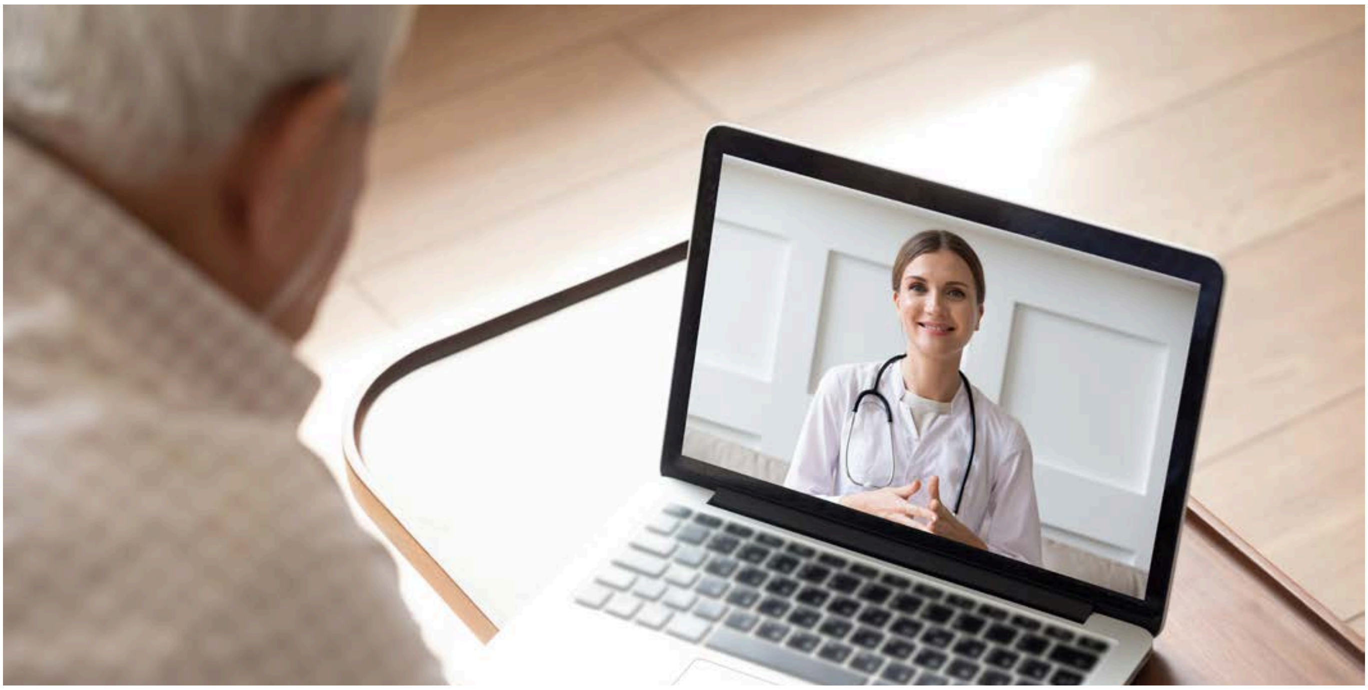
Recommendations

Ease the financial burden

Cancer Council recommends action by government and health services to reduce financial distress, by:

- improving transparency of costs including out-of-pocket costs, differences between public and private pathways and the financial impact of different treatment options.
- enabling people to be informed and find the information needed. The health system can help prevent financial distress by embedding early and routine assessment and referral to 13 11 20.
- making improvements to income support systems to include clearer eligibility criteria. There is opportunity to improve awareness and understanding of these supports particularly for migrants, refugees, and people from regional areas.

6. Telehealth is efficient, but isn't always suitable



Social distancing, travel restrictions and lockdowns limited how people could access healthcare and with many people unable to visit hospitals, telehealth became the primary way of continuing cancer care either by phone or video call.

Some viewed telehealth as one of the benefits of the pandemic

More than half (57%) of people with cancer said that medical appointments had been conducted via telehealth. While there were undoubtedly challenges associated with this shift of care, some (54% of people with cancer and 43% of carers) expressed positive aspects of receiving care via telehealth, especially when it came to the convenience. This was particularly true for regional residents as telehealth reduced time spent traveling.

> ***"We had a couple of meetings via Zoom, but to be quite honest, it worked quite well because my surgeon was far [in a major city], I live [rurally], so that actually went quite well. I don't think I was impacted in a negative way."***
>
> Person with cancer.

Building rapport and receiving bad news

People commonly said telehealth was impersonal and there was less opportunity to build rapport with health professionals. Importantly, telehealth was not thought by some to be an appropriate way to receive bad news.

> ***"Initially, with all the diagnoses and whatnot, everything was via telehealth and remote, which was quite awkward and difficult. So sitting, looking at a computer screen, getting told you got a cancer diagnosis was really, really tough and it was hard to have a proper conversation."***
>
> Person with cancer.

Need for a physical examination

People told us that the main issue with telehealth was that it did not present opportunities for physical examinations. People thought that a virtual appointment could never compensate for a face-to-face appointment where a health professional can examine and assess a person directly.

> ***"The [cancer care team] called and said, "We're just wondering whether we can change the appointment to next Tuesday – and can we make it a teleconference?" And he [person with cancer] looked at me and I just said to him "Tell them no. You need to talk to the doctor. You need to see the doctor. You can't put it off. Don't just say, 'Yeah, I'm fine,' … because you're not fine. You have your bad days with two or three days not eating at all." He had a feeding tube in his stomach, and some days, he was just bringing that [food] straight up back up again. I said, "That's something you need to talk to your doctor about in person."***
>
> Carer.

Missed calls and no follow-up care

Telehealth presented practical challenges. People told us that health care professionals did not always allow people enough time to pick up the phone, or they did not always attend appointments.

> ***"It [my cancer care] was just all over the phone. And sometimes the phone would ring and I'd be in the kitchen, I'd go to answer it after three rings, and they'd hang up. So they assumed I was not attending my appointments, and then I'd get a message saying "You didn't answer your call, so we'll call you back in six weeks." And I'd ring the hospital and say "Look, I didn't miss the call, they hung up after three rings." They said "Oh, they'll ring again," but they never did."***
>
> Person with cancer.

Some people told us they were still missing out on the benefits of face-to-face appointments.

> ***"Some services are still over the phone or video. Getting a face-to-face appointment with a GP [general practitioner] is near impossible. You feel like you're not wanted, and they don't want to see you."***
>
> Person with cancer.

Recommendations

Ensure telehealth is fit for purpose

There should be patient choice in how people receive healthcare. Digital and telephone platforms do not suit everyone, particularly for those who can't easily use these technologies.

People should be involved in decisions about their healthcare, and health professionals should address their concerns to ensure they have the support and care that they need. Telehealth should not result in people being left behind.

Cancer Council recommends:

- To maximise benefits of telehealth, patient-centred guidelines are needed to support equitable access to high-quality telehealth across all Victorian health services.
- Cultural change within health services is required to ensure people are empowered to have a say in how they get healthcare, whether it's in-person appointments or via telehealth.

7. Cancer information and communication was inadequate

Our research showed that whilst health professionals were often the preferred source of health information, they were not able to meet the information needs of people affected by cancer. People shared that they would have liked more information about their cancer and treatment plans so they would know what to expect.

Just under half (44%) of people with cancer, and 63% of carers reported that, during the pandemic they were not given enough information about other support services. Migrants and refugees recommended that health professionals should regularly speak with people to ensure that they know what is happening in their care plans. Others noted that specialists and clinicians often did not have the time to discuss or explain details.

> ***"If the medical staff could mention what option, potentially, there could be, like for example, when they told me "On your right breast, you've got cancer and you have to have a mastectomy so we can get rid of it." I said "Okay." So I had that and then – this was three weeks ago, and then after seeing the surgeon two weeks later, to check that that was healing okay, then they said "You know, now you have to have chemo," and it's like "Well, you've never even informed that it was a possibility for treatment."...it sounded like I needed a mastectomy and that's it. No one ever mentioned that there could be chemo and radiation therapy, all that sort of stuff. So, yeah, I just wasn't really told about what potentially could happen. I felt like I was being drip-fed information."***
>
> Person with cancer.

This experience highlights the need for cancer care professionals to have strong communication skills to ensure they can help people to understand their treatment and management pathway.

> ***"I just like to see a little bit more communication so that we're not treated as another cancer patient. You're not a number. It's not a production line, you know there's the next patient, there's the next patient. We're all individuals. We all have different needs and we just – sometimes just a smiling face and for people to remember the names and things like that."***
>
> Person with cancer.

Several people said that they wanted to quit receiving chemotherapy because they did not have a good understanding of what was happening and how much longer they would need to undergo treatment.

> ***"My idea is that going forward, when someone is diagnosed with cancer, there should be someone else [allied health professional] to talk you through that the side effects [from treatment] are preventable, and make sure you understand so you less likely to quit."***
>
> Person with cancer.

Cancer education for migrants and refugees

Migrants and refugees routinely said that they knew nothing about cancer and wanted more information about the disease as well as its treatment and management. Their sources of information were not from health professionals, instead they relied on or were referred to trusted leaders in the community for advice on how to self-treat the disease.

> ***"Finding information in my language is difficult but imagine how much more difficult this was made by the pandemic."***
>
> Carer.

It is common for newly diagnosed people to experience shock and disbelief. Some language groups thought this shock was more overwhelming because they did not understand cancer and how it can be treated. Typically, this lack of knowledge resulted in disempowerment, reducing their ability to make informed decisions around treatment and management options.

> ***"We [cultural community] don't know about the treatment [options], we don't know what's not true and what we should go for because we never knew about it [cancer] before. So we have to depend on the doctor to make this decision for us."***
> Person with cancer.

People believed that if their community was more educated around the disease and the importance of undergoing screening and treatment, the overall health of the community might improve.

> ***"My community does not understand so much about [cancer], the treatment, and also the benefit [of having treatment]. So we usually stick with the traditional treatment or traditional medication – which doesn't always work."***
> Person with cancer.

Health professional training in culturally sensitive communication

Migrants and refugees were challenged by what they perceived to be culturally inappropriate methods of delivering information about death and dying. They realised that there was a possibility that the person with cancer could die but considered it culturally inappropriate to remind them of this potential outcome.

Plain language cancer information needed for people with low literacy

We interviewed people who were illiterate in both their first language, and in English. Resources needed to be presented in plain language, so that people with low literacy levels, could understand the information and allow interpreters to translate easily into language. This also applies to Australian-born people who were not literate in English or had low literacy levels.

In exploring their information needs, we noted that written materials on cancer, care, and services developed in language did not suit everyone. Some people recommended that information in audio-visual formats would be more understandable for people with lower literacy levels.

> ***"If some of the information will be like pictorial, a little bit like a factsheet with a pictorial – make it more visual, that would be good. Audio visual would be best for some people who don't even read the language."***
> Carer.

Recommendations

Bridge the cancer information gap

The Victorian Government has a pivotal role to play in improving access to cancer information by establishing a communication skills standard for clinicians and investing in cancer organisations and health services to deliver:

- plain language, health literacy, and communications skills training for health care professionals so that they can explain complex information simply.
- cancer information in bi-lingual and plain language using a co-design approach with multicultural organisations and communities.

8. Most people unaware of clinical trials

Best practice patient care, outlined in the Optimal Care Pathways recommend that, where practical, people with cancer should be offered the opportunity to participate in clinical trials. However, most people with cancer (85%) and carers (73%) that we heard from were not involved with clinical trials during their cancer care. Whilst this finding is not unique to the pandemic, we know that, in the early stages of the pandemic, many clinical trials were forced to close recruitment or adapt workflow, due to the reprioritisation of staff, funding and resources and changes to guidelines around patient management and risk.(11)

There are many barriers to participating in clinical trials, including limited awareness and understanding amongst clinicians and the public. Almost all the people who told us they were not involved in a clinical trial (99%) said that they had not been made aware by their healthcare team of any clinical trials that might have been relevant to them.

Some people told us that if they had been provided the opportunity, they would have been interested in taking part.

This means that people may be missing out on the benefits of clinical trials that could help them to live well, or to live longer. People who had participated in a clinical trial told us that it gave them a touch point during the pandemic that helped them feel more supported.

> ***"The trial coordinator really looked after me. They scheduled all future treatments and tests. This freed up my time and headspace so I could focus on my family and friends. I could relax at home knowing my trial coordinator would sort everything out."***
>
> Person with cancer.

> ***"Being on a trial with consistent monitoring was great during the pandemic. It provided a touch point. Having a specific trial nurse to contact in between appointments was reassuring and helped me navigate a complex system."***
>
> Person with cancer.

Most people who we spoke to who resided in regional Victoria and participated in a clinical trial did so at a large specialist centre in a major city.

> ***"They don't have clinical trials out here in the rural and regional areas or very, very rarely…it's a shame because it would be useful if some of those things were actually given to people in rural areas."***
>
> Person with cancer.

A small percentage of people said that they were financially better off by participating in a clinical trial, as often the trial would cover their direct medical costs, as well as some indirect medical costs (e.g. pathology, scans, parking fees etc.)

Recommendation

Invest in clinical trials education

With support from the Victorian Government through the Victorian Cancer Agency, Cancer Council is leading a project to enhance our clinical trial, education, and support services to enable people affected by cancer to become aware of, and access, clinical trials in Victoria.

- Investment in information and education is needed to improve clinician and patient awareness of clinical trials, including in regional areas, and encourage clinicians to discuss clinical trials with patients as a standard part of their care.


Carmel O’Kane, Nurse Practitioner and Manager, Wimmera Cancer Centre.

Unmet needs of specific communities

It is well reported that the burden of cancer is not evenly spread in Victoria. We know there are some individuals and communities who have poorer access to the best possible cancer care. This includes people with a metastatic, advanced, or rarer cancer, Aboriginal and/or Torres Strait Islander communities, people living in low socioeconomic communities, migrants, and refugees, and those in regional areas.

The global pandemic added significant challenges and pressures to Victoria's already strained healthcare system that has impacted its ability to support underserved communities. Common themes emerged for migrants, refugees, rural and regional residents. We have explored many of these themes, including visitor restrictions, cancer information, costs, and emotional supports, and have made recommendations to address challenges and opportunities for all Victorians.

We have also identified challenges and recommendations unique to these two groups. We've set out these findings and recommendations as separate sections in this report.

9. Regional Victorians struggled with cost and navigation

Regional Victorians continued to request financial help from the Victorian Government to pay for travel and accommodation. The challenges in getting this help are not unique to the pandemic and need to be urgently addressed so that rural and regional Victorians can continue to get the care that they need.

The Victorian Patient Transport Assistance Scheme (VPTAS) eases the costs associated with travelling to and staying near medical treatment. These reimbursements cover some of the cost of fuel when travelling over 100 kilometres to a cancer treatment centre.(12)

There are specific problems with VPTAS that the Victorian Government could address by reviewing the scheme and promoting it more widely. People also told us that they did not know about VPTAS. Others told us about challenges with eligibility, administration, and delays with reimbursement.

> ***"It takes them [VPTAS] about four or five months to do the reimbursement...I've got to give them receipts and then that gets pushed into their financing department, and when they process it, they process it – whenever that may be."***
> Person with cancer from regional Victoria.

Some people felt that the VPTAS was too exclusionary and should be changed to include regions that are still considered regional but are located just outside the 100-kilometre parameter. Some did not meet other eligibility criteria, even though they lived in regional areas.

> ***"I was not eligible for VPTAS. I was just under the 100-kilometre range to the accommodation. That's fine. I'm more worried about getting better, but they [VPTAS] just draw a random line in the sand."***
> Person with cancer from regional Victoria.

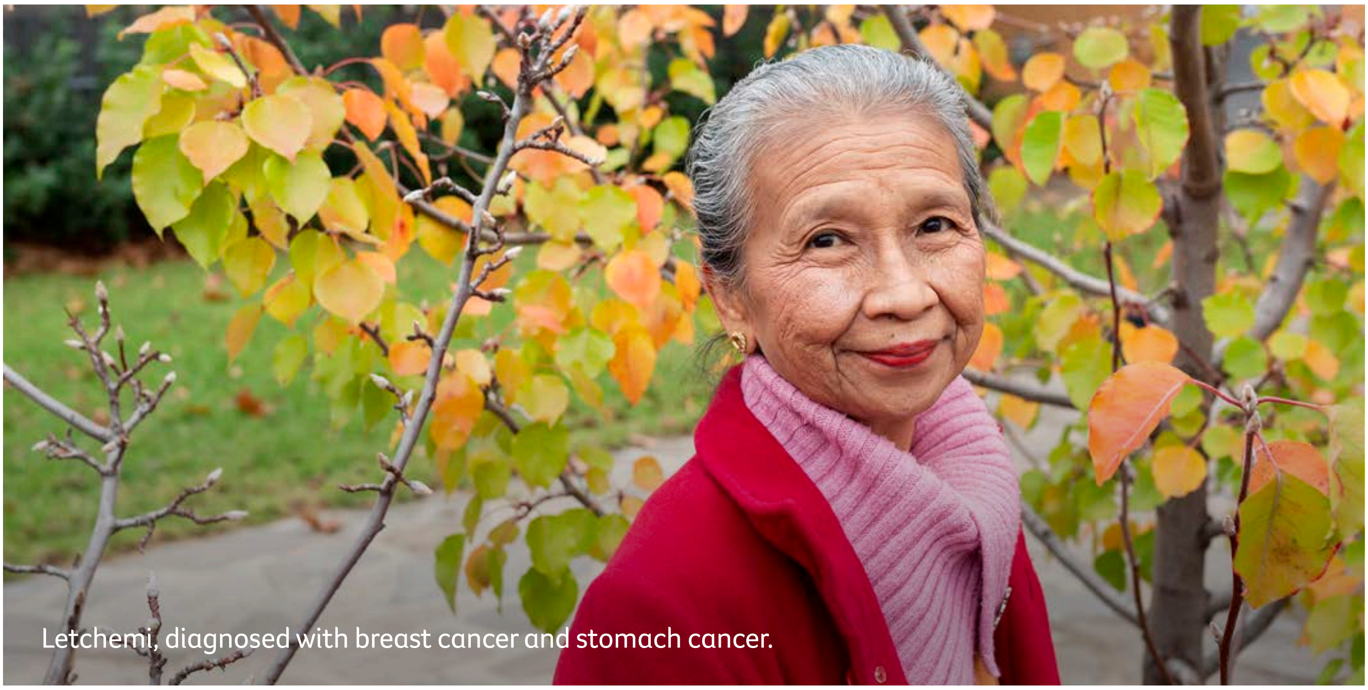
Recommendations

Improve travel support for regional Victorians

Urgently review the Victorian Patient Transport Assistance Scheme (VPTAS), so that regional Victorians can get upfront reimbursement and can access the scheme if they need to travel for clinical trials.

Investment is needed for an awareness campaign so that VPTAS is more accessible and transparent, and so that those who need it, know about it.

10. Migrants and refugees lacked culturally responsive care


Letchemi, diagnosed with breast cancer and stomach cancer.

Communication and language barriers experienced by migrants and refugees are not issues specific to the impact of COVID-19. However, people felt that the disruption associated with the COVID-19 response, intensified the challenges for those affected by cancer.

Challenges in seeking the right emotional and mental health support

All migrants and refugees agreed that psychological support was important but varied in how this could be delivered in the most culturally appropriate ways. They faced key challenges in getting formal mental health support. People may not use psychologists or mental health counsellors because of language or cultural barriers, or because of the stigma associated with these services.(13)

Some people felt as though cancer was a topic that should only be discussed with immediate family, which then presented a barrier to seeing a psychologist or counsellor. Others turned to religious communities to improve their mental health, and to get information.

> ***"I never share about [my] cancer with other people other than family. I just feel like it is something to do with personal, with family stuff, and not a lot of people would ask you about the cancer. So I never talk about cancer with other people."***
> Person with cancer, migrant and refugee.

People who were interested in getting formal mental health support, such as psychological or counselling services, could not do this as they could not find someone who could speak their language, and interpreters were hard to find outside of hospital settings.

> ***"I really needed to have sessions with a psychologist, but I couldn't find anyone to speak in Arabic and I couldn't have this type of session or this type of support."***
> Person with cancer, migrant and refugee.

The need for culturally responsive emotional and mental health support

The Royal Commission into Victoria's Mental Health System in 2021 recommended that mental health service providers work with culturally diverse communities to develop services that could meet their mental health needs.(14)

At present, the cancer sector has an expert psychology and counselling workforce to support the mental and emotional health of people affected by cancer. However, it is at capacity with long waiting times and is not available in many areas. As noted by our research, migrants and refugees are not using these supports, despite the best efforts of the cancer sector.

As subject matter experts on addressing the needs of diverse communities, multicultural organisations are well placed to provide expert advice to the cancer sector on how it can better address mental health needs. By working together in a strong collaborative partnership and with dedicated funding, the cancer and multicultural sectors can address the mental health challenges for people affected by cancer in a culturally responsive and appropriate manner.

Migrants and refugees need better access to interpreters

Visitor restrictions hit hard for people who faced communication and language barriers. People who rely on interpreters, such as those who don't have a strong command of English, have speech or hearing impairment, or disability, need an interpreter or support person to help them communicate with staff about their care.

Visitor restrictions presented unique challenges to people who were not proficient in English. In pre-pandemic times, visitors were able to act as interpreters when there weren't any available.

> ***"[I] also got heavier challenges regarding to the language barrier, particularly when [my] dad needed to attend the emergency department… there's no interpreter in there. One of the staff tried to reach out for the interpreter service. It was really hard to get one during that time [pandemic] and communication has been a barrier for us both."***
>
> Carer, migrant and refugee.

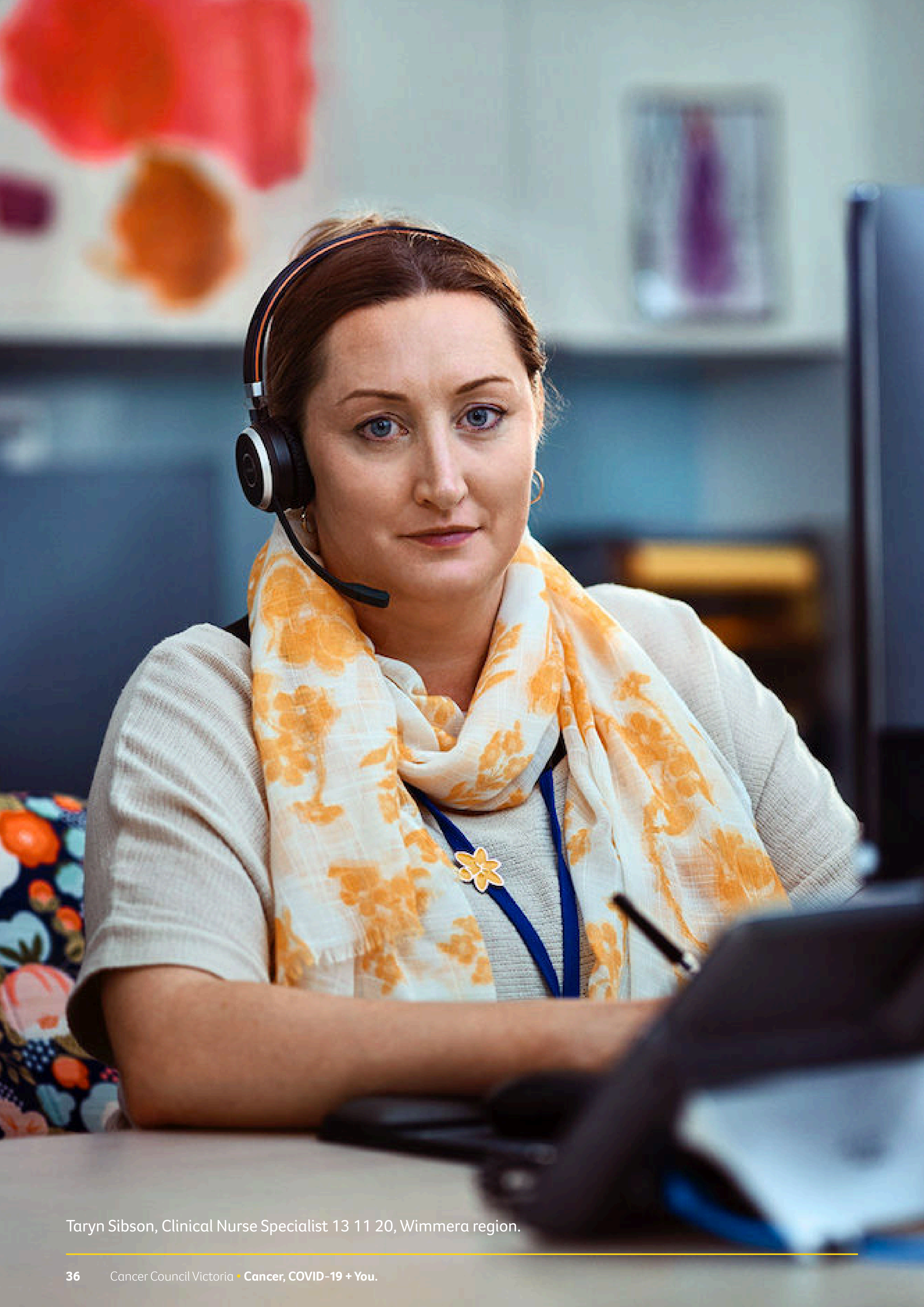
Setting the impact of visitor restrictions aside, language barriers have consistently been an issue in enabling patient-centred cancer care for people who speak a language other than English at home.(15, 16, 17) This issue was exacerbated in cancer care delivery for migrants and refugees during the pandemic. Certified interpreters were difficult to access, and people told us how this language barrier was often a source of distress.

Recommendations

Develop language and mental health supports for migrants and refugees

Investment in partnerships between the cancer sector and multicultural organisations is needed to develop culturally responsive, targeted, and sustainable mental health support.

Expand the capacity and capability of the interpreter workforce so that a certified, professionally trained interpreter is available for those who need one.



Taryn Sibson, Clinical Nurse Specialist 13 11 20, Wimmera region.

Conclusion

This report focused on sharing the voices of people with cancer during the pandemic, however it's also uncovered many concerns and recommendations that are long-standing, systemic issues. There are well-documented challenges for people to navigate to support services and many barriers to equitable access to appropriate care, treatment, and clinical trials. Emotional and mental health supports and financial counselling for people with cancer and their carers are often in short supply and not always offered.

Hospital visitor restrictions over the past few years have exposed the vital role that carers play in communication, managing complex information and providing care and support to people with cancer. Careful consideration needs to be made by health services going forward to ensure hospital visiting policies distinguish 'visitors' from 'carers'.

While restrictions have eased, experts are predicting new strains of COVID-19 and future waves of infections. At the time of producing this report, health services continue to have strict pandemic measures in place including wearing of masks and varying degrees of hospital visitor restrictions. Increased infections are also affecting staffing levels in health services, which is putting pressure on wait times in emergency departments and affecting available services and supports.

People with cancer continue to worry about risks of exposure to COVID-19 as many people undergoing cancer treatment face higher infection risk and more serious complications from COVID-19.

While COVID-19 fatigue has set in for Victorians and health professionals alike, its impact will continue to be felt for years to come. Now is the time to bring together government, cancer organisations, health services and people with lived experiences to ensure we draw on the learnings from the past few years and improve the system for all those who need it.

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