



Cancer Services Plan Consultation Report
WA Health Cancer Clinical Services Planning
Health Consumers' Council Consumer Engagement April 2024

Acknowledgements

We would like to acknowledge that these workshops and interviews were hosted from the lands of the Whadjuk Noongar people and pay our respects to their Elders past, present and into the future. We acknowledge all Aboriginal peoples continuing connection to culture, country, traditions and language and the demonstrated willingness to continue to lead all health services who want to provide a more holistic, person and community led care. We also acknowledge that sovereignty was never ceded, and that Australia always was and always will be, Aboriginal land.

We also would like to acknowledge the consumers and parents/carers who gave their time and shared their experiences so willingly. We thank them for their openness and generosity, all in the hope that by sharing, the system will improve for future consumers and families.

EXECUTIVE SUMMARY

The WA Department of Health (DoH) are revising the Clinical Services Framework (CSF) for a number of clinical services. As part of this work, the DoH has requested Health Consumers' Council (HCC) to undertake some consultation with consumers and carers with experience of cancer services to provide insights to inform the revised Cancer CSF.

Over three weeks in March and April 2024, HCC spoke with 32 people across six workshops and 10 interviews. People had a range of types of cancer, lived in both metro and regional areas, and had a range of experiences with cancer care pathways (29 care pathways across all participants). Within the project constraints of time and resources, feedback from this consultation process provides consumer insights to inform the Cancer CSF and to supplement other in-depth research that has been carried out on this subject both nationally and internationally.

The consultations invited feedback on these questions:

- Cancer service reflections
 - What are your reflections on using cancer services?
 - What parts of your care did you find difficult?
 - What parts of your care did you feel were done well?
 - What improvements could be made?
- Location of care
 - What impact has travelling for your care had?
 - Are there services that you would like to be offered closer to home?
 - Are there services that would benefit from being provided at a larger hub/site and why?

In summary:

- Much of the feedback received through this process reinforces feedback gathered from WA consumers in 2019.
- One theme that was stronger in this consultation process was the critical importance of psychological support for consumers and carers.
- Another theme that was stronger this time related to the cost of parking and travel – in some cases, people may be considering stopping treatment because they can't afford to get to it.
- People referred to the value of comprehensive joined up services:
 - In general, having multiple services in one physical location was seen as being likely to reduce the practical challenges of navigating care across multiple locations and services. Those challenges include clinical communication between different clinical teams, and navigating appointments with different treatment teams, as well as a reduction to the burden of travelling to different physical locations with the associated transport/parking costs.
 - When describing the services to be included, it was universally agreed that comprehensive care included a range of clinical services – including allied health – as well as complementary therapies and non-clinical services such as access to financial support and transport.
 - People also recognised that a physical “one stop shop” would not meet everyone's needs.

- For many people, a cancer diagnosis may be their first experience of serious ill-health and having to navigate a fragmented health system. They may “not know what they don’t know” and may only find out about services that could have made a positive difference months later because they didn’t know to ask about it.
 - Receiving a cancer diagnosis can be a turbulent and stressful time – people need to navigate a high volume of information as well as the mental/emotional impact, the financial impact and the physical health issues.
 - A strongly recurring comment related to people having a trusted source of information – ideally, one person – to turn to for information, support and continuity/coordination. People want someone to help them navigate the wide range of options and make the best decision for themselves.
 - Importantly, there’s a desire for someone to talk to, not just access to information to read.
 - People commented on the value of peer support.
- Many comments relate to the importance of compassionate person-centred care.
 - Where it was available, it had a significant and positive impact on people’s experience and emotional well-being.
 - Where it wasn’t, it added an additional burden to an already very difficult situation – and could contribute to the mental health impacts of a cancer diagnosis.
 - Many comments outlined people’s experiences with “service-centred” care – for example, being told they can no longer access equipment they were being provided by a metro-based service, because they now need to get it from WACHS – but no-one in WA Health following up to ensure this happens.
 - People want to be treated as ‘whole’ and not just a body part or a diagnosis.
- People want to be supported and involved in decisions about their care, not ‘dictated’ to.
 - People don’t always feel informed enough about the options to make an informed choice. Again, access to a care coordinator may assist with this.

“Dealing with PATS was sometimes harder than dealing with knowing my Mum having cancer and was probably going to die. These types of systems make life so much harder than they need to be – it is already hard enough.”

As with the consumer feedback in 2019, there are many strengths to build on: areas identified for improvement by some are already being experienced by others.

- Where people have access to care coordination or navigation, they generally describe it as having made a positive difference to their experience and care.
- People describe positive experiences of peer-led services.
- There’s a desire for a broader range of support and for longer – up to 5 years after treatment.
- The financial impact of cancer is significant including the cost of care, as well as the loss of income.

Implications for the Cancer CSF

- In general, the ability to access a comprehensive suite of medical, nursing and allied services, alongside complementary therapies and practical support and information in one place would have a positive impact on the experiences of many people.
- If a high-quality person-centred service like this was available, people would be willing to invest in the travel to get there, in return for the seamless and integrated “wrap-around” experience.

- However, to realise these benefits, the service would need to go beyond the physical co-location of these services and be resourced to provide true multi-disciplinary care.
 - This would include investing in systems, processes and organisational cultural elements that would truly put the person – and their carers or loved ones - at the centre of their cancer care experience and enable them to experience optimal integrated care.
- Furthermore, for people who are unable to access a physical cancer centre integrated person-centred care, with easy access to care navigation and coordination services, are important.
 - For example, how might it be possible for a person living regionally to be able to access psychology support in their town through the local private provider rather than incurring the travel/environmental and emotional costs to get to the nearest regional centre?
- Additionally, for people unable to access a comprehensive cancer centre, reducing travel requirements – both from a cost point of view, but also from the sheer “hassle factor” point of view – by providing more options for integrated joined up services closer to home, or by Telehealth, would make a positive difference to many people’s experience – both metro and country.

*We have a psychologist in town but she’s a private practicing and not a [WA Health] psychologist. **You have the health department keeping itself insular rather than utilising the local services.** I think a process where, if they are going to pay a health department OT, why can’t she access a local OT and they use a Medicare number to get their payment through? That seems like a simple thing.”*

Implications for the planned update to the WA Cancer Plan

- Consumer feedback on cancer services remains consistent between the consultation in 2019 and this consultation.
- One theme that emerged stronger in these discussions was the value and importance of peer support.
- Another was the issue of financial toxicity¹.

It’s clear that many of the issues facing WA consumers with experience of cancer in 2019 remain today. It’s also clear that people with lived experience have an enormous amount to contribute to identifying solutions for the challenges faced by the WA community.

We look forward to working with WA Health staff to integrate new approaches to citizen and community partnership in the design, delivery and evaluation of sustainable cancer care services and reported outcomes as envisaged in Recommendation 4 of the Sustainable Health Review.

¹ <https://www.cosa.org.au/media/q3ohepgs/financial-toxicity-in-cancer-care-7.pdf>

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INTRODUCTION

Cancer services planning is a priority for WA Health. In 2020 WA Health published the *WA Cancer Plan 2020–2025* to provide high level direction to guide the optimal delivery of cancer control and research to meet the needs of Western Australians impacted by cancer”.² This was underpinned by extensive consultation with multiple stakeholders including consumers assisted by Health Consumers’ Council. Whilst the guiding principles and priorities of the WA Plan remain, the context for WA service delivery has changed.

The Australian Government has since released the Australian Cancer Plan (2023-2033). This plan is designed to improve cancer outcomes and experiences for all Australians and provides a framework for the continuum of cancer delivery which includes jurisdictional providers.³

The funding environment and range of services to be provided has also changed. The Commonwealth announced investment to commence a new National Lung Cancer Screening Program (NLCSP) by July 2025. Furthermore, in 2022-23 it pledged \$375.6 million funding towards establishing a Comprehensive Cancer Centre for WA (WACCC) and this has been reaffirmed in subsequent budgets.⁴ This is part of a national initiative in the Australian Cancer Plan for “a nationally consistent comprehensive cancer care model, considering the strengths and challenges of international and jurisdictional models of networked comprehensive cancer care”.⁵ Such a centre was not considered as an option in developing the WA 2020-2025 Cancer Plan. The State has provided joint funding with the Commonwealth for the development for a business case for a WACCC with Harry Perkins Research Institute.

In response to this changing context and the opportunities and challenges it presents WA Health is considering the future service delivery options and configurations for cancer services in WA. It is doing so in the context of the need to plan for a NLCSP, its previous commitments and priorities as identified in the WA Cancer Plan and to ensure that strategies align with the Australia Cancer Plan.

Priority five of the WA Plan requires Statewide leadership “to set clear principles for planning, design and commissioning of cancer services. This is underpinned by principles that include ‘optimal, safe and sustainable care, ‘person-centred care with equitable access’ and the ‘engagement of stakeholders and partnerships.’⁶

As part of its engagement strategy WA Health contracted Health Consumers Council to assist in creating evidence-based findings from consumers and the community to provide feedback and strategic input to service delivery and the future configuration of cancer services.

This report provides an overview and summary of the findings of those consumer and community consultations. It locates them within a broader context of consumer perspectives on service delivery and policy developments. It suggests what the implications of these findings may be for the future configuration of cancer services in WA.

² <https://www.health.wa.gov.au/Reports-and-publications/WA-Cancer-Plan>

³ <https://www.canceraustralia.gov.au/australian-cancer-plan>

⁴ www.health.gov.au/sites/default/files/documents/2022/03/budget-2022-23-western-australian-comprehensive-cancer-centre.pdf

⁵ <https://www.australiancancerplan.gov.au/actions/3.2.2>

⁶ Department of Health Western Australia. *WA Cancer Plan 2020-2025*. 2020. Perth: Health Networks, p.40

A: ENGAGEMENT OVERVIEW

Consultation Method

Consumers and carers with experience of utilising cancer care services in WA were recruited to participate in group workshops or individual interviews. Recruitment was conducted through a wide range of communication channels, with a prioritisation to ensuring diversity of demographics (particularly to prioritise recruitment of regional and Aboriginal consumers and carers). Many participants had not participated in a consultation to input to work being undertaken by Department of Health before.

Six workshops and ten interviews were conducted, all following the same consultation questions listed below. Workshops conducted online were 2-3 hours in length. Interviews conducted took 45-90 minutes in length. The consultation format and questions were developed in partnership with Health Consumers' Council and DoH Clinical Planning Unit.

Consultation Questions:

- Cancer Service Reflections
 - What are your reflections on using cancer services?
 - What parts of your care did you find difficult?
 - What parts of your care did you feel were done well?
 - What improvements could be made?
- Location of Care
 - What impact has travelling for your care had?
 - Are there services that you would like to be offered closer to home?
 - Are there services that would benefit from being provided at a larger hub/site and why?

Participation

32 participants discussed the journey of 29 separate people diagnosed with cancer and their associated care pathways.

- 22 are reported by person diagnosed alone.
- 3 are reported by person diagnosed and carer.
- 4 are reported by the carer alone.

Types of cancer in the 28 separate pathways discussed:

| TYPE OF CANCER | NUMBER OF CASES / PATHWAYS |
|----------------|----------------------------|
| Prostate | 2 |
| Breast | 13 |
| Melanoma | 2 |
| Colorectal | 1 |
| Lung | 2 |
| Lymphoma | 2 |
| Head and Neck | 2 |
| Stomach | 1 |
| Myeloma | 1 |
| Leukaemia | 1 |
| Bladder | 1 |
| Brain | 1 |
| Other Cancers | 2 |

Location of patient cases / pathways by residence during treatment (multiple locations listed where applicable)

| LOCATION | NUMBER OF CASES / PATHWAYS |
|---------------|----------------------------|
| Metro (North) | 7 |
| Metro (East) | 8 |
| Metro (South) | 5 |
| Bunbury | 3 |
| Busselton | 1 |
| Bridgetown | 1 |
| Jurien Bay | 1 |
| Exmouth | 1 |
| Port Hedland | 2 |
| Northam | 1 |

Diversity of attendees

| POPULATION GROUP | NUMBER OF PARTICIPANTS |
|---------------------------------------|------------------------|
| Aboriginal | 3 |
| Culturally and Linguistically Diverse | 3 |

Limitations of Consultation

Conversations were conducted for the purpose and within the scope of the cancer planning work being currently undertaken by the Department of Health. **This report should not be considered a comprehensive account of the cancer journey for WA consumers.**

This report identifies common themes of discussion with respect to the consultation questions. Additionally, findings from other relevant consultations and work (e.g., WA Cancer Plan 2020-2025, Australian Cancer Plan) have been noted to provide additional context and relevance for the presented themes of discussion.

B: CONFIGURATION AND LOCATION OF CARE

The six or more possible configurations of care that may be being considered by WA Health were not something that could be put directly to consumers in this consultation. People were asked to reflect on the location of their care and the impact (if any) it had on their care pathway. The suggested improvements were rarely site-specific and instead applicable to all sites and focused largely on the accessibility of the sites whilst experiencing low or no income, poor health and, for regional consumers, a significant distance to their appointments.

Many people found it easier to talk about the care they had direct experience of rather than how care might be configured and located in the future from a systems perspective. For some it was hard to consider a Comprehensive Cancer Centre without knowing more about what it is. One consumer said:

“When it comes to it what is a comprehensive cancer centre going to be, what does that actually mean? Is it DD block on steroids? It would need to be integrated with support services, it would need to enhance the patient experience and not make it exactly the same. ...The end of the day is that it needs to increase the equity of care and having treatment closer to home for some things.”
Metro (East) Consumer, Rare Cancer

Others, however, had an idea of what a comprehensive cancer centre might be.
“If you had a comprehensive cancer centre, it wouldn’t completely meet the needs of cancer patients, particularly complex cancer patients, but I do know the Peter Mac Centre is extremely good in Melbourne.”
Metro (East) Carer for Young Adult, Brain Cancer

Comprehensive Cancer Centres were seen to have the potential to offer more holistic care and to provide a way for people to offer peer support to others.

“I know other states have cancer centres; I do think having everything in the one place would be really good. More connection as well would be good if there was a central centre though, less isolating. Dieticians, exercise physiologists, exercise groups. the research is always changing, exercise has been shown to be really good. The recommendations keep changing, and I think if something was attached to research, and you could continue contact so you can prevent a reoccurrence. You could then become a peer, be involved in helping with the research, consulting, there are lots of benefits with having it at one place. People say, once you finish treatment you are out, and you feel this massive fear and loss. You lose a bit of security.”
Metro (South) Consumer, Breast Cancer

Another Metro consumer said:

“Where possible trying to make things a one-stop-shop would make things a much better experience. Clinics, pathology, radiology all in the same building. Parking sorted, and having shopfronts of support services that are welcoming. Not having to go to 3-4 different places across the metro area and capture some of your care. You can make use of the time around your appointments. Get your bloods done, have a coffee and talk to support services and chat about structuring your super or your will, linkages for your kids that need supports. Things that are nice and open, visible, so people know they are welcoming. Rather than here’s a list of services to call, fill out an online inquiry form and someone might get back to you in a week.
I think there are many Scandinavian countries that do that really well, making a community around it and allowing people to give back to that as well. I’d really like to talk to someone who’s volunteering, has lived experience and can help us navigate that process. I guess from a health consumer, I want to feel I can connect to another person in something like this.”
Metro (East) Carer, Rare Cancer

Amongst the suggestions from Metropolitan consumers for the range of services to be delivered in one location were:

- *“Potentially oncologist, psychologist, diagnosis – although I’m unsure about the diagnosis side.”*
- *“All patients being offered counselling, and at multiple times is something that would be expected and would be good on-site. Radiotherapy needs to be closer to home.”*
- *“I think oncology, radiation, dietician, psychotherapy”.*
- *“Social work as well”*
- *“Cancer navigator/coordinator could be there as well”.*
- *“It would be best practice to have cancer navigators for all patients. You get all the relevant information at first point; it would probably reduce the amount of psychological distress in all people.”*
- *“If you are going to have a centre, you need to have support services in place. No healing takes place in isolation. You need to be able to have your family available.”*

From a non-Metropolitan carer:

“it’s almost like everything should be under the one roof. There’s treatment in Joondalup, treatment in Perth, there’s different organisations. They are all over the place as well. If there was one major centre, then that had rooms attached to it where people could stay if they have a treatment and can stay overnight.”

Carer of consumer in Midwest

Some consumers expressed a preference for more use of Telehealth and that included those in metropolitan locations.

“I am a huge fan of telehealth. I hate sitting waiting for hours for appointments. I can get a bus to SCGH, but it takes me nearly 2 hours. I can arrange a NDIS worker to give me a lift, but it can be very difficult. I can’t drive on my own after treatment because that’s a risk. To need a support worker for four hours is a lot. Parking is also a significant issue to find, as is the cost of parking.”

Metro (North) Consumer, Skin Cancer

Another said that whilst they had not had much access to Telehealth, but it could work well for people who were neurodivergent such as those with autism. Although they thought it could go either way and worked better once relationships were established.

Whilst consumers were not able to talk about a comprehensive cancer centre service model from direct experience, they were able to discuss whether they would have preferred for any of their cancer care to be provided closer to home, and which parts of this care if so.

Metropolitan Consumer Preferences

On reflection of the location of their care, the vast majority of participants expressed no preference for a change in the location of their care. However, among those who did express a preference for more localised care, the services that some identified included chemotherapy, immunotherapy, and supportive care for managing side effects, such as intravenous fluid administration be available closer to home (or in the home). Providing local pathology services was also considered positive for both metropolitan and regional consumers. It was also suggested though that some of these services could be located in one location such as a comprehensive care centre.

Regional Consumers Preferences

Regional consumers were consistent with Metropolitan consumers in their suggestions of services that could be provided closer to home. Chemotherapy and Immunotherapy provided closer to home (or at home) were suggested.

Regional consumers had less consistency with their preferences around the location of their care. Some consumers shared mixed experiences with care provided locally.

"I have no real preferences; I would extend it be in the metro region though. I would only go as far as Fiona Stanley Hospital, but not Joondalup. You have to get from the airport to your accommodation, then your appointment. That's quite a way out. preferably, regionally gets treated in the Perth parameters... Most patients that have had cancer, I understand the surgery won't be local, but the ongoing treatment. Anything that can be done locally would be a better service and I'm quite happy to have the chemo local. If they can broaden that and do more chemo types that would be brilliant."
Pilbara Consumer, Uterus Cancer

"It needs to happen straight up in your care. You need to be put in touch straight away. Thinking about having care in Perth seemed in exhausting. But, having had the experience I have, I would have chosen my care to be had in Perth if I could. Because of the better surgeons."
South West Consumer, Breast Cancer

"The coordination for me, the difference, is quite exceptional [regarding care at FSH]. The appointments, the communication, having somewhere central to call and have something relayed. Here, because St John of God is private and public, and then there's radiation separate, and the surgeon which is totally separate again. If you're not used to the health system that is very confusing."
South West Consumer, Breast Cancer

*"My original treatment was in Bunbury, but the complications I had were not managed, and it meant I was getting sent to hospital every few weeks. It was so traumatic for my kids. I was getting nowhere. It took the cancer physio to step in multiple times to my radiation oncologist, because we couldn't get in touch with him as he's part time in Perth and here. the surgeon washed his hands and there was nobody actually looking after my care."
South West Consumer, Breast Cancer*

There was not a consensus amongst all participants that one configuration and location of services was right or wrong: it was not as simple as one location is best. People were concerned about the range of services, the care pathway and their experience of it and that account should be taken of where the person is located and what their circumstances are.

Further Context

The idea of a "one stop shop" was used by a lot of people in the 2019 survey of WA consumers and carer experiences of cancer in WA conducted by HCC, as part of the engagement strategy in the development of the WA Cancer Plan. There was interest in having multiple services providers and care providers under one roof in a timely manner to minimise the stress and hassle of navigating between care sites. This was not, however, something that was pursued in the development of the WA Cancer Plan as it was considered out of scope at that time. The change in the funding environment and national policies towards having a network of comprehensive cancer centres in all jurisdictions, however, means that further consideration needs to be given to consumer perspectives on the configuration and location of care services in general and in a comprehensive cancer centre in particular.

C: EXPERIENCE OF CARE

In this consultation cancer consumers were asked to reflect on their interactions with cancer services: what was difficult, what was done well and what improvements could be made. Many of the issues raised were about the process and experience of care rather than a clinical or survival outcome. Some did identify where things happened during the pathway and their experiences that have had lasting impacts on both quantity and quality of life.

Consumers most commonly discussed issues covered within Priority Three (Western Australians with cancer and their families live well) of the WA Cancer Plan 2020-2025; particularly the objective to “support people affected by cancer”. The majority of participants discussed, in detail, an experience of poor awareness of, and limited access to supportive and psychosocial care through their journey. Participants definition of psychosocial care, and the role of the Department of Health in this, is likely beyond the scope outlined within the WA Cancer Plan 2020-2025. Participants also felt there was a responsibility to provide support where there was no existing or readily available support provided by community services.

Difficulties with attending appointments were often discussed, and many consumers felt there was a need to ensure transport support was provided by Department of Health, particularly for consumers with low income and from regional areas.

Consumers and carers also discussed objectives related to Priority Two within the WA Cancer Plan 2020-2025 (Western Australians receive optimal care). Participants shared stories regarding poor coordination of their care and difficulties with communication to their team. Many consumers also discussed their ability to make informed decisions about their care and felt the role of a nurse coordinator (for those who had access) and/or peers who had lived experience with similar treatment were extremely important to this.

These experiences will be considered in two sections:

C1: Navigation and Coordination of Supportive Care pathways.

C2: Access to Optimal Care.

Further Context

Cancer care historically has been evaluated in terms of outcomes such as five-year survival. The *WA Cancer Plan* identified that WA had higher survival rates than other countries participating in an international bench marking project. Although many cancers and many people have experienced great improvements, survival rates have not improved for some cancer types and there are also disparities for those living in rural and remote WA and Aboriginal people.⁷ The Australian Cancer Plan shows how the gap in age-standardised mortality rates between indigenous and non-indigenous Australians cancer has got bigger since 1998.⁸

Cancer outcomes are linked to the care experienced by those affected by cancer. As the *WA Cancer Plan* quoted “the outcome measure of their cancer care is not simply about their quantity of life,

⁷ *WA Cancer Plan*, p.4
⁸

www.canceraustralia.gov.au/sites/default/files/publications/pdf/2023_ACP%20Summary%20Report%20DIGITAL_V9.pdf p.4

whether they live or die, but, crucially, outcome is also about their quality of life through their treatment and beyond: that depends on the care pathway that they traverse”.⁹

In the cancer care pathway, care navigation and coordination are major challenges for many people affected by cancer, as is the lack of supportive care. All.Can International's *Patient Insights on Cancer Care* is one of the largest surveys of patient perspectives on cancer care, with more than 4,000 respondents in 10 countries: 22% of the respondents were in Australia and 68% of these had breast cancer which is commonly thought of as having more coordinated and supported care with the provision of breast cancer nurses by a number of organisations.¹⁰

Despite an over-representation of those we might have thought had more access to supported and coordinated care, many Australian respondents discussed a lack of coordination in their care. 30% did not have access to a specialist cancer nurse, 19% said that support from allied health professionals was not available when needed, 63% were not offered complementary therapies as part of their cancer treatment, 64% reported that they needed some sort of psychological support during/after their cancer care but, of those, 35% said it was not available.¹¹ As one respondent said, “Psychological support should not just be offered in the form of a brochure stating, “If you need help, you can get it here.” Many people will say they are “coping” when, in reality, they need support readily at hand. Australian Respondent”¹² Overall it was found “that cancer specialist nurses played a critical role in filling this gap, acting as the respondents’ companion and ‘navigator’ through the cancer care journey”¹³

The *Australian Cancer Plan 2023-2033* has prioritised improvements in care coordination and navigation in the first wave of implementation projects with an investment of “\$166 million to establish a new Australian Cancer Nursing and Navigation Program. The program will ensure all people with cancer have access to high quality and culturally safe care, irrespective of their cancer type or location.”¹⁴ This will include navigation tools such as online resources and navigators in the form of more cancer nurses and seeks to establish an agreed national framework to ensure these are available in all jurisdictions in conjunction with local provision.

These consumer perspectives on their experiences of care and already identified policy priorities both in WA and nationally provide context for the future delivery and configuration of WA cancer services.

C1: Navigation and coordination of supportive care pathways

From early stages of their cancer care pathway many consumers reflected on the difficulties they had in navigating the cancer care pathway they had been thrust upon and accessing the assistance they needed.

Importance of Early Connection to Supports Outside of Core Clinical Care

Some consumers were linked with support services during their cancer care, however, many expressed that an earlier connection or awareness of available support services could have resulted in a substantial improvement of their experience. Other consumers were not linked to support

⁹ *WA Cancer Plan*, p.3

¹⁰ <https://www.all-can.org/what-we-do/policy-research/patient-survey/> p.9 on navigators

¹¹ <https://www.all-can.org/what-we-do/policy-research/patient-survey/> pp.66-67

¹² <https://www.all-can.org/what-we-do/policy-research/patient-survey/> p.40

¹³ <https://www.all-can.org/what-we-do/policy-research/patient-survey/> p.9 on navigators

¹⁴ <https://www.health.gov.au/our-work/australian-cancer-nursing-and-navigation-program>

services they felt were necessary, which could have significantly influenced their experience. These services often focused on the role of a nurse coordinator (or similar), even though many were unaware of their availability for some population groups. Other services consumers discussed focused on supporting their psychosocial health and financial and other practical supports.

“Those first few weeks were probably the worst weeks. There were so many unknowns as we were waiting for the first few rounds of tests. You get cast back to the world with a piece of paper but nothing in between. That’s a couple of weeks of rumination, what might be happening, that’s I think where you need to potentially need to be checking in with people. Even just a phone call from someone who’s part of a care team. Ask how things are going, it doesn’t have to be the Oncologist. And then the journey or process could continue on, and the check-ins might not need to be so regular. Perhaps once a month after tests or something.”

Metro (East) Carer, Rare Cancer

“The psychosocial needs are things that might be missing often. It’s all very much, you’ll need this and this. Very rarely is it, ‘you might also need this’. If you know what’s ahead of you, you can prepare. ... People don’t know what to ask for. If you didn’t know you’re left very much high and dry.”

Metro (South) Consumer, Breast Cancer

“Then, the next time I came in I had another oncologist. I was trying to find information on stress management and dietary stuff, they told me they had no idea. Then I asked another oncologist, and they told me to just reduce sugar and there’s nothing I can access. Then I found my own way to the psycho-oncology services, I knew they existed because I did a lot of searching and then self-referred to it. At no point was I told about Solaris even though they offered diet, medication, counselling, services in the same building and are funded by DoH.”

Metro (East) Consumer, Rare Cancer

This sentiment was echoed by many consumers from regional areas. A subset of these consumers felt that the issues were more pronounced for them due to their location, resulting in not only a lack of services available, but also a lack awareness or connection to these.

“It would be good to know how to contact the Cancer Council, Millroy House, places you can stay for free. Depending on what type of cancer you have there are different types of supports available like Pancare, BreastWA; I think different packages for different types of cancer. They might not need it, but something they can look at in their own time. All of that would be a great benefit and can ease part of your burden. Even the counselling available.”

Midwest Regional Consumer, Melanoma

“We need to make sure the oncologists are utilising the service here as much as they can. Some clients have had to push the oncologist to refer them up here as the oncologist naturally refers them to Perth.”

Pilbara Consumer, Uterus Consumer

There was also a lack of service coordination between sites which is particularly problematic for those travelling large distances.

“I have to drive down for my appt the day before (for blood tests) because Jurien Bay is Western Diagnostics, and it takes 4-5 days to get to SCGH apparently.”

Wheatbelt regional Consumer, Myeloma

It was also thought in some settings there was a reluctance to offer some potentially supportive services.

“There is a stigma associated with palliative care and children. Oncologists are a bit reluctant to bring that into the picture. Even though [name] doesn’t have a cure, it really wasn’t until the last two or three years within the hospital that we were allowed to access the palliative care service through oncology, and that was through my own request. It wasn’t something they brought up or discussed. The earlier they are involved in the journey, whether it be a successful outcome for a child or not, it is a really important part of the cancer journey. They can provide a great service.”

Metro (East) Carer for Young Adult, Brain Cancer

It is worth noting that WA Cancer Plan priority 3, objective 3 is to “integrate Palliative Care Services”.

For those that did find out about and gain access to them there was particular praise for some of the supportive care offered by health consumer organisations. Solaris Cancer Care was frequently mentioned as was Dot’s Place in Bunbury. Access to complementary therapies, exercise, psychosocial support from counsellors and peer support were all highly valued and seen as key elements in holistic supportive care pathways.

Nurse Coordinators or care navigators

Some consumers who were assigned a nurse coordinator, or someone else, such as a social worker or carer, who took on that role for them during their cancer treatment, frequently emphasised the significance and influence of this role. Most consumers highlighted the necessity for a position that is typically served by a nurse coordinator, and the potential effect it could have had on their care (even without having been assigned someone in this role). The most frequently cited advantages of having a nurse coordinator were psychosocial support, help with comprehending medical information, and assistance with care planning.

“One of the things I found with the Oncologists, and one thing I found extremely difficult, they gave me three choices of different drugs for chemotherapy... It was basically the information was given to me and I had to choose what to do, and it was just given some written information. You were between a rock and a hard place, and you had to choose the one you can handle. It’s good to have choice, but at the same time you don’t know. If I had that nurse available, it would have been helpful. It’s so clinically driven, and you want it more contextualised so it can fit in your own situation”

Metro (South) Consumer, Breast Cancer

“We weren’t referred to anything, it was only by accident [name] found out they could self-refer to the spleen association. Having a care navigator or something like that, you get referred to and they can go through a checklist of seeing if you’ve been referred to things like the Cancer Council. Go back and investigate things for you then come back. That would be a really positive piece to the journey. Especially in the first few weeks, there’s a lot of things occupying your mind.”

Metro (East) Carer, Rare Cancer

“It took me five weeks to confirm what stage. Nobody was in touch with me, I had five weeks of not knowing if I had a death sentence or not and I was separating with my husband at the time without a support network... For five to six weeks, I didn’t know if I was going to survive. Six weeks into my journey is when I saw a breast care nurse, she was extremely good, but they are also limited as to what they can do.”

South West Consumer, Breast Cancer

Communication to Consumers

Numerous consumers voiced concerns regarding the absence of effective communication as well as coordination in their care. Some consumers reported challenges in communication between

themselves and their care team caused by a lack of a designated contact point. Additionally, consumers indicated the communication abilities of their clinicians, particularly when it comes to discussing sensitive news was poor at times.

“The GP’s I don’t think have got enough experience on how to tell somebody you’ve just been diagnosed. I know one friend was given a diagnosis, a list of surgeons and told to go find one. That’s devastating because you’ve just been told you have cancer, the first thing that comes to my mind is death. You are leaving that very first diagnosis and going to find a surgeon, you are in this bubble. That’s not an easy thing to do and make all those phone calls, then to deal with the next steps. Unless you’ve had to use the PATS system, you don’t know that exists. The doctors aren’t giving the whole package. Right at that time, the GP’s should be giving you a package that says, ‘there’s this local service available’.”

Pilbara Consumer, Uterus Cancer

Another consumer was told devastating news about their diagnosis from a tertiary care site.

“The next day I went to work and got a phone call to say it was unlikely it was a primary cancer; it was metastatic as well. I felt I knew what they were saying but it was significant news. I felt it should either be delivered face to face, or preface someone should be with me. There was then a sense of urgency, I felt I was going to die. I had no connection with services, no offer for a follow-up call. She also told me she wasn’t the right oncologist to manage the case.”

Metro (East) Consumer, Rare Cancer

The communication needs of different people varied too.

“These are young people (patients) getting to the system, they don’t have the skills. There are people that do not have those communication skills, I feel it is important for particularly oncologists to take into consideration family and carers as part of the team.”

Metro (North) Carer, Brain Cancer

Lack of access to interpreters was also identified by a carer of linguistically diverse parents. This put pressure on the carer who was also trying to absorb the information and attend to their own and their parents’ emotional needs.

Care Co-ordination and Communication between disciplines and care sites

Of the 28 different experiences of cancer care pathways discussed in the consultation 16 of these explicitly referred to experiences of care in multiple sites and settings. This was more common for those living in regional and remote locations, but it was also the case for 7 of those based in metropolitan areas.

Receiving care across multiple sites, between primary and tertiary and allied care services created challenges for the coordination and navigation of care, communication in general and the flows of information between people. Even for those being treated in one main site the navigation and coordination of cancer care pathways was often mentioned as a challenge. Although experiences of coordination at Fiona Stanley Hospital were generally positive there was some concern raised about coordination, navigation and communication within the Sir Charles Gardner Hospital site.

“The cancer centre sits separate to radiology which is separate to Pathwest but there doesn’t seem to be anyone taking carriage and ownership of coordinating that. The ability to have transparency yourself even, whether through a web portal an app, to at least see here’s my appointments and where they are booked in. So, you know there’s a clinic appointment coming up, and having prompts.

I think as well though, is it the patient's responsibility to be making sure these things are being actioned and followed up? I think with the type of situation, it's quite an emotive place and journey, people are looking for support. We have quite good health literacy, and there are many who don't. I can only imagine how frustrating and difficult it might be to navigate. I think there is a need for a central contact, and coordinator. They can be an admin person almost with cooperation to the oncologist. It doesn't appear people are talking to each other. "

Metro (East) Consumer, Rare Cancer

Being referred from one site to another within the metropolitan region was also problematic. For one patient referred from RPH to SCGH they felt "there was no real pathway". There were delays between sites, referrals went to the wrong place, and then when seen they were "told off for how long it came to my appointment." Even when they were in the system:

"I've seen three oncologists at SCGH, you're never told your oncologist has retired and your new referred one... I understand the role of the oncologist is different to a GP, they are a consultant who focuses on a particular thing. But a cancer support nurse, social worker, peer navigator, something like that who is assigned to an individual, when they receive a diagnosis. If you are on the watch and wait, you are still on the watchful eye of the oncology team, if there is someone to help you find the support you need or you meet with them after and they provide you with the range of services available for people in WA, and their carers and their family."

Metro (East) Consumer, Rare Cancer

A number of consumers shared instances where clinicians displayed a lack of understanding of their care needs, requiring the consumer to inform the clinician of their medical history in their appointment time. Additionally, many stories of communication breakdowns within care teams were shared, of which many could have had significant health implications to the consumer had they been unable to identify them.

"The communication has been really hard. I've had to tell them how to do their job at times. I'd have to mention I'm meant to have an ultrasound as well as a mammogram. The oncologist would forget to include one of the recommendations, and things fell off. Sometimes I would have stand-in oncologists as well and they wouldn't understand."

Metro (South) Consumer, Breast Cancer

"Every time I have sat down, the oncologist has opened my files and test results and reads them for the first time in front of me. Except one time, the most recent. They are scanning the test results and doing diagnostics as I am there. "

Metro (East) Consumer, Rare Cancer

I think the better access to notes would be the reason I would have better treatment at Fiona Stanley Hospital. (When moving between sites) they look at me and go, why are you here? They can't see the journey, the ultrasounds, they also to some level didn't necessarily believe me. Some of them were quite serious surgeons. I would go all the way up to Perth, tell them my story, and they would say I have to go back home and come again for another appointment. They didn't fully believe my story."

South West Consumer, Breast Cancer

Once consumer felt they had to provide the communication and coordination between members of their care team.

"I had a MDT. When you have that, how the different people work is great. I had a radiologist, doctor, oncologist, surgeon and GP. I'm quite good at grasping things, but I had to navigate communicating with that team. At times I found myself writing to all of them. Even just a flyer to know who to talk to, you have a MDT and this is what it means. That would've helped me navigate. Even the breast care nurses, I was given a card, but I was never in touch with them really. They were too busy. On the card, how long they are going to be working with you. Medical oncologist, surgeon, I am seeing them for

*five years. It would've been nice to know that. How often to go to my GP as well. the other people were so involved, but I struggled to keep my GP involved.
Metro (North) Consumer, Breast Cancer*

There were also concerns about how Emergency Departments interfaced with cancer services within and between sites. Those who were diagnosed as a result of admission via ED felt they were not referred to appropriate services as a result. For those already diagnosed and high-risk oncology patients Emergency Departments did not necessarily want to admit them.

*“When I finally got home from being diagnosed, I woke up on Christmas day and had a temperature, even then I went to the ED, and she was trying to turn me away. I sat down and cried, another nurse came in, and said I’ve just recently been diagnosed with cancer, told I have to go to ED, and I wasn’t being allowed to check-in. I ended up being in hospital for 3 weeks and had covid, and a serious bowel infection. I had to go again, I had myeloma in my eyeballs, she tried to turn me away and give me drops, saying there’s nothing we can do.”
Wheatbelt Consumer, Myeloma*

*“With ED waiting areas, going into ED you are not obviously going to be seen straight away. For people that have chronic pain and illnesses and are immunocompromised or palliative, they aren’t really taken care of in the waiting areas. An idea I’ve discussed with the care team at FSH is having an area that is separate for people to wait who are immune compromised. The waiting time is always going to be an issue, but the waiting area and hard seating, being stuck there for hours, we waited five hours for these seats. [name] had an enormous amount of pain due to having to sit in this waiting area. we are sitting there with people coughing. Being exposed to viruses. You already have stress and that really heightens it.”
Metro (North) Carer, Brain Cancer*

In summary, the main potential improvements to cancer services identified by consumers centred on the need for more psychosocial supports to accompany their clinical care, better communication and assistance in navigating and coordinating their care.

These supports often focused on supports that assist with the consumers psychosocial needs (such as nurse coordinators (or similar), counselling and psychiatry) as well as financial and practical supports (such as transport assistance, assistance with navigating financial supports available). A significant number of consumers and caregivers found the support beyond their primary clinical care to be immensely advantageous and impactful to their care. The value of these services was universally acknowledged by all consumers.

This finding is consistent with earlier consultations in WA. In 2019 the HCC received 183 responses to a survey of consumers and carer experiences of cancer in WA. The findings were presented to WA Health as part of the engagement strategy for the development of the WA Cancer Plan and were used to inform the development of the priorities and actions in the plan.¹⁵ Key findings included:

- Many people experienced uncoordinated and fragmented care.
- Communication and information flows were problematic between members of the clinical team, and the team and consumers.
- People valued having one person to turn to for information, support, coordination and to help them with care navigation. Cancer care coordinators and cancer nurses were both identified.
- People wanted more information about care in a centralised place and for GPs to have more information to share. That information should be easier to navigate.

¹⁵Cancer Healthcare in WA. Consumer insights – June 2019, Health Consumers’ Council.

In October 2022 HCC co-hosted a community conversation with Consumer and Community Involvement Program (CCIP) for people with lived experience of cancer. Over 50 people registered to attend and 23 attended virtually on the night. Not everyone contributed to discussion given the format, but several key themes emerged in consumers' perspectives on cancer care in WA. Fragmented and uncoordinated care that was hard to navigate was an issue raised by six people. Inadequate support, particularly of a psychosocial nature and from peers was also a concern raised by six.¹⁶

Priority three of the *WA Cancer Plan* is that "Western Australians with cancer and their families live well". It identifies the importance of strategies to "ensure access to supportive care for all following a cancer diagnosis", for that care to be culturally appropriate and for consumers to be empowered in their treatment pathways.¹⁷ This issue is still of primary importance for the delivery and configuration of cancer services in the future and further action is needed.

We will now consider what the barriers to access to optimal care may be.

C2: EXPERIENCE OF CARE – Access to Optimal Care

Optimal care pathways are designed to assist those in delivering services to offer evidence-based pathways to achieving the best cancer outcomes. Access to optimal care is a central concern of both the WA and National Cancer plans. The second guiding principle for the implementation of the WA Plan is that there should be "person-centred care with equitable access" although it is known that the burden of cancer and access concerns were greater for "Aboriginal people and those living in rural and remote locations".¹⁸

The *Australian Cancer Plan* "is designed to improve cancer outcomes for all Australians, and particularly for those groups whose **health outcomes** are poorest. Achieving **equity** in cancer outcomes will be a fundamental measure of success for the Plan."¹⁹ It emphasises that "To succeed in improving cancer outcomes for all Australians, the implementation of the Plan is a shared responsibility and will require joint efforts from the entire **cancer control** sector." Equitable access to optimal care is an important goal for the future delivery and configuration of cancer services in WA.

Person-centred care is also an underlying principle of cancer care. In a value-based health system this can include people being able to access what they need, when and where they need it, within the constraints of a sustainable health system.²⁰ Whilst health systems are not individual in their design when considering future service delivery and configuration it is informative to explore what consumers see as the barriers they encountered in their care pathway and what could help facilitate better access.

Those people who felt that they had good access to care were often those who had some experience of someone acting in some sort of navigation and coordinating role for them, whether that be a nurse, or social worker or another member of their treating team or carer who assisted in that role.

¹⁶ Connecting and communicating consumer perspectives on cancer care in WA Discussion Summary, Health Consumers' Council, 2022

¹⁷ Department of Health Western Australia. *WA Cancer Plan 2020-2025*. 2020. Perth: Health Networks, pp.26-28

¹⁸ *WA Cancer Plan*, p.2

¹⁹ <https://www.australiancancerplan.gov.au/welcome>

²⁰ Add reference value-based health care??

There were, however, multiple barriers to access encountered by people whether they were based in the metropolitan area or not, although the difficulties for those in non-metropolitan areas were greater when they had to travel for appointments. These barriers regarded appointment times, physically accessing care sites, and the need for more financial assistance to cover travel costs and in some cases accommodation. These will be considered in turn.

Impact of Appointment Times to Consumers

Numerous consumers expressed that one of the most significant challenges in their cancer journey has been navigating the inflexibility and short notice of their appointments wherever they were located.

“It was like a full-time job managing my appointments. I was juggling work, school, everything else. You are in the cycle of being where you are told to be. When you are in the system, you have to surrender yourself to that, and be at their beck and call. ...Sometimes you might get appointments at the same time, and they clash, and you have to work that out.... I don’t know if preferences of appointment times can be considered of if you can have a few on the one day to be smarter about it.”
SMHS catchment Consumer, Breast Cancer

Even when consumers identified that they could not attend at certain times providers did not take this into account. For some this had impacts on their caring responsibilities for children and their ability to attend school. For others it meant missing out on parts of their life.

“They will always book appointments at 8:30 or 3:30, even though I tell them I need things in between school times. Then they never change them, and my son misses school. I can accept it sometimes, if I have to go to Perth, but that I can’t manage a half hour appointment in Bunbury is very frustrating.”
South West Consumer, Breast Cancer

“Recently they planned an appointment for me while I was travelling ...They told me you can’t cancel this appointment otherwise you have to wait another six months. I had to tell them, I had been waiting eight months for this appointment, and I told them I was going away during this period of time. I had put it in writing, I had rung them, SMS’d the patient experience service, and also told them verbally that I was not going to be available during that time. They told me if I put the appointment back, I could lose my treatment altogether. They expect you to be available for them.”
SMHS catchment Consumer, Breast Cancer

One carer talked about the difficulty of appointments in multiple places and at irregular times.

“If you knew it was at 11 o’clock every 21 days it would be good. Because you don’t know until short notice with a piece of cardboard, I’ve had to cancel a lot of my things. I’ve recently found a community transport that can help out on Saturdays, I’ve managed to get them to take over more of his transport to his treatments which has taken a bit more of the pressure off me. I seem to spend all my weeks taking him to various appts. Whether that’s Fiona Stanley, Armadale for a group, whether its physio.”
Carer of SMHS Catchment Consumer, Lung Cancer

Irregularity of appointments and short notice was raised by others.

“Because I was going to be traveling to FSH over a period of times, it would’ve been great to know the dates it was going to be. Surely you could know more than a few days ahead. The planning of your treatments coming from the country to the city would be better done much further in advance.”
Consumer resident in South West being treated in SMHS, Head & Neck Cancer

The needs of the person being treated may not routinely be taken into account when scheduling appointments. An 84-year-old person being admitted for surgery at a hospital about 100km from their home was told:

"I had to be at the surgery appointment by 6am, so I asked to be admitted overnight so I didn't have to travel into town. I have private health insurance, but the hospital or insurance said it couldn't happen. They told me it was for social reasons, although I didn't consider it a social reason. The surgeon managed to intervene, and I could be admitted."
SouthWest Consumer, Breast Cancer

In some households there may be more than one person with cancer and appointments are not coordinated in their scheduling.

"She had breast cancer first, then she got another cancer and now has multiple myeloma. Now her husband has skin cancer. The two of them have chemo down in Perth on separate days. They are separate diseases and being handled. They are spending so much time on the road, so much money, because they're both dealing with cancer."
Carer in Wheatbelt

Inflexibility of appointment times not only affects access to care, but it can also affect patient safety not only for them driving in the dark but also because they have to leave their son home alone for longer.

"The treatment is pretty good; the bad thing is not getting the appropriate times. I have treatment once a week, I have to drive down once per week. It's just shy of 300km to a hospital. They always have my appt late in the day, I always ask them to bring them to before 11am so I'm not driving home in the dark, but they never do. Apparently, they have patients in the morning that take priority over me, I keep requesting and I had one once, but they keep saying no. I don't like driving back in the dark regionally with kangaroos. They say it's a 5-minute appt, but it always takes a few hours."
NHMS consumer resident in Wheatbelt, Myeloma

"So, she has to go to Perth for two days. She can't go in the morning because it's all the people have IV in the morning; she can only have her treatment in the afternoon. Which means she's down there two days and she's been travelling straight back after her treatment. It's two-hour drive, it's too much for a body. Each two-day trip means her son is two days home alone. And the cost of parking is ridiculous, why do we have to pay for parking. It costs between 22 and 35 and no financial help for parking."
Carer of above NHMS consumer resident in Wheatbelt

In general, it would seem that appointments are scheduled according to the needs of providers without necessarily taking into account the circumstances of those receiving care and whether or not they have created barriers to their access.

Physically Accessing Care Sites

A recurring issue highlighted by consumers is the struggle they faced in physically getting to their appointments. These difficulties were both practical and financial. The practicalities centred on transport and parking issues. The need for financial assistance and the workings of the PATS scheme will be discussed in the next section.

Consumers regularly discussed parking issues for all metropolitan sites highlighting the financial and physical difficulties with attending their appointments. Some consumers expressed the costs being prohibitive, to the point of considering ceasing treatment. Some consumers also expressed the accessibility concerns when walking large distances and being very unwell.

"Last year I had eight admissions for up to two to three weeks a time. It cost my family genuinely thousands of dollars in parking. I can't work, but do we go into further debt? It's really, really difficult financially. We would've spent at least \$2,000 for my family to see me and support me."

Midwest Consumer, Melanoma

"The cost of parking is ridiculous, why do we have to pay for parking. It costs between 22 and 35 and no financial help for parking."

NHMS consumer resident in Wheatbelt, Myeloma

"It's not just the cost, you can't even find a spot sometimes at Fiona Stanley."

Metro (South) consumer, Bladder Cancer

"I have found the cancer side of FSH to be really, really good. Parking is horrendous and it is one of my biggest stresses. There is nowhere to park nearby if you can't get a spot. There is always a stress."

Consumer resident in South West being treated in SMHS, Breast Cancer

But experiences of accessing different hospitals and parking varied.

"In terms of travelling there, it was pretty good as it's the first hospital. We never struggled to find parking in 2015. I've had experience in Charlies as well, but my preference was to go to Fiona Stanley Hospital."

Consumer resident in South West being treated in SMHS, Head & Neck Cancer

"It being at FSH it has been fairly convenient because it is a relatively short drive. I had to use uber a fair bit though. Occasionally I had a friend that could drop me off. Then when I had to have radiotherapy, 5 days a week for 5 weeks.... I chose to have my sessions first thing in the morning at 7am so parking was available and free. Any heavy treatment you go through, it would be great if there were particular spots where if you were going at different times of the day, short term in and out, like a 15-minute spot"

Metro (South) Consumer, Breast Cancer

"He was at Charlies for a couple of weeks, which was a nightmare for parking.... I have an ACROD sticker but the closest parking and the time I was able to get in to go see him, and certain times of the evening, they close certain doors within the hospital. You can't even get through departments."

Carer of SMHS resident treated at multiple sites.

"Cost of parking is stupid, accessing general public carpark is really frustrating. Scheduling appointments between 8:30 and 10:30 and late afternoon should almost be a no-no purely because of how hard it is to get there. The (SCGH) cancer centre was pretty easy to access. Underground parking was okay, never had issues with that. We only found out the cancer centre had a separate carpark later on and that was really helpful, we never had issues. "

Metro (East) Consumer, Rare Cancer

The use of public transport was also discussed. Whilst it made access to some sites easier as it avoided the need to park it was not without risks.

*"Travelling to Fiona Stanley was really easy, the parking was **** though. I had to stay in hospital for two days, and with the trains I don't have a problem, but when you have to drive it's much, much harder."*

Metro (East) Consumer, Head & Neck Cancer

"Once I was in Perth, I was using trains and buses because of the expense of parking, but of course you aren't meant to be in public spaces with your immune system. That's something I feel strongly and passionate about, the survival outcomes shouldn't be dictated by where you live."

Consumer from Wheatbelt who moved to Perth for treatment, Breast Cancer

Others pointed out that it was sometimes assumed that they would be able to organise their own transport regardless of the time of day, the state of their health or the availability of others to care for them.

*"I had to go back in one time for surgery and told I was staying overnight, then at 8.20pm they told me I can go home. I told them I'm not feeling well, and I have nobody to pick me up. I was basically kicked out, the anaesthetic wore out when I got home, and the next day I told them I'm not feeling well. I think the shift was finishing or something. There is an assumption you have supports around you."
Metro (South) Consumer, Breast Cancer*

An Aboriginal person from the Pilbara had experience both of having cancer themselves and caring for their mother who subsequently died. She described the burden on the whole family of taking turns to take her mother to Perth for treatment.

*During chemo. mum had to come to Perth every 3 weeks for a day. This meant flying down to Perth, getting a taxi to the hotel, leaving luggage as it was too early to check in, going to RPH, having chemo, going back to the hotel, sleeping, getting a taxi back to the airport, flying home.
Pilbara Carer, Breast Cancer, Aboriginal*

Family members took time off work and away to other caring responsibilities to accompany her. Furthermore, owing to the difficulties of actually travelling between all the sites they needed to in the Metro area for her care they brought a car down to use once they had flown in. On many occasions she said they also came to Perth for an appointment that was unnecessary or had to be delayed because tests that were required hadn't been ordered.

*"...one incident before ... Mum's cancer surgery ... they hadn't had a required radiology scan and they needed to get from SCGH to FSH for a scan within an hour – on public transport as they didn't have a car – or the surgery would have to be delayed."
Pilbara Carer, Breast Cancer, Aboriginal*

The fear and distress this demand caused was so unnecessary to a family already highly stressed. Miscommunication and unrealistic requests were common throughout this journey.

There was also discussion of bureaucratic barriers to accessing care with boundaries between care providers and contracts meaning care was not centred on the person.

*"One of the first things that challenged me was the concept of ownership by hospitals. I was diagnosed by an ENT guy in Bunbury then sent to RPH. Had the biopsy up there before Christmas. When I came back to Bunbury, I left RPH with a whole raft of equipment. I had to go from Bunbury to Perth every month to get a checkup and get more equipment (from FSH). About 3 months into that, when I was told, FSH no longer provides equipment to consumers as it's cost prohibitive. They said I am a Bunbury patient, and it has to be supplied there. That never happened."
South West Consumer, Head & Neck Cancer*

Other regional consumers said that whilst it may be closer for them to access services in one location they could not because contractually they were considered to fall within the remit of another catchment area. This was the case for clinical and supportive care services.

Again, some consumers described experiences of provider driven systems that did not adequately take into account the barriers they may experience in physically accessing their care in the way it was configured and delivered.

Financial Support, PATS eligibility and access

A number of consumers who had difficulty physically accessing their care indicated that their financial difficulties, which are often intensified by a decrease in income due to their illness, made the cost of transportation a significant burden. There is a common suggestion among consumers that the availability of patient transport services needs to be increased.

Consumers also suggested implementing a means-tested approach could be an effective solution if demand was a concern.

"I was in a very familiar position in terms of not qualifying for any fuel reimbursement by, I think, 5 kilometres as well. That was huge, because we went from a 2-income family to a 0-income family. I don't know what people would do. If there's nobody to drive you, you'd be stuffed."
South West Carer, Stomach Cancer

"Just like older adults get a home care package, I don't understand why someone who is extremely ill can't get something like that. Travel, having a card to use. "
South West Consumer, Breast Cancer

"Rules of PATS means everyone gets treated the same. For example, you can be 20 and healthy, have a rich family and know the city very well and break your leg and have to come to Perth for a specialist and that person is treated exactly the same way with the same rules as a 75 year old Aboriginal woman with no family support and no money and who is undergoing chemotherapy for cancer and is chronically unwell, doesn't know the city or the transport system or the hotel accommodation system. It doesn't make any sense and is very unfair."
Pilbara Consumer & Carer, Breast Cancer, Aboriginal

Consumers found the process of applying for PATS assistance could be both burdensome and stigmatising.

"Being isolated on my farm.... I might have accessed PATS. During it, it is chaos, trying to figure out how you are going to complete your treatment for a day, how you are going to feel. The PATS involved getting pieces of paper signed, very labor intensive and all the onus on you to get things submitted and signed off. I don't even think the subsidy was even close to covering any of the costs either. the PATS forms were so patronising. They made me feel like I was scrounging, like I was going to headmistress to get my permission slip. The whole way it was done, it felt like I was scrounging for \$20, having to get signatures for my treatment, it was horrible."
Wheatbelt Consumer

"My friend ...is dyslexic. For her to have to deal with multiple forms is debilitating. It adds a level of stress where her disability already makes her feel inadequate. But when she has to deal with that on top of her illness it makes it really hard"
Carer of above NHMS consumer resident in Midwest

When people were eligible for PATS, they found that the criteria for use and the system for reimbursement meant it may not meet their needs regarding both travel arrangements and cash flows. Whilst forms needed to be filled in every time it could take 6 to 8 weeks for reimbursement which was a long time for those on very limited incomes.

*PATS is too rule bound, bureaucratic and tight. They only want to book the cheapest flights, which can mean that you must fly at times that can be really difficult. They don't understand that with mobility issues you need more time to be loaded into a taxi and airplane.
PATS tell you that if you miss the flight you must pay for your own way home. If a hospital appointment runs over, and you miss your flight for no fault of your own, what are you supposed to do? Often you can't contact them after 3pm to let them know.*

Dealing with PATS is soul destroying. Dealing with PATS was sometimes harder than dealing with knowing my Mum had cancer and was probably going to die. These types of systems make life so much harder than they need to be – it is already hard enough.
Pilbara Cancer Consumer and Carer

Some of the problems with PATS are – we had to go and come back in the shortest amount of time. You can't stay down for multiple days. My first appt would be at like 7:30am at the hospital, I would have to get up earlier than 6:30 in pain and on drugs. That was a nightmare. It was not fun. Then you get on the soonest flight after your appointment, and if it ran late, you'd miss your flight. I eventually let them agree to a later appointment as it wasn't possible for me physically to get to those. More flexibility is needed. To have a day of appointments is shattering, flexibility to fly down the day before. A bit of flexibility on that would've been really helpful. You would often come down and they'd say, we need to have an extra test, another scan, and you're just worrying about trying to arrange yourself with PATS.

Midwest Cancer Consumer

The level of funding which was available was also considered insufficient by some.

PATS doesn't cover much – accommodation reimbursement is very low. It doesn't recognise the fact that accommodation (hotels) costs a lot more than that. The taxi voucher never covers the whole trip to the accommodation or hospital and taxi drivers can and do refuse service and drive off.

PATS can be more stressful if you don't have much money – trying to come up with any extra money can be really hard for Aboriginal people who mightn't work or have much money.

Pilbara Cancer Consumer and Carer

Access to a range of services

Whilst it is a guiding principle of the implementation of the WA cancer plan that care should be “person-centred and equitable” this does not seem to be the case for all, particularly with respect to location. Access to a range of quality services in different sites was also raised. In the 2022 community conversation about cancer services in WA some concerns were raised about geographical inequity saying that in regional areas access to care is not equivalent to metro.²¹ This is consistent with the findings from this consultation too.

“If I had the choice, everything you need or want is in Perth. I was still working, my house, family, work was in Bunbury. Your choices are a little bit limited. You can go for periods of time, radiation therapy, chemo, to stay in places in Perth. But the cancer treatment process is 12 months plus long.... the big thing I felt when I was in Bunbury, the surgeon and people who looked after me in Perth, is that you feel isolated. It's only a two-hour drive and a phone call but you are isolated you feel like you weren't getting the best treatment possible. Maybe the best available, but it certainly wasn't the best possible. Telehealth might be great to have a phone to pick up and talk to. When you're living regionally and your doctor is in Perth, it can be very hard to contact you and to contact them. ...The other thing is drug trials are often not offered to regional patients as you're too far away. There's certainly room to improve the medical situation of country patients.”

South West consumer received care in SMHS and South West

A consumer living in a rural location when diagnosed, moved to Perth to access care. This was due to the difficulty of travelling to appointments as a carer of two young children, the lack of local supportive care and concerns about cancer outcomes in rural areas.

I never anticipated to come back to live in the city at any point. Initially through my treatment I tried to commute. I had two kids in primary school, that meant I had to leave them down there in the care of my ex's family and come up to Perth. Anyone that has cancer knows you want to hold your nearest

²¹ Connecting and communicating consumer perspectives on cancer care in WA Discussion Summary, Health Consumers' Council, 2022.

and dearest close to you. I can remember one of those commutes, 2.25 hours drives, and I would have to stop multiple times, be unwell, or rest with two kids in the car. Quickly realised that wasn't going to be sustainable... Living in that isolated community it quickly became apparent the mental support was not there."

Wheatbelt Consumer

It was also suggested that some people's expectations were lower in regional and rural locations.

"I don't think people expect the same standard of care. Services can't be replicated for sparse populations, we get that, but one thing really scared me, and it was like, hearing of the data of survival outcomes of rural community members. It was so much worse. It's partly because they are choosing treatments that are less effective too as well, I think."

There was also concern that outcomes were worst for those in remote areas and that people needed access to culturally sensitive care and if coming off country they may need to bring their family with them. Furthermore, there was concern that barriers were put in the way of accessing local allied health services when they were available.

More integration with them around physio, OT, the mental health. We have a psychologist in town but she's a private practicing and not a DoH psychologist. You have the health department keeping itself insular rather than utilising the local services. I think a process where, if they are going to pay a health department OT, why can't she access a local OT and they use a Medicare number to get their payment through? That seems like a simple thing.

Carer of a Wheatbelt Consumer

Anything cancer related, nothing is done in Hedland, it's all done in Perth. The Karratha Hospital has opened a chemo ward and only doing certain types of chemo and trying to broaden that. If that's the case, that would be huge. If you're not well enough you're not allowed back on the plane. All you want to do is to go home. Be at home and go through your recovery through treatment at home. If I had chemo today, I probably won't make the plane as the last one is at 3.30pm. by then, the chemo reaction has kicked in.

Pilbara Consumer, Uterus Cancer

C: Experiences of Care: Summary

We know that people want supportive or holistic care, and this was discussed in terms of seeing the whole person, not just their cancer diagnosis and the treatment they are receiving for that at a particular time. It was not just whether and when it is offered, but what is the burden involved in accessing it? Whilst different people may need support with different things at different stages in their care depending on their individual characteristics, the characteristics of their cancer and their location there were three common areas discussed that all constituted dimensions needed to enable access supportive and holistic care. These were psychosocial, practical and financial support. Priority three of the *WA Cancer Plan* is that "Western Australians with cancer and their families live well". It identifies the importance of strategies to "ensure access to supportive care for all following a cancer diagnosis", for that care to be culturally appropriate and for consumers to be empowered in their treatment pathways.²² The engagement undertaken for this report shows these issues are as important now as they were back in 2019 when HCC received 183 responses to a survey of consumers and carer experiences of cancer in WA. These findings were presented to WA Health as part of the engagement strategy for the development of the *WA Cancer Plan* and were used to inform the development of the priorities and actions in the plan.²³ Amongst the key findings then were that people:

²² Department of Health Western Australia. *WA Cancer Plan 2020-2025*. 2020. Perth: Health Networks, pp.26-28

²³ Cancer Healthcare in WA. *Consumer insights – June 2019*, Health Consumers' Council.

- wanted to be supported and involved in decision making about their care.
- wanted to be treated as a “whole” not just a body part or diagnosis.
- People valued more support emotionally and mentally and practically and financially.
- People wanted a broader range of support for longer, up to five years after treatment.
- The financial impact of cancer was significant in terms of costs and loss of income.

This consultation also found the predominant topic among consumers and caregivers concerning potential improvements to cancer services centred on the need for more psychosocial supports to accompany their clinical care. These supports often focused on supports that assist with the consumers psychosocial needs (such as nurse coordinators (or similar), counselling and psychiatry) as well as financial and practical supports (such as transport assistance, assistance with navigating financial supports available). A significant number of consumers and caregivers found the support beyond their primary clinical care to be immensely advantageous and impactful to their care. The value of these services was universally acknowledged by all consumers. Consumers regularly discussed improvements that could be made to their cancer care within the clinical setting including improvements to communication and a need for flexibility with appointment times.

Any consideration of future service delivery and service configuration needs to consider outcomes and experience and align with goal two of the *WA Cancer Plan* “to ensure consumers have the best experience of cancer control”. Priority two states that “Western Australians receive optimal care” and “Optimal care is person-centred, safe, high quality, multidisciplinary, supportive, (and) well-coordinated”.²⁴ This consultation has shown there are still issues that need to be addressed.

D: SUMMARY AND RECOMMENDATIONS

Wherever care is located, and whichever care settings people may move between a key consideration is whether its configuration is provider or person-centred. Many of the difficulties of care coordination, navigation and access consumers told us about were because care was structured around bureaucratic and geographical boundaries that did not take account of their needs. In the absence of clear alternative options, it was difficult for people to identify a particular model that was preferred.

The feedback on current care experiences, which is consistent with many other findings, does suggest that the status quo is not delivering optimal, equitable, person-centred, and supportive care for many people.

It is clear from this community and consumer engagement and previous ones undertaken by HCC since 2019 that care navigation and coordination remain one of the biggest challenges faced by people affected by cancer. There is also inequity of access to various services. This is also consistent with national findings.

The idea of co-location of cancer services under one roof in some form of a comprehensive cancer centre was popular with many and participants identified some of the services it would be good to include. They were also keen to explore what services could be given closer to home or at home.

²⁴ Department of Health Western Australia. *WA Cancer Plan 2020-2025*. 2020. Perth: Health Networks, pp.20-23

A central theme of the consultation was consideration of what consumers need to experience person-centred, coordinated and holistic supportive care. They also wanted what they considered to be optimal care to be accessible equitably. Key considerations for a comprehensive cancer centre therefore include:

- how eligibility for access would be determined
- how it could be delivered in a way that improved the experiences and outcomes for many
- whether it could demonstrate a model of care delivery that levelled up that provided elsewhere

Consideration also needs to be given to how that care can be delivered in the most holistic and supportive way which still enables consumers to access the support they need from others such as family and community members.

Participants regularly talked about the importance of connection and linkage to psychosocial support services available to them early in the journey. Participants also regularly talked about the difficulty of the time between testing and results, and it is the facilitators opinion that consumers and carers should be connected or made aware to psychological services during this time.

Communication between staff and an understanding of the patients medical history was poorly experienced by consumers, as was the inflexibility of appointment times and the experience of the PATS. These issues are not isolated to cancer consumers, however improvements to these areas, in the facilitators opinion, would have a significant impact to consumers and carers.

Acknowledgements

HCC would like to acknowledge that these workshops and interviews were hosted from the lands of the Wadjuk Noongar people and pay our respects to their Elders past, present and into the future. We acknowledge all Aboriginal peoples continuing connection to culture, country, traditions and language and the demonstrated willingness to continue to lead all health services who want to provide a more holistic, person and community led care. We also acknowledge that sovereignty was never ceded, and that Australia always was and always will be, Aboriginal land.

We also would like to acknowledge the consumers and parents/carers who gave their time and shared their experiences so willingly. We thank them for their openness and generosity, all in the hope that by sharing, the system will improve for future consumers and families.