



Government of **Western Australia**
Department of **Health**

Culturally and linguistically diverse (CaLD) cancer information needs for consumers and carers project

Community consultation outcomes

Acknowledgements

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Executive summary

The Cancer Network at the Western Australian (WA) Department of Health undertook the 'Culturally and linguistically diverse (CaLD) cancer information needs for consumers and carers' project to better understand the cancer information needs of CaLD consumers and carers affected by cancer.

The network awarded 5 grants to community organisations across WA to conduct small group discussions and interviews with CaLD consumers and carers affected by cancer.

Discussions and interviews were held from August to October 2022. The findings are the result of engaging with 175 CaLD consumers and carers affected by cancer in WA through:

- 53 interviews
- 16 group discussions
- 2 written responses.

The 5 organisations captured 4 key themes relating to cancer information that were important and helpful to CaLD consumers and carers on their cancer journey. These themes included:

- how participants accessed cancer information
- how participants would like information delivered
- types of cancer information that are important to participants
- cultural needs important to participants.

Participants accessed information through a range of channels, including health professionals, family members and carers, interpreters and online information. Family members also played an important role in interpreting information. Information that is person-centred, easy to understand, and provided in stages was identified as ideal to help participants absorb information and avoid feeling overwhelmed. Participants also expressed the desire to be able to access information from a centralised place.

The different types of cancer information that were important to participants included:

- diagnosis and prognosis
- making an informed decision on treatment
- treatment costs and financial supports
- support services
- how the Australian health system works and
- lifestyle changes.

Several cultural needs were raised by participants, including language needs, cultural beliefs about cancer, respecting religious and cultural beliefs, the role of the family, and empowering CaLD people to advocate for their health needs.

Awareness and barriers to accessing and using cancer screening services was also explored. Despite a high awareness of screening programs amongst participants, participation in screening was lower. Identified strategies to increase participation in screening programs included general practitioners (GPs) encouraging screening, improving messages around eligibility for screening, and providing translated resources.

The network also captured detailed learnings from implementation to improve recruitment and engagement with CaLD communities. Strong community relationships and established trust were found to be essential, especially for recruiting and engaging with CaLD men and CaLD people living in regional WA.

Based on the findings from the project, the network recommends:

1. utilising established relationships and partnerships to recruit and engage with CaLD people
2. increasing the availability of co-designed cancer information and resources for CaLD consumers and carers, including access to online information in languages other than English
3. increasing the confidence and healthy literacy skills of CaLD consumers and carers to communicate their cultural and health needs to their healthcare and support team
4. investigating the role of health professionals, particularly GPs, in supporting the health and cultural needs of CaLD consumers and carers.

The project has contributed towards implementing key policies and strategies including, the [WA Cancer Plan 2020–2025](#), [Sustainable Health Review](#) and [Western Australia Multicultural Policy Framework](#).

1. Introduction

Western Australia (WA) is ethnically diverse with 32.2 per cent of the population born overseas.¹ Of those born overseas, 17.5 per cent were born in non-main English speaking countries, including India, Philippines, Malaysia, China and Italy.¹ The most common languages other than English (LOTE) spoken at home in WA include Mandarin, Italian, Vietnamese, Punjabi and Cantonese.¹

Currently there is no standard definition for CaLD status. CaLD status can be related to country of birth, speaks a LOTE, speaks a LOTE at home, proficiency in English, ancestry, cultural background and length of time since migrating to Australia.² People from CaLD backgrounds may also face greater challenges when navigating the Australian healthcare system, including language and cultural barriers and not knowing where to seek help or access services.³

Cancer is the leading cause of death and disability in WA.⁴ In 2017, the estimated risk of being diagnosed with cancer by age 75 was one in 3 for men and one in 4 for women in WA.⁵ Despite the high incidence of cancer diagnosis, cancer survival rates continue to increase in WA. From 1993 to 1997, the 5-year survival rate for all cancers in WA was 60.4 per cent, and rose to 71.7 per cent from 2013 to 2017.⁵ Greater awareness of cancer and its risk factors, participation in screening programs and improvements in cancer treatment and care have contributed to higher survival rates in Australia.⁶

The [WA Cancer Plan 2020–2025](#)⁴ outlines the direction and key priorities for cancer care in WA. The plan identifies a need to address health disparities for priority groups including Aboriginal people, people living in rural and remote areas, and CaLD people.

A desktop review and consumer survey was conducted by the Cancer and Palliative Care Research and Evaluation Unit (CaPCREU) to assess cancer information needs for Western Australians.⁷ The review found that limited CaLD specific cancer resources were available and CaLD communities were significantly underrepresented in the consumer survey. The CaPCREU reporting team recommended an investigation into alternative engagement strategies to identify cancer information needs for CaLD communities across the cancer journey.

Additionally, CaLD communities in WA may face more barriers to accessing and understanding cancer information compared to non-CaLD Australians. Language barriers and cultural differences may prevent CaLD people from receiving health information, and lead to delayed treatment and worse health outcomes.⁸ As a result of these barriers, the network undertook a project entitled the 'CaLD cancer information needs for consumers and carers' project to better understand the cancer information needs for CaLD consumers and carers affected by cancer.

2. Aims, objectives and strategic alignment

The aim of the project was to explore the cancer information needs of CaLD consumers and carers living within WA. The objectives were to identify:

1. strategies and learnings to recruit and engage with CaLD people affected by cancer, particularly CaLD men and CaLD people living in regional WA
2. the key information needs of CaLD people affected by cancer, including useful sources of information and gaps in the sources of information
3. language and modality preferences to inform the development and provision of information for CaLD people affected by cancer
4. CaLD peoples' awareness of and barriers to accessing and using cancer screening services.

This project has helped the department progress towards achieving key policies and strategies including:

Sustainable Health Review⁹

- Recommendation 3: Reduce inequity in health outcomes and access to care with focus on priority groups including CaLD people.
- Recommendation 4: Commit to new approaches to support citizen and community partnership in the design, delivery and evaluation of sustainable health and social care services and reported outcomes.

WA Cancer Plan 2020-2025⁴

- Priority 2, Strategy 6: Provide consumers with reliable information about their cancer care, treatment pathway and potential costs.

WA Department of Health Multicultural Plan 2021–2023

- Priority 2: Culturally responsive policies, programs and services.
- Priority 3: Economic, social, cultural, civic and political participation.

Western Australia Multicultural Policy Framework¹⁰

- Priority 2: To develop and implement culturally responsive policies, programs and services.

3. Consultation methodology

From May to July 2022, the network conducted a competitive expression of interest (EOI) process to identify key stakeholders to lead consultation with CaLD consumers and carers across metropolitan and regional WA. The network awarded 5 grants to community organisations to conduct discussions and interviews with CaLD consumers and carers affected by cancer to better understand their cancer information needs.

The successful organisations were:

- Ethnic Communities Council WA (ECCWA)
- Health Consumers' Council (HCC)
- Ishar Multicultural Women's Health Centre (Ishar)
- Multicultural Services Centre of WA (MSCWA)
- Umbrella Multicultural Community Care Services (Umbrella)

The successful organisations were asked to recruit and engage with CaLD people that were either cancer consumers or carers of someone with cancer. The organisations were encouraged to use a range of recruitment and consultation approaches that best suited their communities. The timeframe for consultation was August to October 2022.

3.1 Recruitment scope

Participants recruited for the project were CaLD cancer consumers and carers. A cancer consumer is a person who has experienced a cancer diagnosis. A carer is a person who provides unpaid care and support to family members and friends who have cancer.

For ethical requirements, all consumers and carers were required to be aged 18 years or older. This included carers of cancer patients under 18 years of age.

Currently there is no standard definition for CaLD status. Country of birth, speaks a LOTE, speaks a LOTE at home, proficiency in English, ancestry, cultural background and length of time since migrating to Australia can all be related to CaLD status.²

The EOI defined a settings-based approach to recruit CaLD participants. Rather than a list of inclusion and exclusion criteria, the organisations were encouraged to use existing connections and networks.

Participants were recruited through different methods depending on the capacity of the organisation and whether they already engaged with CaLD groups through their core business.

Strategies for recruitment included:

- word of mouth
- holding discussion sessions with existing CaLD groups that meet on a regular basis
- contacting friends or family members through the organisation's own networks
- being flexible and contactable outside usual business hours
- flyers and external advertising.

Each organisation applied their own knowledge and experience to tailor the consultation to suit their community needs. Interviews and discussion groups were conducted in-person, on the phone and via video call. The sessions were conducted at various times to suit each community group, including evenings and weekends. Some participants provided written responses.

Additional recruitment was focused on 2 CaLD sub-groups, men and those living in regional WA.

3.1.1 CaLD men

In WA, men have higher rates of cancer-related causes of death and experience a greater total disease burden than women.¹¹ The network recognises that to address men's health, there needs to be specific attention and resources tailored to men as outlined in the [Western Australian Men's Health and Wellbeing Policy](#).¹²

To increase the representation of men within the project's participant cohort, as well as identify key learnings on how to recruit and engage men from CaLD backgrounds, HCC was asked to recruit CaLD men living in WA.

Several approaches were used to recruit CaLD men including:

- existing panel member lists
- a WhatsApp message from a multicultural ambassador
- friends and family networks
- the Indian Society of WA committee.

3.1.2 CaLD people living in regional WA

Western Australians who reside in rural and remote areas are more likely to have preventable hospitalisations for several conditions, including cancer, compared with those living in metropolitan areas.⁹ People who live in remote areas face geographic isolation and have reduced access to health services, education and employment opportunities which can impact health and wellbeing outcomes.⁶

Therefore, the network selected regional CaLD communities as a key focus for the project to:

- improve representation across the WA regions
- capture their cancer information needs
- identify key learnings to recruit and engage CaLD people living in regional WA.

The HCC was asked to recruit CaLD people from regional WA for this project. Several channels were explored for recruitment including:

- neighbourhood and community resource centres in the Peel, South West and Great Southern regions
- Multicultural District Health Advisory Councils run by the WA Country Health Service (WACHS)
- local settlement and multicultural organisations, such as the Katanning Migrant Resource Centre, Great Southern Migrant Services and the People's Place in Busselton
- local cancer services, such as Genesis Care Bunbury, Solaris Cancer Care in Bunbury and Albany, and cancer support groups across the regions
- Crawford Lodge, which is Perth metropolitan accommodation for regional cancer patients.

3.2 Quality assurance and participant support

In line with the [Ethical considerations in quality assurance and evaluation activities](#)¹³ by the National Health and Medical Research Council, this project followed ethical principles and legislative requirements to ensure participants and people involved were kept safe. Each organisation attended a briefing meeting prior to implementation that covered appropriate steps to protect participants during the project.

Due to the nature of the project and that a discussion about cancer might cause distress for participants, organisations were briefed on strategies to minimise this risk and offer support to participants if they became distressed (see Appendix C). Organisations were encouraged to advise participants that they can contact the Cancer Council Helpline for support. Some organisations had additional support available during workshops, including having counsellors and social workers in attendance.

Organisations were also briefed on obtaining informed consent from participants to participate in the consultation, including giving participants the option to opt-out at any time. If consent was provided in writing, organisations were briefed to store this separately to attendance sheets and other identifiable information.

To ensure privacy and anonymity, organisations were required to collect non-identifiable data and were briefed on these requirements. This included not collecting individuals' names, images of participants, date of births and addresses. Organisations were also encouraged to remind participants to respect other participants' privacy and to not share information outside of the group discussions and interviews.

In addition, the network offered to assist the organisations to hold cancer education sessions for their community members with Cancer Council WA (see Appendix D).

Participants were remunerated for their time in alignment with the department's 'Consumer, carer and community paid participation in engagement activities' policy.

3.3 Community organisation activities

The organisations were asked to consult participants on the following 4 questions relating to cancer information:

1. what cancer information was helpful to you or your relative/carer during your cancer journey? Why was it helpful?
2. what cancer information was not helpful to you or your relative/carer during your cancer journey? Why was it not helpful?
3. a) Thinking about your cancer journey, what information would have made your experience better?
b) How would you have liked this information to be provided?
4. overall, have you encountered any gaps (issues, problems) in finding or understanding cancer information, that we have not talked about?

If organisations had time, participants were also asked questions relating to awareness and use of national cancer screening programs (see Appendix A and B for the full discussion questions and facilitator guide).

3.4 Data collection, reporting and analysis

3.4.1 Community organisation data collection

For data collection, measures for CaLD status included country of birth, main LOTE spoken at home, and proficiency in English as recommended by the Office of Multicultural Interests.¹²

Consultation data was collected by each organisation and collated into consultation reports that were submitted to the network. These consultation reports included summarised participant demographic information and a summary of the key discussion themes from the community engagement.

As part of the reporting, organisations were also asked to reflect and describe learnings from the recruitment and engagement process. Consultation materials such as demographic sheets, promotional and marketing resources and visual aids were also attached to the report.

3.4.2 Data reporting and analysis

The network collated the information from consultation reports submitted by the 5 organisations. Quantitative demographic data were analysed and presented using descriptive statistics. Qualitative data were analysed using thematic analysis to identify recurring themes that represented common views of the respondents.

The discussion themes were organised into sub-themes to avoid the risk of reporting similar ideas and duplicate responses under each consultation question.

4. Demographics

A total of 175 people participated in the project with the majority being carers, female and born overseas (see Table 1). Most participants lived in Perth (n=161, 92 per cent). Other regions participants lived in were Peel (n=6, 3.4 per cent), South West (n=4, 2.3 per cent) and Great Southern (n=4, 2.3 per cent).

Table 1: Demographics of participants.

Consumers and carers	N = 175	%
Consumer	63	36.0
Carer	101	57.7
Both consumer and carer	7	4.0
Other	4	2.3
Sex		
Female	147	84.0
Male	27	15.4
Other	1	0.6
Age groups (years)		
19 and under	2	1.1
20 – 29	2	1.1
30 – 34	4	2.3
35 – 49	35	20.0
50 – 54	15	8.6
55 – 59	14	8.0
60 – 64	24	13.7
65 – 69	19	10.9
70 – 74	24	13.7
75 – 79	13	7.4
80 - 84	12	6.9
85 +	10	5.7
Prefer not to say	1	0.6
Country of birth		
Overseas	165	94.3
Australia	10	5.7

Of the participants who identified as a consumer*, one-third of participants reported they were zero to 5 years post-treatment in their cancer journey (n=22, 31.4 per cent), and over one-quarter reported they were more than 10 years post-treatment (n=19, 27.1 per cent) (see Table 2).

Table 2: Stage of cancer journey among cancer consumers.

Stage of cancer journey	N = 70	%
Diagnosis/pre-treatment	8	11.4
Treatment	9	12.9
0-5 years post-treatment	22	31.4
6-10 years post-treatment	12	17.1
More than 10 years post-treatment	19	27.1

When participants were asked what type of cancer they had or cared for, the most reported were breast cancer (n=47, 24.5 per cent), prostate (n=21, 10.9 per cent), upper gastrointestinal (n=16, 8.3 per cent) and gynaecological cancer (n=16, 8.3 per cent).

Table 3: Type of cancer among participants.

Cancer type	N = 192 ^a	%
Breast	47	24.5
Prostate	21	10.9
Upper gastrointestinal	16	8.3
Gynaecological	16	8.3
Head and neck	14	7.3
Lung	12	6.3
Leukemia	10	5.2
Bowel	9	4.7
Liver	8	4.2
Melanoma (skin)	5	2.6
Lymphoma	5	2.6
Thyroid	4	2.1
Kidney	3	1.6
Pancreatic	3	1.6
Sarcoma	3	1.6
Other/I don't know/did not answer	16	8.3

^aParticipants could choose more than one cancer type.

*This includes participants who identified as a consumer only or as both a carer and a consumer.

When participants were asked for their country of birth, 38 different countries were reported (Figure 1). The 3 countries most reported were Iran (n=15, 8.6 per cent), Italy (n=14, 8 per cent) and Malaysia (n=14, 8 per cent). The 3 regions of birth most reported were Southeast Asia (n=41, 23.8 per cent), South Asia (n=33, 19.2 per cent) and Middle East and Northern Africa (n=30, 17.4 per cent) (see Figure 2).

Figure 1: Country of birth among participants (n=175).

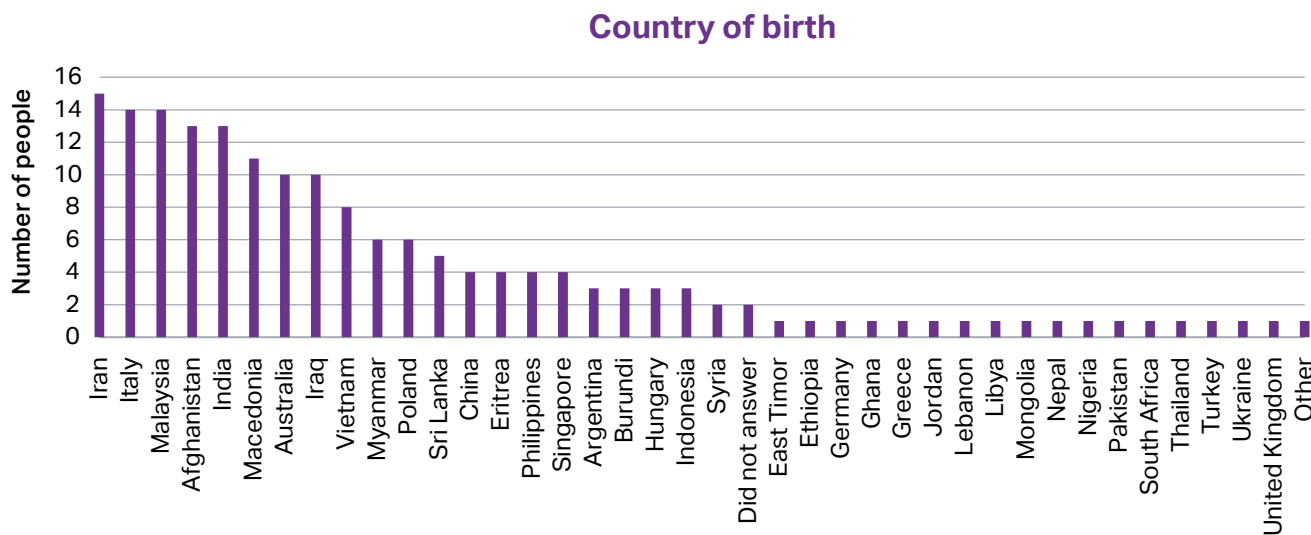
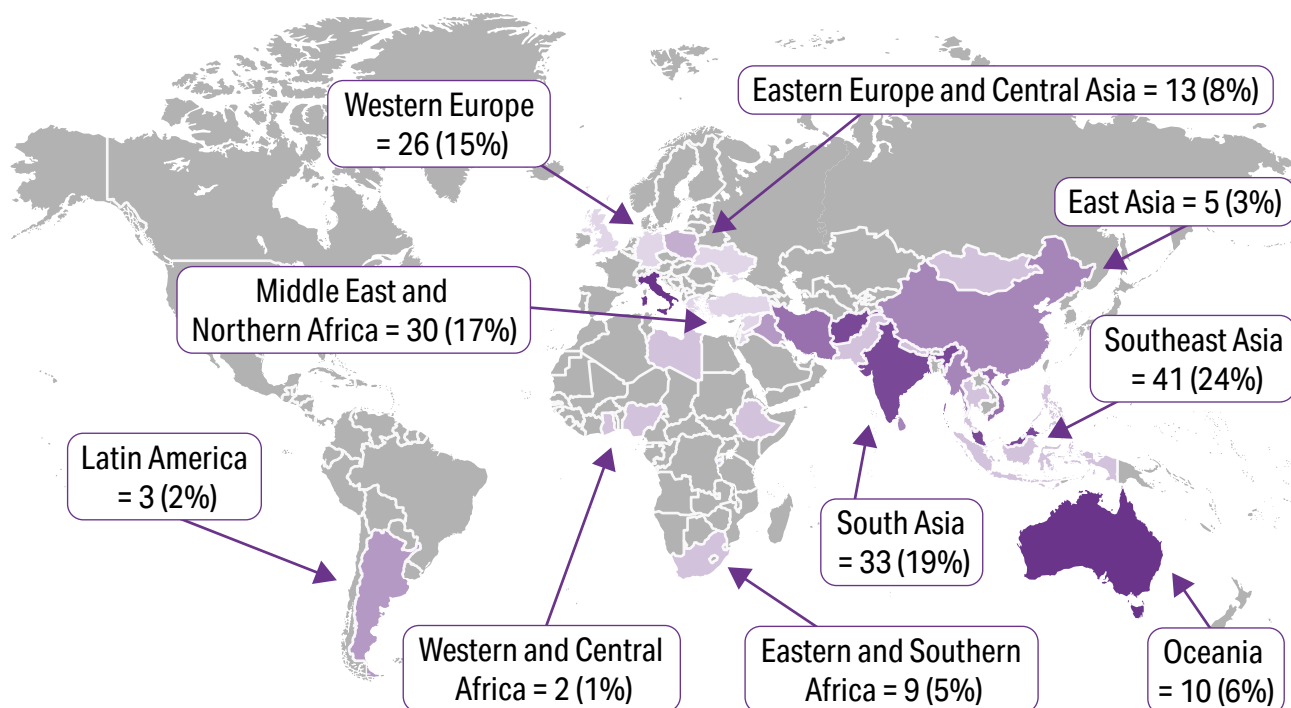


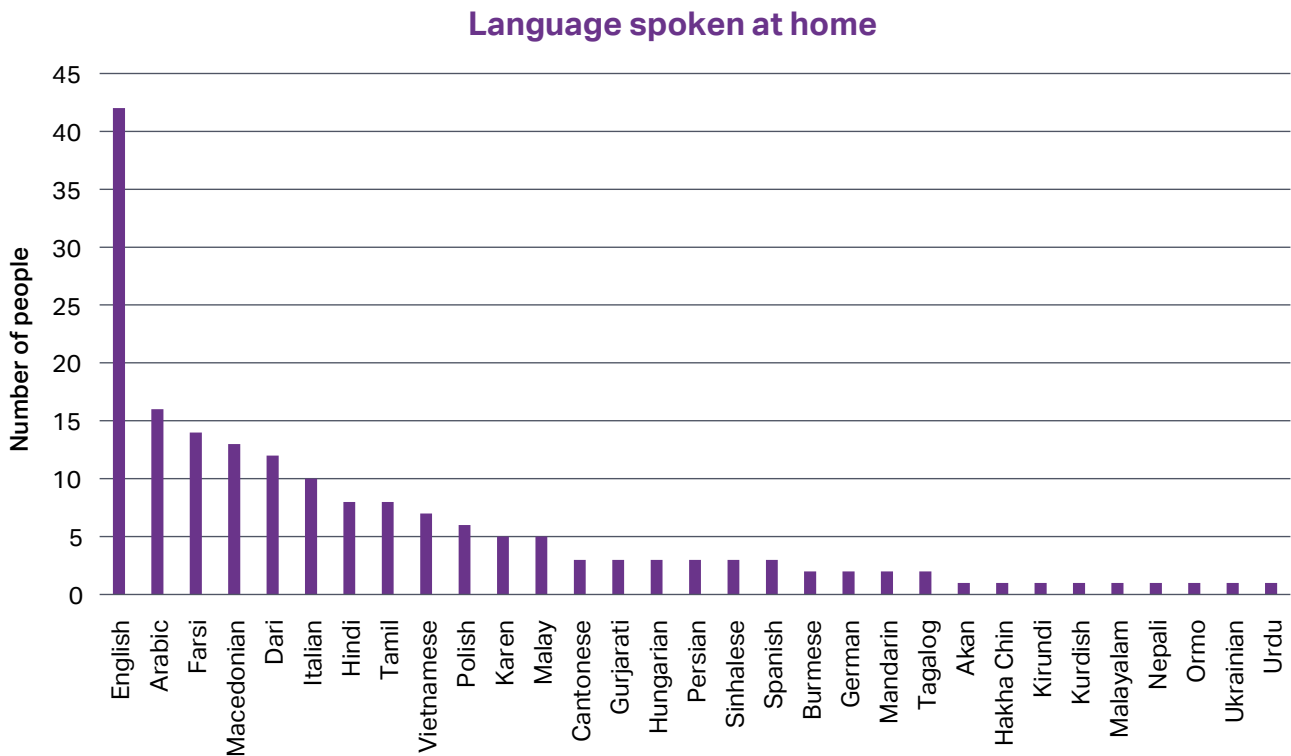
Figure 2: Country of birth by region among participants (n=172).^b



^b Excludes responses 'other' and 'did not answer'.

When participants were asked the primary language they spoke at home, 31 different languages were reported. The most frequently spoken languages at home were English (n=42, 23.2 per cent), Arabic (n=16, 8.8 per cent) and Farsi (n=14, 7.7 per cent). Some participants spoke more than one language at home (see Figure 3).

Figure 3: Language spoken at home among participants (n=181).^c



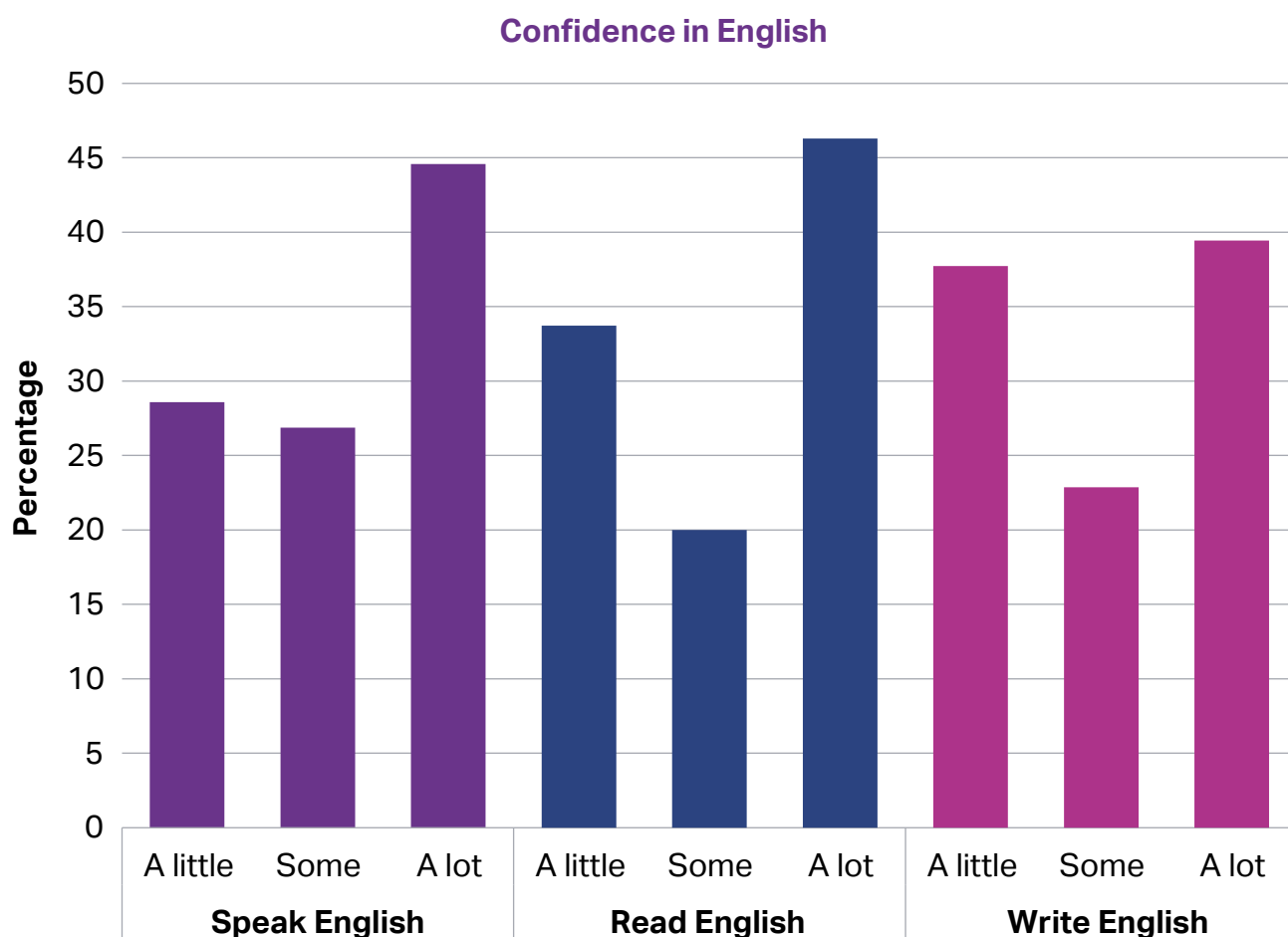
^c Participants could choose more than one language.

Almost three-quarters of participants reported they had lived in Australia for more than 10 years (see Table 4). However, when participants were asked about their confidence to speak, read and write English, more than half of the participants reported they spoke (n=97, 55.4 per cent) and read (n=94, 53.7 per cent) a little to some English, and more than 60 per cent of participants reported they wrote a little to some English (n=106, 60.6 per cent) (see Figure 4).

Table 4: Time living in Australia among participants.

Time in Australia	N = 175	%
Less than one year	1	0.6
1 – 5 years	17	9.7
6 – 10 years	22	12.6
More than 10 years	130	74.3
Did not answer	5	2.9

Figure 4: Self-reported confidence to speak, read and write English among participants (n=175).



To understand people’s cultural needs and considerations, participants were asked what religion they followed. The 2 religions most reported were Christianity (n=59, 33.7 per cent) and Islam (n=43, 24.6 per cent), while 14 per cent reported they were not religious (n=25, 14.3 per cent) (see Table 5).

Table 5: Religion among participants.

Religion	N = 175	%
Christianity	59	33.7
Islam	43	24.6
Not religious	25	14.3
Other	16	9.1
Hinduism	16	9.1
Buddhism	9	5.1
Did not answer	7	4.0

5. Recruitment and engagement key learnings

5.1 Recruitment key learnings

All organisations in the project were asked to reflect and report on any key learnings during the recruitment and engagement process.

Word of mouth was a more effective recruitment strategy than external advertising through social media and flyers to reach CaLD communities. The trust and relationship built between community organisations, community leaders, and members were shown to be an essential part of the recruitment process. If trust is not built, it can lead to recruitment issues such as no-shows, last minute cancellations, and poor communication which can delay the project.

Some CaLD people were reluctant to participate as they did not want to talk about their illness with someone they did not know. For example, MSCWA noted that many cancer consumers did not want to share their cancer experience in front of other people and preferred a one-on-one interview. Ishar reported they had more success if potential participants heard about the interview from someone they trusted in their own language. ECCWA reported some participants took some time to understand the project and required 2 to 3 phone calls prior to participating.

Therefore, time and resources need to be allocated towards building relationships to maximise consultation success.

When organisations reflected on ways to improve the recruitment process, suggested strategies included:

- seeking assistance from health professionals who care for cancer patients
- investing more time to build rapport and trust with community members about the project
- recruiting and registering participants by telephone rather than email
- ensuring all contact information, including phone number and email address, was confirmed to send project follow-up information.

Lack of response was a common barrier among many organisations during recruitment. Other reasons CaLD people chose not to participate included:

- felt too overwhelming
- not being interested
- not having permission from family to participate
- having work commitments
- being overseas.

5.1.1 Recruitment key learnings – CaLD men

The HCC recruited a total of 13 CaLD men. HCC reported that the most effective strategy was word of mouth from trusted community contacts, while the least effective was social media and email distribution. However, HCC reported that trusted community contacts still had a difficult time recruiting CaLD men given cancer may be a taboo topic.

Two key learnings were identified by HCC to improve recruitment for CaLD men.

Firstly, more time and resources were needed to recruit additional CaLD men as successful recruitment relied heavily on established trust and relationships in the CaLD community. HCC stated that with more resources and a longer timeline, they could have conducted more follow-up calls and built key relationships to improve recruitment.

Secondly, multiple organisations were already recruiting in CaLD communities under the same grant which made it difficult to advertise and promote the project. HCC could not approach the CaLD organisations already involved in the project and did not have enough time and resources to partner with other organisations.

5.1.2 Recruitment key learnings – regional WA

The HCC recruited a total of 6 CaLD people who lived in regional WA. HCC reported several strategies, including mass media, to recruit and engage with CaLD regional members.

HCC identified 3 key learnings to improve recruitment for CaLD regional consumers.

Similar to recruitment of male CaLD consumers, HCC felt they required more time and resourcing to successfully recruit regional participants. HCC reported that with more resources and a longer timeframe, they could have partnered with more multicultural organisations and built the required relationships.

HCC also reported that multiple organisations working on the same grant made it difficult to recruit participants from regional WA and that it might have caused confusion amongst consumers. To mitigate recruitment issues, the network reassigned grant requirements so that HCC were the only organisation targeting the regions.

Lastly, HCC reported administrative problems using Eventbrite for recruitment. In the future, HCC recommend including screening questions and a phone number to help streamline recruitment.

5.2 Engagement key learnings

Below is a summary of engagement learnings reported by all the organisations that participated in the project.

All the organisations found that providing information upfront during discussions helped participants answer the questions. Across all organisations, emphasising to participants that they will help other CaLD people encouraged them to be more involved in the sessions.

Other strategies reported for successful engagement included:

- providing an information sheet and flyer so the participants knew what to expect
- explaining the purpose of the consultation in a simple and concise manner
- providing the survey questions before starting the discussion
- providing examples to help prompt discussion
- offering interviews and written responses for those who felt uncomfortable sharing their experience in front of others.

Interestingly, some organisations found discussions held with an interpreter led to briefer responses compared to discussions in English. Anecdotally, organisations reported some participants may not have understood the interpreter due to the low literacy in their preferred language, or the interpreters struggled to find an English equivalent expression and might have oversimplified the response.

All organisations found it difficult to focus on cancer information only during the discussions as some participants were willing to share personal health information. One organisation found that the questions prompted distress among some participants and required counselling support. This risk had been identified and organisations were briefed on providing access to social support and resources to participants (see section 3.2 and Appendix C for more information).

6. Findings

Consultation was conducted via either interviews (n=53, 74.6 per cent), group discussions (n=16, 22.5 per cent) or written feedback (n=2, 2.8 per cent).

Analysis of the consultation reports identified 4 key themes. Themes included:

- how participants accessed cancer information
- how participants would like information delivered
- types of cancer information that participants found important
- cultural needs important to participants.

Several sub-themes were identified below:

How participants accessed cancer information	How participants would like information delivered	Types of cancer information that participants found helpful	Cultural needs important to participants
<ul style="list-style-type: none">• Health professionals• Family and carers• Interpreters• Online• Residential lodge	<ul style="list-style-type: none">• Person-centred• Clear and easy to understand• Timely follow-up information and help	<ul style="list-style-type: none">• Diagnosis and prognosis• Making an informed decision• Treatment costs and financial support• Support services• How the Australian health system works• Lifestyle changes	<ul style="list-style-type: none">• Language• Beliefs about cancer• Religious and cultural beliefs• Experiences with other health systems• Family• Health advocacy

6.1 How participants accessed cancer information

Participants reported 5 main channels of how they accessed cancer information.

1. Health professionals
2. Family and carers
3. Interpreters
4. Online
5. Residential lodge

5

6.1.1 Health professionals

Most participants received information from doctors, nurses and bilingual hospital staff throughout their cancer journey. They also perceived that health professionals had greater knowledge and authority to provide reliable advice.

Many participants said that the information from their general practitioner (GP) was more useful and understandable than reading brochures and factsheets. Some participants also preferred speaking to a GP from a similar cultural background rather than using an interpreter.



'He [the GP] could speak both English and Vietnamese so it helped my family.'

'My doctor is Arabic, so he understands me.'

Interestingly, GPs from the same community was reported as a barrier by some participants.

'When a GP is linked to your family or friends, there is a lot of information that is not given easily. It was seen as taboo to talk about advanced stage cancer, as if talking about it would make it worse.'



Male participants reported feeling more comfortable accessing information from a specialised male GP to discuss men's health issues.



'Just like multicultural people may seek out GPs that are also multicultural, a men's GP may be more comfortable for many people to discuss those [men's health] issues.'

6.1.2 Family and carers

Family and carers were another important source of information for participants. Participants felt that sharing information with a friend or someone from their community who shared similar experiences helped them to understand and absorb cancer information.

'I found it helpful to talk to others who had gone through the same journey, and I have now been able to help others.'



Participants identified that information provided to family members and carers during appointments was important to help interpret and translate information for the patient. Participants also mentioned that it was important to not make the family or carer feel 'side-lined' during the cancer journey.



'The doctors and nurses were all very understanding and supportive of the family.'

'My husband was very ill; he can't speak English and I can't speak English too. But we both can understand a little. My daughter was there helping us all the times talking to [doctors], nurses, hospital staff and arranging for all the treatments with [the] hospital. Without my daughter, we couldn't have managed.'



Participants also mentioned that they found useful information about diagnosis and treatment options through family, friends and other patients with the same cancer.

6.1.3 Interpreters

Interpreters played an important role in helping some participants understand cancer information.



'When I saw the doctor, if they have translator, it makes it easier and less stressful.'

Some participants also raised cultural barriers for using an interpreter. It was reported that some interpreters were too afraid to translate body parts in relation to sexual health. Another barrier was that some interpreters spoke a different dialect and the participant could not understand. Using interpreters for small communities can also raise confidentiality issues when disclosing personal health information during appointments.

6.1.4 Online information

Participants reported that the availability of online information had significantly improved in recent years. Online information helped consumers to take time to read and understand their diagnosis, treatment options, outcomes and other relevant information.

Search engine Google was reported as a good option to find information but required computer literacy skills and an understanding of what to look for. Participants shared that they had to search extensively to find information and that they would like to access information about vouchers, discounts and services in a centralised place for people diagnosed with cancer.

Participants also reported that online information was helpful if they did not receive enough explanation from their doctors. Specific examples included:

- Cancer Council website
- YouTube channels featuring medical doctors
- 'My Care' app which helps people manage their health conditions
- local Facebook groups.

Male participants suggested web-based tools that take consumers through a series of questions to ensure all information needs are met before or during medical appointments would have been useful.

'Surveys/questionnaires that will guide you to the right advice. It is very hard for GPs to ask every question and a lot of things get missed.'



6.1.5 Residential lodge

Regional participants reported that the Crawford Lodge, a metropolitan-based residential lodge for regional and rural medical patients, was a helpful source of information. At the lodge, participants reported receiving Cancer Council leaflets about caring for themselves throughout the cancer journey and information about support groups, which were especially helpful. The lodge also offered a support group which they found helpful as support groups were not available in the participant's local area.

6.2 How participants would like information delivered

Participants reported on their experiences receiving cancer information and provided suggestions on how to improve information delivery. Three key themes were identified.

1. **Information is person-centred**
2. **Information is clear and easy to understand**
3. **Timely follow-up information and help is available**

3

6.2.1 Information is person-centred

Participants reported it was helpful when negative language was avoided and when patients received reassurance about the health system from their doctor. Kind, warm and positive words helped participants feel comforted, consoled, and hopeful and was therapeutic during critical stages of the cancer journey. Participants mentioned that staff and nurses during hospitalisations and treatment were very kind and informative when questions were asked. Participants also appreciated it when information regarding their diagnosis, test results and treatment options was delivered in a timely way.

The need for a person-centred approach was highlighted as participants reported situations when doctors delivered the diagnosis to the patient bluntly without compassion and empathy. Participants described during appointments with doctors, they felt patients were treated as a diagnosis rather than a person with a condition. Participants shared that they would have liked to have heard 'something positive' when discussing the cancer diagnosis with their doctor.

Other participants reported poor experiences when they were told information at the wrong time. Some participants reported that they were told about their diagnosis during an appointment without family support.



'My aunty did not have anyone with her when she was told she had breast cancer. She was so stressed and scared.'

Some participants were told about their diagnosis on the phone by their GP. A carer shared a story when her husband was told of his positive cancer result over the phone while home alone. When she returned home, she found her 'husband on the floor sitting in tears.'

Timeframes, chance of survival and side-effect information was provided to patients who were not ready, had poor mental health, or did not want to know. Carers requested to be told the information first, then interpret for the patient. Participants also mentioned timeframes for survival provided by specialists were too ambiguous, such as 'could be months or could be years.'

6.2.2 Information is clear and easy to understand

Participants reported that information that was simple, concise and suited low literacy levels was very helpful. This helped them to feel safe and comfortable to ask questions. Participants also found that information provided in their own language and in English helped them, their carer, and family members to better understand their cancer diagnosis.



'I wanted both information because my children can read English, but my husband cannot.'

A key barrier reported was that a lot of online information is hard to find and not in a language they understand. Participants described that there are a lot of resources in English, but fewer resources provided in other languages.

'People say there is a lot of support for people with cancer, but I don't know how [to access it].'



'Some people tell me to go to Cancer Council or websites but there is no information in my language. I am not good with [a] computer too.'

'Brochures and hard copies are helpful, but I don't know where to find them.'



Participants reported the need for information to be culturally appropriate and to look relevant for them. One participant shared that when they looked for information on support groups, pictures of Caucasian people in the pamphlets and online made them think that the group was not suitable for them.

Literacy was also mentioned as a barrier, even if the information was translated.



'Some people gave me information in my language, but I can't read it.'

'Translated information is not always correct or the words are not the same as what we use in everyday life. It is in a 'higher' language, not 'conversational' language.'



Many participants also reported on the importance of providing information in stages to avoid feeling overwhelmed and experiencing 'information overload.' Large amounts of resources being provided at once was reported to be overwhelming and made them feel that they cannot keep up.



'[It was helpful when] the information given by my GP was clear and he explained the stages.'

Some participants shared that they wished their doctor spent more time explaining and helping them understand how to process the information, particularly if they were unsure what information to use.

Participants reported that the amount of information provided at the stage of diagnosis was very important. At diagnosis, participants can be in a state of shock and unable to process information they receive as cancer can be perceived as a death sentence. Patients and their carers may not be in the right mental state to accept the diagnosis and understand information. Participants recommended that another appointment with the GP may help prepare patients and their families to understand the information better.

Some participants reported that using an in-person interpreter or their family to help translate information was helpful, especially for medical terms and concepts. Other ways mentioned by participants to help make information more accessible included:

- providing pictures with simple English to help family interpret the information
- avoiding the use of medical terminology and abbreviations
- using online websites for translated materials for their children and younger family members, but not recommended as the main source as it is not personalised
- providing printed and hard copy resources for older generations, but do not provide too much as it can be confusing
- providing a booklet for each stage of the cancer journey and questions for consumers to ask their doctor
- ensuring that treatment consent forms and other important documents are available in language or are verbally translated.

6.2.3 Timely follow-up information and help is available

Participants reported that it was difficult to absorb and remember all the information during appointments to relay back to their carers and family. A written summary of the medical diagnosis and treatment plan was found to be helpful, especially for family who needed to translate the information for the patient.

Other helpful written materials included:

- information booklets that included information about lifestyle changes and treatment options and their side-effects
- brochures for carers and family members to read
- a patient folder that contained all the treatment information for carers.

Participants also mentioned that services who provided follow-up information and support were helpful on their cancer journey. Examples included:

- a private hospital provided a phone number to call at any time for more information
- Cancer Council WA hotline, which is staffed by nurses to answer questions and provide information
- nurses in radiotherapy clinics being readily available to help and answer questions at any time during visits
- weekly generic information sessions about cancer held at the hospital
- a private hospital offered a 2-hour information session facilitated by nurses about treatment, side-effects and consequences in lifestyle
- the Symptom and Urgent Review Clinic at Sir Charles Gairdner Hospital.

6.3 Types of cancer information that participants found important

When participants were asked the types of cancer information that was helpful and unhelpful, 6 main themes were identified.

1. **Diagnosis and prognosis**
2. **Making an informed decision on cancer treatment**
3. **Treatment costs and financial support**
4. **Support services**
5. **How the Australian health system works**
6. **Lifestyle change information**



6.3.1 Diagnosis and prognosis

Participants reported that they found information related to their diagnosis and prognosis helped them to understand the different procedures and tests available.

Specific information included:

- explaining the process of the test (e.g. a biopsy)
- navigating information about the hospital system for further care
- sharing a copy of the referral letters between the GP and oncologist
- sharing all the medical test results with the patient
- sharing positive statistics related to prognosis.

Participants reported that they valued being told detailed information upon diagnosis and prognosis, including how to access new technologies and tests. Participants also wished that they received information on the signs and symptoms of cancer and an explanation of how they may present differently between people.

Some participants also mentioned that medical terminology needed to be explained as CaLD people have varying levels of health literacy. For example, some participants shared that they conducted their own research to find alternative diagnostic tests, while other participants reported that they did not understand what 'advanced cancer' meant and would have liked more information.



'We did not receive an explanation of what an "advanced" stage of cancer is. We were told, "it is cancer, and it is advanced cancer" and that was it.'

6.3.2 Making an informed decision on cancer treatment

Participants reported that it was helpful being provided with different options to make an informed decision about how to manage their cancer. When treatment options were explained, participants reported it was helpful when the patient's medical history and existing conditions were taken into consideration and how the treatment might impact their health.

Specific information about treatment and surgery options that would have been helpful included:

- statistics about tests, side-effects and outcomes, and the likelihood of cancer returning when undergoing treatment and/or surgery
- treatment process, outcomes and side-effects (including medication side-effects)
- surgery process and outcomes, and rehabilitation options available after surgery
- options to not have treatment or surgery
- wait times
- aftercare
- palliative care options.



'It was helpful when the patient was shown the chemotherapy chair and explaining what it involved in detail.'

Participants reported that palliative care staff and leaflets and information from the hospital about what to expect after the patient has passed was helpful.

In contrast, some participants reported situations where they did not receive enough information about the risks, side-effects and costs of surgery and/or treatment, and the patient's right to make choices (such as stopping or refusing treatment).

'My dad wanted to know what would happen if he didn't use conventional methods of treatment and what the evidence was for unconventional treatments.'



Information about patients' rights and decision-making capacity to choose and deny treatment options and tests was frequently raised during the consultations. Some participants shared that when they were provided urgent treatment, they were unaware of the severity of the side-effects or risks for other illnesses such as hearing loss, other cancers and fractures. The risk of these side-effects was often not known until after treatment. One participant shared that their emergency operation experience was 'horrendous' and that they 'never wanted to go through that again.'

Some participants raised the issue that all their consent forms were in English and wished it was presented in their own language. Participants who were enrolled in clinical trials shared that detailed information about the diagnosis, treatment, timeline and side-effects were provided, but was in English and had to be translated by a family member.

6.3.3 Treatment costs and financial support

Participants reported that receiving information about treatment costs was an important part of the decision-making process and some participants wished they had more information about it.



'Chemotherapy is not free, and it wasn't disclosed to me before. I had to pay an extra \$1,800 on top of what the government gave for bulk billing.'

Some participants also reported that they wanted more information about transport to medical appointments.

'Even with a 50 per cent discount scheme from the state government, I still had to pay out roughly \$2,500 for transport to and from hospitals.'



Other financial support and cost information participants wished they received more on included:

- what is covered under Medicare rebates and the Chronic Disease Management Plan
- how to access Centrelink benefits if a consumer or carer must stop working
- what private health insurance coverage is available and how to access it
- how to make withdrawals from superannuation
- how to access life insurance payouts based on clinical diagnosis
- an explanation of the financial gaps for treatments and tests.



'[I] wish we had been given more information about incontinence and the costs involved, it's not cheap.'

Some participants raised that there can be a lack of awareness among health staff and government agencies regarding access to financial support when diagnosed with cancer.

One community organisation noted that:

'Staff within the health and government systems are not always aware of what support services are available to cancer patients. For example, one participant found out herself that federal legislation clearly states that if you have a chronic illness, like cancer, you can get up to 12 months leave approved. The staff at Centrelink did not know about this, and she had to point it out to them.'



6.3.4 Support services

Participants mentioned that they wanted more information about support services who can provide general help during the cancer journey. Many participants were also unaware of hospital social support workers.

Participants reported this information could be provided in several ways including:

- in-person in their language
- on the phone in their language
- in a brochure with a list of services to call to answer questions.

The most frequent support services that participants wanted more information about were:

- free support services available
- transport for tests and treatments
- food and fuel vouchers
- childcare
- translation/interpreting services
- household help including gardening and house cleaning
- personal support, such as showering post-surgery/post-treatment and cooking
- information about positive mental health and complimentary therapies
- information about continence products, discounts and subsidies
- where and how to access wigs.

Emotional support information during the cancer journey, including the psychological impact after diagnosis and after the patient has passed away, was highlighted during the discussion sessions. Participants shared it was helpful when their GP recognised signs of distress and quickly referred them to a counsellor who spoke the same language and were from a similar cultural background.

Many participants reported that information for carers regarding counselling and mental health was very important. When asked how they would like this information delivered, participants preferred in-person, a video featuring someone from their community speaking their language with translated subtitles, and written information in English and their own language.

Other specific types of emotional support information participants wanted were:

- formal support for carers
- educational materials on how to deal with cancer and support emotional wellbeing
- a reflection on the journey as part of the treatment plan
- cancer support groups, including where to go to share experiences with others experiencing cancer
- traditional medicines and healthy lifestyles and diets that can be used with cancer treatment
- information about Reiki and mediation sessions
- religious support.

For regional participants, more information about the Patient Assisted Travel Scheme (PATS) would have been helpful. One consumer reported that there is a lack of knowledge and awareness of PATS in their community and among doctors in Perth, which leaves patients feeling overwhelmed and stressed about how they will return home. When asked how they would like to receive information about PATS, participants requested being told by their doctor as well as printed materials in simple English and translated in their own language. A video with people from regional communities explaining PATS was also suggested.

Regional participants also wanted more information about regional support groups, preferably support groups in languages other than English.

6.3.5 How the Australian health system works

Participants wished that they had more assistance to navigate government and health systems. When asked how they would like this information delivered, participants suggested a cancer-orientated welfare officer to support CaLD cancer patients who lack family support and have language barriers.

Participants also suggested providing opportunities for cancer survivors to share their stories and experiences with other CaLD patients recently diagnosed with cancer. The aim of this would be to provide practical information, guidance and advice on navigating the health system.

The lack of information about the referral process across the cancer journey was also highlighted as an issue amongst many participants. Participants mentioned they found it unhelpful when their GP told them to attend hospital or an urgent specialist appointment without a clear explanation. Participants also reported that they found the health system difficult to navigate and being told 'someone will contact you' was particularly unhelpful.



'I was told to go to hospital by my GP, but I did not know why. My GP only added "we have spotted something".'

After discharge, some participants reported the lack of information relating to a plan and risk assessment. For example, one participant mentioned that a risk assessment was not completed by the surgeon or nurses regarding the type of supports at home, other household members, who would be assisting her, food preparation, showering, wound care and social support. The participant was not asked if she was confident enough to go home and care for herself.

After completing or choosing to stop treatment, some participants reported they received no information or referrals to homecare and palliative care options such as Silverchain.

Other useful examples participants mentioned in relation to navigating the health system were:

- Breast Cancer Care WA booklet and breast cancer support network
- Symptom and Urgent Review Clinic at Sir Charles Gairdner Hospital
- dietitian referrals
- Leukemia Foundation information package.

6.3.6 Lifestyle change information

Participants found it helpful when they were provided information on available food options during and after treatment. Food and nutrition information was highlighted as very important among participants throughout the cancer journey. The availability of hospital food that was culturally appropriate and information about bringing food from home was also raised as an information gap. Participants also reported that lifestyle advice tailored to their existing medical conditions, such as diabetes, was also helpful.



'He [the doctor] gave clear information on how to help my husband follow a good lifestyle program including food.'

'Information that helped me go through my treatment in less pain. I was told to reduce my fibre well ahead of my surgery and that helped a lot.'



6.4 Cultural needs important to participants

Six key cultural considerations were raised among participants during the discussion groups and interviews.

1. Language
2. Cultural beliefs about cancer
3. Respect for religious and cultural beliefs
4. Experiences with other health systems
5. Family
6. Health advocacy



6.4.1 Language

During the interviews and discussion groups, many participants identified language as a significant cultural barrier to receiving and understanding cancer information.

One organisation reported that 2 participants did not understand their diagnosis because they and their family could not understand English. Participants also shared that interpreters were not always available, particularly during treatment stages.

As reported by an organisation:



'He has also had issues as an inpatient because the interpreter could not be there 24/7 and then his children were thrown out when visiting hours ended. He feels strongly that nursing staff need to understand that translating provisions are not visiting privileges.'

Interestingly, language barriers were also faced during the consultation sessions for the project. Some organisations reported the language and literacy barrier was too difficult for some participants to carry out the discussion in detail.

6.4.2 Cultural beliefs about cancer

During the interviews and discussion groups, participants described talking about cancer as scary, risking a bad omen, and something that can be depressing. The word 'cancer' can be culturally stigmatising, and some cultural beliefs associate cancer with death. Some participants avoid using the term 'cancer' altogether. There were several different views shared about the cultural attitudes and beliefs for managing a cancer diagnosis.

Some consumers reported that a cancer diagnosis can be shameful and that they did not want to disclose it to others, while other consumers wished they had a family member with them at the time of diagnosis for support.



'Getting the news and then having to tell the rest of the family afterwards was a burden and made things worse. Everyone had so many questions that I [could not] answer.'

From the carers' perspective, participants reported the family often wished that the doctor did not disclose the diagnosis to their family member with cancer for fear it may worsen their condition.

'My dad became so stressed when he found out he had cancer that I think it made him pass quicker.'



In contrast, other participants reported that they wished carers were told the diagnosis first to help deliver the news to their family member. Some participants believed the way doctors delivered the diagnosis was 'too honest' and 'delivered difficult news without hesitation,' which can negatively impact the patient's mental health. Participants shared if families and carers were told of the diagnosis first, they can translate the information in a way that does not overwhelm the patient.

Male participants also raised the need for cancer myth buster information to target cultural attitudes such as:

- the doctor cannot help
- herbal medicine is the answer
- positive thinking can cure cancer
- cancer is always a death sentence
- cancer is a punishment for wrongdoing.

Community presentations and peer support workers were suggested by participants as a way to help educate the wider CaLD community and encourage adherence to treatment.



'The conversation needs to be pushed forward that it is OK to talk about cancer, it is okay to be open about it. It will show people that you can get better.'

6.4.3 Respect for religious and cultural beliefs

Participants found it helpful when their religion and cultural beliefs were acknowledged and included in their cancer journey. Participants reported that including their cultural beliefs during their cancer journey made them feel safe. Religious organisations were also reported as a good source of emotional and practical support throughout the cancer journey.



'The hospital had a chaplain service which was good.'

'My husband felt comfort being supported by our family's priest.'



6.4.4 Experiences with other health systems

Participants reported that the country they were born in had different health systems and care coordination. Overseas health systems can set different attitudes and expectations towards cancer treatment and care. Some participants also mentioned that their poor experience from their country's political system makes it difficult to trust the government.

Other participants reported that in their country, people who are considered 'old' are not treated nicely in their healthcare system as they are 'dying anyway'. They were surprised to learn how caring the Australian healthcare system is and if they knew about this, they would have sought help earlier.

Some participants mentioned they felt uncomfortable talking to a GP or specialist who was not from a similar cultural background.



'I don't trust a doctor unless they're from my culture.'

6.4.5 Family

Family members were reported to play an important role to help find and interpret cancer information. The limit on the number of people permitted to attend appointments with the patient can be difficult for large families. Participants wished they could have invited more than one person to medical appointments to ensure that information was relayed correctly and to have received family support. Family members were also viewed to be able to translate information at the appropriate health literacy level.



'My children had to help translate because we didn't understand.'

Participants shared the lack of family support can be traumatic, particularly for patients who cannot understand and speak English.

As reported by one organisation:

'One participant explained that she had not been allowed in with her mother when her mother went through for a biopsy. This was despite her mother having no English and no interpreter. The consumer felt strongly that people who do not speak English should not be allowed to go through something like that alone as they are trapped [and] unable to ask questions.'



Other participants raised that decision-making responsibilities differ between cultures.



'Health professionals need to be aware who the decision maker in the family is. Sometimes it will be the oldest son, or the maternal uncle or the patient themselves.'

6.4.6 Health advocacy

Many participants reported that they lacked the skills and confidence to advocate for their healthcare and support needs. For some people, cultural reasons may prevent them from questioning the authority of medical professionals. Additionally, many CaLD patients and families do not necessarily know how to question or confront healthcare workers or doctors, especially if English is not their first language. They presume that the healthcare professionals are the experts and that they will not make mistakes. Because of this, many CaLD people do not ask many questions and accept whatever is given to them.



'Doctors and medical people are specialists in their work, and they know what they are doing. We trusted them and their work. That's why we don't question them – questioning them is as though we are checking on their work.'

Participants indicated that they needed to be confident to ask for what is needed, but not everyone is. They were concerned about how many CaLD people just accept what the doctor or nurses tell them, for example, not asking for more time in hospital or information about side-effects.

'The doctor looked very busy, so I felt that he did not have the time to answer all my questions.'



Participants also mentioned the need to be more confident and proactive to ask for help, but it is difficult when they don't know what to ask for and what is available.

7. Cancer screening awareness and participation

Organisations were encouraged to ask participants cancer screening-related questions if they had time during the discussions. Participants could choose not to answer. Overall, the response rate for the questions was 90 per cent (n=158) or higher.

Participants were asked if they were aware of cancer screening programs and if they had participated in them.

Table 6: Number of participants who were aware of cancer screening programs.

Are you aware of any cancer screening programs?	N	%
Breast cancer screening (n=164)		
Yes	128	78.0
No	36	22.0
Bowel screening (n=163)		
Yes	118	72.4
No	45	27.6
Cervical screening (n=163)		
Yes	128	78.5
No	35	21.5

Table 7: Number of participants who used cancer screening programs.

Did you use any cancer screening programs?	N	%
Breast cancer screening (n=158)		
Yes	88	55.7
No	70	44.3
Bowel screening (n=159)		
Yes	63	39.6
No	96	60.4
Cervical screening (n=159)		
Yes	92	57.9
No	67	42.1

7.1 Reasons for screening non-participation

During interviews and discussion groups, participants reported the following reasons for not using screening programs.

7.1.1 Lack of access

Some participants shared that due to low English literacy, they were unable to understand how to access cancer screening services. There were also barriers for people with disabilities, such as sight impairment, which made it difficult to complete self-test screening. As reported by one organisation, a participant with visual impairment asked for assistance at her GP clinic to complete self-screening and was told 'to go home and do it herself.'

7.1.2 Lack of awareness

Participants expressed that they were not aware of the availability of screening or were not informed by their GP if they were eligible. Some participants only became aware of screening programs after their cancer diagnosis. Some participants also indicated that they did not receive the bowel cancer screening kit in the mail.



'I was never told about them or asked to take those screening tests by my doctor.'

'A screening test letter has not arrived in my mailbox'



7.1.3 Unclear communication

Participants reported that cancer screening is not widely promoted or contains confusing messages on who can access the screening program, where to go to screen and how often people need to screen.

For breast screening, some participants reported that they were advised to test from 40 years old onwards, but believed the test was not free until they are 50 years old.

For bowel screening, some participants reported the messages were inconsistent and were confused as to why not all people received a bowel cancer kit. Some participants also reported they were advised by their GP that they did not need to do the bowel screening if they have regular colonoscopies.

7.1.4 Not eligible for screening and lack of perceived need

Participants reported they were not in the eligible age bracket to access cancer screening services. Several participants also reported that they did not believe they needed to screen if they were living a healthy lifestyle, had no signs and symptoms and no family history of cancer. Other participants reported they were 'too lazy' to do the test.



'I don't need it. I am healthy. I don't want to know.'

'I was [too] lazy to use the bowel cancer screening program.'



7.1.5 Cultural issues

There were several cultural issues raised amongst participants when accessing screening services, such as the gender of the health professional. Participants stated that female health practitioners and women's health services were essential to have before accessing cervical cancer screening services.

Other participants also reported they felt uncomfortable with the screening process, which included:

- embarrassed or shy about cervical screening
- worried about pain with cervical screening
- scared of the result or would rather not know.

Some participants held beliefs that the bowel screening test was difficult and disgusting. It was reported among some participants that the idea of using the bowel screening test kit was uncomfortable and they 'just felt icky about doing the test.'

7.1.6 Lack of trust in accuracy of the screening programs

Some participants indicated there may be lack of trust in the accuracy of screening programs. They noted for example, that the bowel cancer screening kits might sit in a mailbox for a few days during summer before they arrive at the pathology testing service.

Other participants thought that the cervical screening test needed to be done by a gynaecologist because of their experience of health systems overseas.

7.2 Strategies to improve cancer screening awareness and participation

When participants were asked for ideas and suggestions on how to improve screening awareness and participation amongst CaLD populations, responses included:

- GPs encouraging screening
- clearer messaging for symptoms, eligibility and cost
- using culturally appropriate language
- promoting screening through multicultural networks
- targeted education for CaLD people
- policy.

7.2.1 General practitioners to proactively encourage screening

Many participants shared the belief that it was the role of the GP to inform their patients about screening programs, including the benefits of screening and getting to know cancer early. Participants suggested that GPs can remind their patients to complete screening as well as share screening resources in GP clinics.



'The GP should make sure that the patient knows that these regular check-ups and screenings are very important.'

As reported by an organisation:

'One participant said the GP insisted he do [a] bowel screening because he had never done one before. The result came back with blood stain. The GP made a personal call to do a CT scan and colonoscopy immediately and he was found to have early-stage bowel cancer. The participant noted that their GP speaks the same language and is from the same country, so it was easy to communicate and open up to the GP.'



7.2.2 Clearer messaging for symptoms, eligibility and cost

Participants reported that clearer messaging on the eligibility and benefits of screening should be widely promoted. Some participants reported pamphlets about screening should be sent to all eligible people.

Specific cancer screening messages that participants reported as important included:

- encouraging people to get tested and what tests are free of charge
- not waiting until symptoms appear
- promoting regular screening even if there are no symptoms
- people living healthy lives can still get cancer.

7.2.3 Use language that is culturally appropriate and easy to read

Participants reported it was important to use simple language and pictures tailored to different languages and cultures to deliver cancer screening messages. Instructions on how to screen needed to be simple, concise, easy to understand, and provided in large font. Translated information also needs to be accurate.

Participants emphasised that understanding the cultural taboos associated with cancer was important when delivering cancer screening information. It was suggested to avoid technical language and use reassuring language as there is a lot of fear about cancer among CaLD communities. Information needs to consider religious and traditional practices, particularly gender roles, and use culturally respectful images.



'Sending information in a different language, so everyone can understand by using their own language.'

'Ideally the pack in the post should come in the right language or have a QR code to select the right language, but they still need to be pictorial to help understanding and for those who do not read at all.'



As reported by an organisation:



'Three consumers commented that the bowel cancer test pack is pictorial and easy to use.'

7.2.4 Multicultural networks

There are several multicultural networks across WA. These networks are gatherings with government and non-government agencies and community groups that can be leveraged to share information about cancer screening. This can be a useful way to share information in regional WA.



'You don't necessarily need someone from each community either. I have been in the Great Southern for such a long time now that I have trust and relationships with many communities, as well as my own, and I know who to go to in terms of community elders.'

7.2.5 Targeted education for CaLD communities

To bring awareness of cancer screening programs for their community, participants suggested targeted information evenings specifically for CaLD people that discuss cancer prevention and screening. Participants reported that in-person education sessions are preferred and can be tailored for regular cultural gatherings and genders. For example, mosques have different sitting times for men and women.

Other education opportunities included developing videos about cancer screening that are shown during cultural or religious events for different communities in different languages. It was also suggested that cancer screening education is taught in secondary schools to help pass information onto family members. Some participants suggested advertising cancer screening through ethnic media channels, such as social media and radio, to reach cultural communities.

7.2.6 Policy

Some participants believed that policies that support cancer screening could encourage more people to take up screening.

'If [the] health system makes [screening] mandatory or highly recommended for eligible groups, I think most will use it.'



8. Summary of findings

The purpose of this project was to better understand the information needs of CaLD consumers and carers affected by cancer. The results of the consultation provided valuable information on the recruitment and engagement of CaLD people, the information needs of CaLD people affected by cancer and the accessing of cancer screening services.

A range of strategies were used by the community organisations to recruit participants for the project. Word of mouth and leveraging existing relationships were the most effective strategies, while advertising on social media and flyers were the least effective. Establishing trusted relationships with CaLD people was also important for recruitment and engagement success, especially for CaLD men and those that lived regionally. Successful engagement strategies to support consultations included providing information upfront and offering interviews instead of group discussions.

The group discussions and interviews identified the experiences and preferences of how participants received cancer information. Participants accessed information through a range of channels, including health professionals, family and carers, interpreters and online information.

While information about diagnosis, making an informed decision on treatment, treatment costs, lifestyle changes, and how the Australian health system works were raised by participants as important, participants also requested more information about financial supports and services that can help the cancer journey experience.

The way information was delivered, including timing, was highlighted to be just as important as the content of the information. Information that is person-centred, easy to understand, and provided in stages or can be accessed in a centralised place, was identified as ideal to help participants absorb information and avoid feeling overwhelmed.

Consultation revealed that it is important to consider the impact of cultural needs when identifying cancer information preferences among CaLD communities. There were several cultural needs raised by participants throughout the consultation, including language needs, cultural beliefs about cancer, respecting religious and cultural beliefs, the role of the family, and empowering CaLD people's confidence to advocate for their health care.

Extra questions related to cancer screening were completed by most participants. Despite a high awareness of screening programs, participation in screening was lower. Identified strategies to increase participation in screening programs for CaLD people included GPs encouraging screening, improving messages around eligibility for screening, and providing translated resources for screening.

Overall, the project identified a wide of range of cancer information needs for CaLD consumers and carers affected by cancer. It is important to note that the participants in this project do not reflect all the different CaLD groups that reside in WA. Therefore, specific individual group differences may need to be explored further. This includes gender and age difference and proficiency in English.

9. Recommendations

Based on these findings, the network made 4 recommendations for the WA health system:

Recommendation 1: Utilise established relationships and partnerships to recruit and engage with CaLD people.

Recommendation 2: Increase the availability of co-designed cancer information and resources for CaLD consumers and carers, including access to online information in languages other than English.

Recommendation 3: Increase the confidence and healthy literacy skills of CaLD consumers and carers to communicate their cultural and health needs to their healthcare and support team.

Recommendation 4: Investigate the role of health professionals, particularly GPs, in supporting the health and cultural needs of CaLD consumers and carers.

10. Conclusion

Improving cancer outcomes for CaLD populations is a key priority in WA. This is identified in key policies and strategies such as the [Sustainable Health Review](#), [WA Cancer Plan 2020–2025](#) and [Western Australia Multicultural Policy Framework](#).

Empowering CaLD consumers and carers affected by cancer to make well-informed decisions about their care and improving service delivery is a shared responsibility. Forming partnerships with key stakeholders, such as healthcare providers, peak CaLD community organisations, and CaLD consumers and carers, will help progress towards achieving these outcomes.

The discussion groups and interviews provided an opportunity for CaLD people affected by cancer to share their lived experiences, stories and perspectives on how cancer information is provided in WA. As a result, the project identified a wide spectrum of cancer information needs and new opportunities to improve the quality of cancer information for CaLD communities in WA.

It is envisaged that these project findings can help inform Western Australian government agencies, service providers, and non-government organisations to develop resources and strategies to support CaLD communities affected by cancer.

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Glossary

Term	Definition
Cancer	Cancer is a term used for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. Cancers can develop from most cell types and are distinguished from one another by the location in the body where the disease began or by the cell type involved. ⁶
Cancer control	All actions that reduce the burden of cancer in the community. It includes every aspect of care, from prevention and early detection to curative treatment and palliative care, all underpinned by the best scientific evidence available. ¹⁴
Carer	Friends or family who support the person with cancer. Carers are people who provide support that is unpaid and not part of paid work or community work arrangement. ¹⁵
Consumer	People with a personal experience of health and/or social service issues; irrespective of whether they have a formal diagnosis or have accessed services and/or received treatment.
Clinical trial	Research conducted with the patient's permission that usually involves a comparison of 2 or more treatments or diagnostic methods. The aim is to gain better understanding of the underlying disease process and/or methods to treat it. A clinical trial is conducted with rigorous scientific method for determining the effectiveness of a proposed treatment. ¹⁴
Culturally and linguistically diverse (CaLD)	Groups and individuals who differ according to religion, language and ethnicity and whose ancestry is other than Aboriginal or Torres Strait Islander, Anglo Saxon or Anglo Celtic. ¹⁰
Diagnosis	The process of identifying cancer based on its signs and symptoms. A health history, physical exam, and tests, such as blood tests, imaging tests, and biopsies, may be used to help make a diagnosis. A definitive diagnosis of cancer can only be made by a pathologist. ¹⁶
Incidence	The number of new cases of a disease diagnosed each year. ¹⁴
Palliative care	Health care focused on improving the quality of life of people with a life-threatening illness or condition, including their families and carers. Palliative care recognises the person and the importance and uniqueness of their family/carers. It considers physical, social, financial, emotional, and spiritual distress, all of which can influence the person's experience and their treatment outcomes. ¹⁷

Term	Definition
Patient-centred care	Patient-centred care considers patients' cultural traditions, their personal preferences and values, their family situations, and their lifestyles. It makes patients and their families an integral part of the care team who collaborate with healthcare professionals in making clinical decisions. Patient-centred care provides an opportunity for patients to decide important aspects of self-care and monitoring. Patient-centred care ensures that transitions between providers, departments and healthcare settings are respectful, coordinated, and efficient. When care is patient-centred, unneeded and unwanted services can be reduced. ¹⁴
People affected by cancer	People who have had a personal experience of cancer, including patients, people living with cancer, cancer survivors, caregivers and family members. ¹⁴
Prevention	Action to reduce or eliminate the onset, causes, complications or recurrence of disease or ill health. ¹⁴
Regional	Regional Australia includes all of the towns, small cities and areas that lie beyond the major capital cities. ¹⁸
Risk	A measure of how likely a person is to develop a disease or a side-effect. ¹⁴
Risk factor	A substance or condition that increases an individual's chances of getting a particular type of cancer. ¹⁴
Screening	An organised program, such as tests, examinations or other procedures, to identify disease such as cancer, or changes which may later develop into disease, such as cancer, before symptoms appear. Can only be done if there is a reliable and simple test for the disease, such as the cervical smear test or breast mammogram. ¹⁴
Treatment plan	A detailed plan with information about a patient's disease, the goals of treatment, the treatment options for the disease and possible side-effects, and the expected length of treatment. A treatment plan may also include information about how much the treatment is likely to cost and about regular follow-up care after treatment ends. ¹⁶

Term	Definition
<p>WA health system</p>	<p>The WA health system is comprised of the Department of Health, Health Service Providers including:</p> <ul style="list-style-type: none"> • Child and Adolescent Health Service • East Metropolitan Health Service • Health Support Services • North Metropolitan Health Service • PathWest • Quadriplegic Centre • South Metropolitan Health Service • WA Country Health Service <p>and to the extent that contracted health entities provide health services to the State, the contracted health entities.</p>
<p>Wellbeing</p>	<p>Physical, mental and social wellbeing is affected by an individual's perception, emotions and behaviour as well as their ease of movement and levels of any discomfort. Mental health is fundamental to the wellbeing of individuals, their families and the community as a whole. Wellbeing can be measured by self-assessed health status and the prevalence of psychological distress in the population.¹⁹</p>

Appendix A. Participant question sheet

Questions

Discussion group/interview: Understanding Culturally and Linguistically Diverse (CaLD) Consumers' Needs for Cancer Information

Today we would like to hear your views about the information needs of those affected by cancer in the **(insert language group)** speaking community, and what information would be helpful throughout your cancer journey/experience with cancer.

1. What cancer information was helpful to you or your relative/carer during your cancer journey? Why was it helpful?

.....

2. What cancer information was not helpful to you or your relative/carer during your cancer journey? Why was it not helpful?

.....

3. A) Thinking about your cancer journey, what information would have made your experience better?

.....

B) How would you have liked this information to be provided? I.e.

- i. in English
- ii. in a language spoken at home
- iii. pictures
- iv. in-person
- v. online
- vi. telephone
- vii. print/hard copy
- viii. written
- ix. audio
- x. video.

4. Overall, have you encountered any gaps (issues, problems) in finding or understanding cancer information, that we have not talked about?

.....

If you have time:

5. Have you heard of any of the following cancer screening programs?

- a. breast cancer screening Yes No
- b. bowel screening Yes No
- c. cervical screening. Yes No

6. Have you used any of these screening programs?

- a. breast cancer screening Yes No
- b. bowel screening Yes No
- c. cervical screening. Yes No

7. Why have or haven't you used these screening programs?

.....

8. How could awareness and use of these screening programs be improved?

.....

Appendix B. Facilitator question sheet

Discussion group/interview: Understanding Culturally and Linguistically Diverse (CaLD) Consumers' Needs for Cancer Information

Today we would like to hear your views about the information needs of those affected by cancer in the **(insert language group)** speaking community, and what information would be helpful throughout your cancer journey/experience with cancer.

The Department of Health wants to develop cancer resources for our community but need to know what works and does not work, and where to improve.

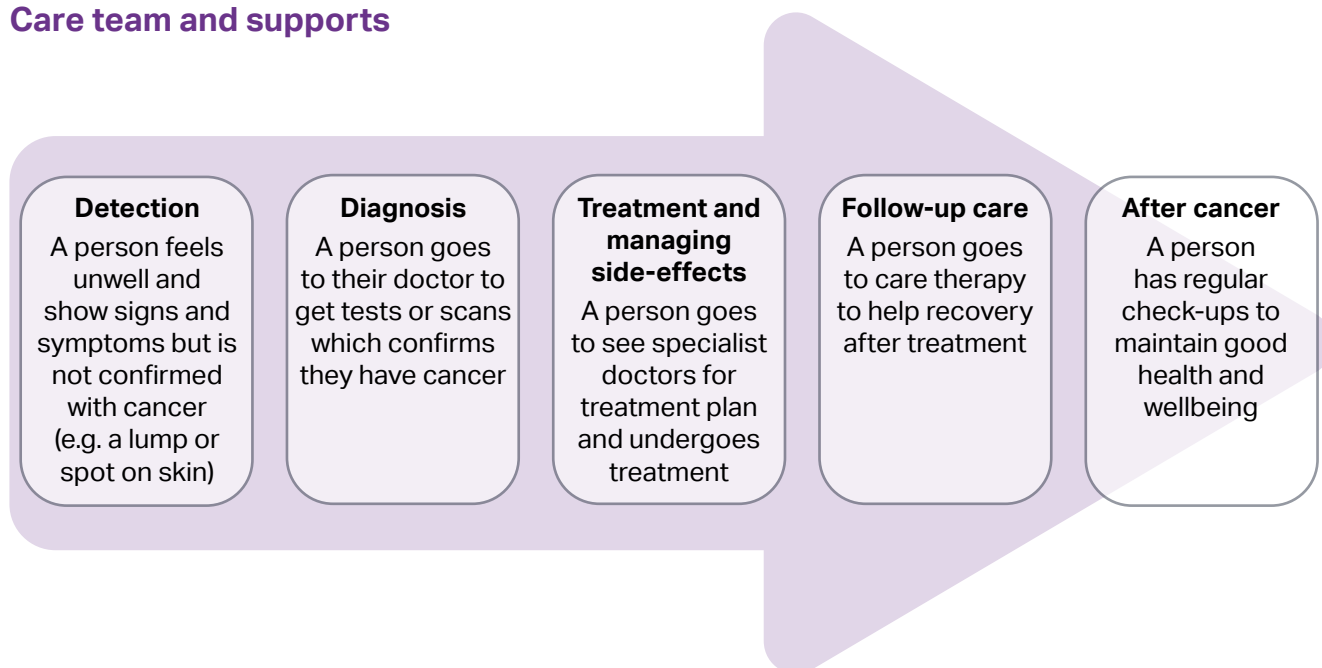
During this discussion, we will not be asking for or discussing specific names of hospitals, doctors or for you to share any personal health information.

We will go through a series of questions and when you answer these questions, we would like you to think about the stages of your cancer journey. Where relevant, we encourage you to state which stage of the journey you are referring to in your response.

*Explain the stages of the cancer journey using the diagram below:

Cancer journey

Care team and supports



Cancer information

Types of cancer information can include, but not limited to, topics:

- cancer types and conditions
- chance of recovery and after cancer care
- managing symptoms and side-effects of treatments
- support groups
- how to navigate the health system
- clinical trials (trying new treatments).

1. What cancer information was helpful to you or your relative/carer during your cancer journey? Why was it helpful?

We want to know what types of cancer information makes you:

- feel more in control
- feel less stressed or anxious
- feel more confident
- know where to go and what to do.

Participants may talk about:

- a specific website or cancer organisation
- a specific brochure, booklet, video or support group (in-person/online)
- specific advice provided by their doctor, nurse, pharmacist or support group
- how the cancer information was provided to them.

2. What cancer information was not helpful to you or your relative/carer during your cancer journey? Why was it helpful?

We want to know what types of cancer information makes you:

- feel more confused
- feel more worried and stressed
- feel more frustrated
- not know where to go or what to do.

Participants may talk about:

- information they did not understand – too complex, not in their language, or could not read it
- information that was not relevant – not tailored, not about them, or not WA specific
- information that was not culturally appropriate
- information they were told at the wrong time or by the wrong person
- a specific website or cancer organisation
- a specific brochure, booklet or video
- specific advice provided by their doctor, pharmacist or support group.

3. A) Thinking about your cancer journey, what information would have made your experience better?

We want to know information that:

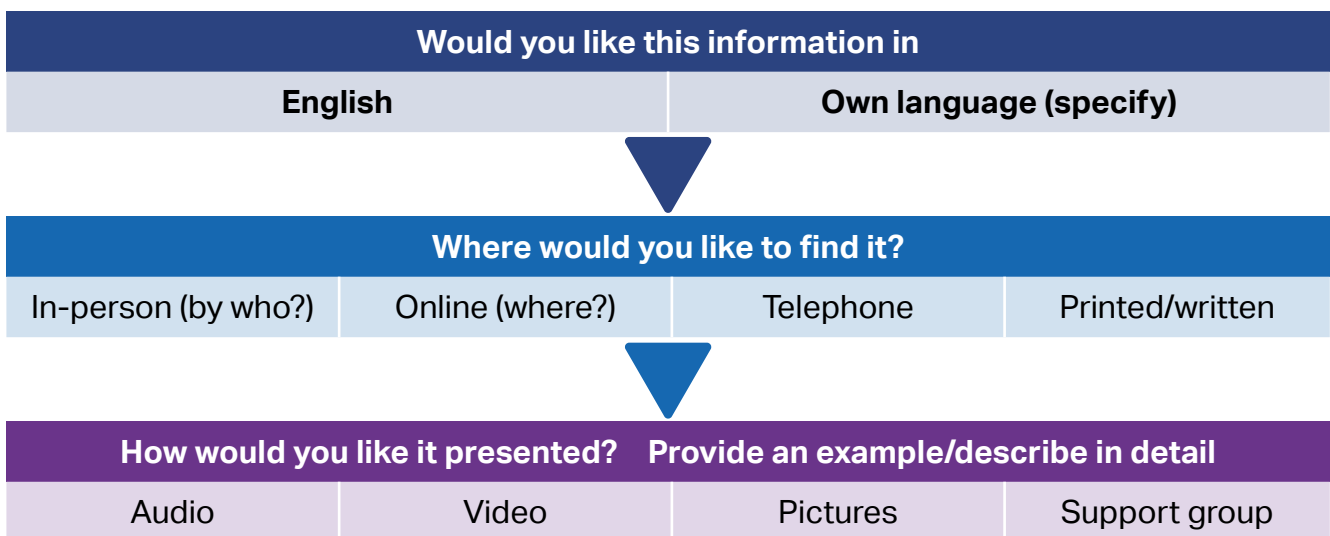
- you need to make better decisions
- is important to you and would share with others on their cancer journey
- would have helped you manage your physical health/symptoms better
- would have helped you manage your emotions and mental health better.

It may include, but not limited to:

- more information on a specific cancer (specifically if the person has a rare cancer)
- more translated information in a specific dialect or language
- more visual resources and pictures that are culturally appropriate.

3. B) How would you have liked this information to be provided?

Information can be funnelled from broad to specific like below.



4. Overall, have you encountered any gaps (issues, problems) in finding or understanding cancer information, that we have not talked about?

Provides an opportunity for participants to share other ideas and thoughts.

Tell participants that it is ok if there were some things they did not know about and emphasise there are supports for them. *Provide cancer resources*

If you have time (Note: if you are confident that there will be enough time to cover the above questions, these questions could be discussed at the start of the session.)

5. Have you heard of any of the following cancer screening programs?
a. breast cancer screening
b. bowel screening
c. cervical screening.

Count of 'yes' and 'no'.

6. Have you used any of the following cancer screening programs?
a. breast cancer screening
b. bowel screening
c. cervical screening.

Count of 'yes' and 'no'.

7. Why have or haven't you used these screening programs?

Reasons may include but not limited to:

- knowledge of the programs
- positive and negative attitudes about the programs
- beliefs and what they have heard about the program.

8. How could awareness and use of these screening programs be improved?

Reasons may include but not limited to:

- knowledge of the programs
- positive and improving attitudes about the programs
- changing beliefs and what they have heard about the programs
- specific forums such as workshops, campaigns, or getting community leaders to encourage screening.

Appendix C. Support services and resources

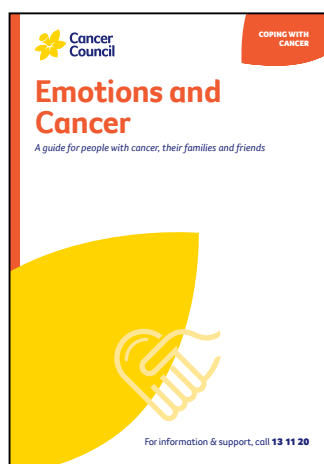
Risk and benefit information for organisations

Most people will experience a range of strong emotions after a cancer diagnosis and during their cancer journey. A discussion about cancer may cause distress for participants.

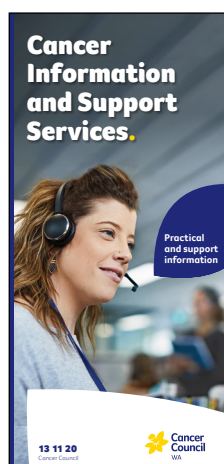
Strategies to minimise risk can include:

- Clearly frame that the discussion is about cancer information and resources rather than sharing personal health information.
- Preparing participants with the purpose of the session and including the option to opt-out of the discussion if required.
- Using careful and mindful wording of questions to suit the target audience and promote respectful and inclusive participation.
- Establishing a referral pathway and action plan for participants that become distressed talking about cancer. You can also have a health professional in the room during discussion.
- Encouraging participants to call the Cancer Council Helpline on 13 11 20 if they become distressed.
- Remunerating consumers and carers for their time.

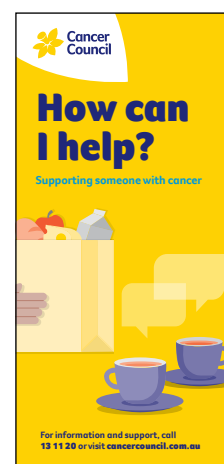
Example resources for participants



'Emotions and Cancer' guide by Cancer Council WA



'Cancer Information and Support Services' brochure by Cancer Council WA



'How Can I Help?' brochure by Cancer Council WA

Appendix D. Cancer education sessions

As part of the project implementation, the network supported participating organisations to hold cancer education sessions for their community members. These sessions were facilitated by Cancer Council WA.

Ishar held a cancer education session on women's cancer for their 5 health educators. MSCWA held 2 cancer education sessions in August and September 2022. Across the 2 sessions, 39 women from different communities, including Afghanistan, Burmese and Iranian, attended.

MSCWA conducted their own survey evaluation for the sessions and shared the findings with the network. Before the sessions, 12 participants reported they were 'not confident' in preventing cancer, and 25 participants reported they were 'confident' in preventing cancer (2 participants did not answer). After the sessions, one participant reported they were 'not confident' in preventing cancer, while 38 participants reported they were 'confident' in preventing cancer. All participants reported that the workshops were 'somewhat useful' or 'very useful' after the session.

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