



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

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

Summary of key findings

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About the project

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 CaLD people's cancer information needs.

The project has helped the department deliver a key priority of the [WA Cancer Plan 2020–2025](#) to provide reliable cancer information to consumers (Priority 2, Strategy 6). It has also helped the department progress towards achieving Recommendations 3 and 4 of the [Sustainable Health Review](#).

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. 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)

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.

Special thanks and appreciation to these 5 key organisations, their staff, consumers and carers who conducted and participated in the interviews and discussion groups.

Who we reached and engaged



175

CaLD consumers and carers affected by cancer

15

different types of cancer reported



3 out of 4

participants with cancer completed treatment

Top cancers

25% breast

11% prostate

8% upper gastrointestinal

8% gynaecological

Top languages spoke at home

English

Arabic

Farsi



One third

of participants were 35 – 54 years old

84%

were female



74%

have lived in Australia for more than 10 years

95%

were born overseas in 38 different countries

31 different languages spoken at home

Top 5 countries of birth

Iran

Italy

Malaysia

Afghanistan

India



Confidence in English

55%

spoke a little to some English



54%

read a little to some English



60%

wrote a little to some English



How participants accessed cancer information



Most participants received cancer information from health professionals throughout their cancer journey. This information was perceived to be accurate and helpful. Participants also preferred it if their GP was from a similar cultural background.

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



Participants said that sharing cancer information with a friend, family member or someone from their culture who had similar experiences helped them to better understand cancer information. Friends and family also helped to interpret cancer information for the patient during appointments.

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



Online information was helpful for participants to read and understand cancer information in their own time. But this required computer literacy skills and sometimes help from a family member. Sometimes they had to search extensively to find information.

Participants said that interpreters helped them to better understand cancer information. However, barriers for using interpreters included different dialects, lack of availability and confidentiality issues. Some participants preferred to have their family members interpret information.



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



Regional participants said that the residential lodge in Perth for regional patients was a helpful source of information. The lodge provided helpful information, such as pamphlets and brochures, and access to support groups during their stay.

How participants liked to receive cancer information



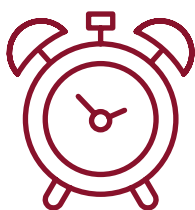
Participants said they wanted to receive person-centred information that used positive and caring language. Participants also found it helpful when they could ask questions and receive information in a timely way with family present. This was particularly important when they received their cancer diagnosis.

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



Participants said information that was simple, concise and suited low literacy levels was very helpful. Participants mentioned that translated information was difficult to find and understand. Receiving the right amount of information in stages also helped participants from feeling overwhelmed.

'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.'



Participants said it was difficult to absorb and remember all the information during appointments. A written summary and treatment plan was found to be helpful, especially if they needed their family to help interpret the information. Other helpful follow up services included a hospital helpline, education sessions at hospitals and a helpline with a cancer nurse.

'The information given by my GP was clear and he explained the stages.'

Types of cancer information important to participants



Diagnosis and prognosis information

- information on the signs and symptoms of cancer
- the different types of tests and procedures that are available
- explaining cancer-related and medical terminology.



Making an informed decision on cancer treatment

- different options are explained including the risks and benefits
- the treatment process side-effects are explained
- all treatment options are provided including palliative care and alternative treatments.



Treatment costs and financial support information

- information about treatment costs
- how to access government subsidies and superannuation
- how to access health insurance and life insurance.



Support service information

- how to find and access free support services, discounts and subsidies including:
 - transport supports and fuel vouchers
 - food vouchers
 - childcare
 - interpreting services
 - household help and personal services
 - mental health and emotional support services
 - wig access.



How the Australian healthcare system works

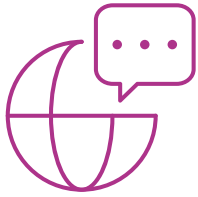
- how to navigate the Australian healthcare system
- information about the process of health referrals
- at-home and palliative care options after completing treatment.



Lifestyle information

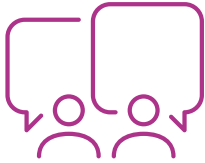
- what to eat during and after treatment
- tailored lifestyle advice to suit their needs and existing medical conditions.

Cultural needs



Language

Language was identified as a significant barrier to receiving and understanding cancer information. Interpreters and family members were not always available to interpret information, particularly during treatment stages.



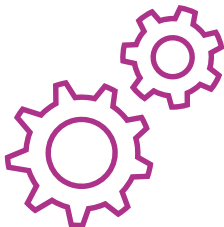
Cultural beliefs about cancer

Participants highlighted that talking about cancer can be scary and stigmatising in some cultures. Some participants reported that they did not want to share their cancer diagnosis with their family, while others wished they had a family member with them at the time of diagnosis for support.



Respect for religious and cultural beliefs

Participants found it helpful when their religious and cultural beliefs were acknowledged and included in their cancer journey. It helped them to feel safe and religious organisations were an important source of emotional and practical support throughout the cancer journey.



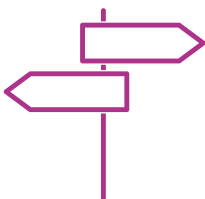
Experiences with other health systems

Participants reported that the country they were born in had different health systems and this can set different attitudes and expectations towards cancer treatment and care. For example, some countries may not have a lot of support for older people compared to Australia and people from those countries delay seeking help.



Family

Family members played an important role to help find and understand cancer information. Family support was especially important during medical appointments to help interpret information and ask questions. Family members can also be decision makers and influence the type of treatment the patient receives.



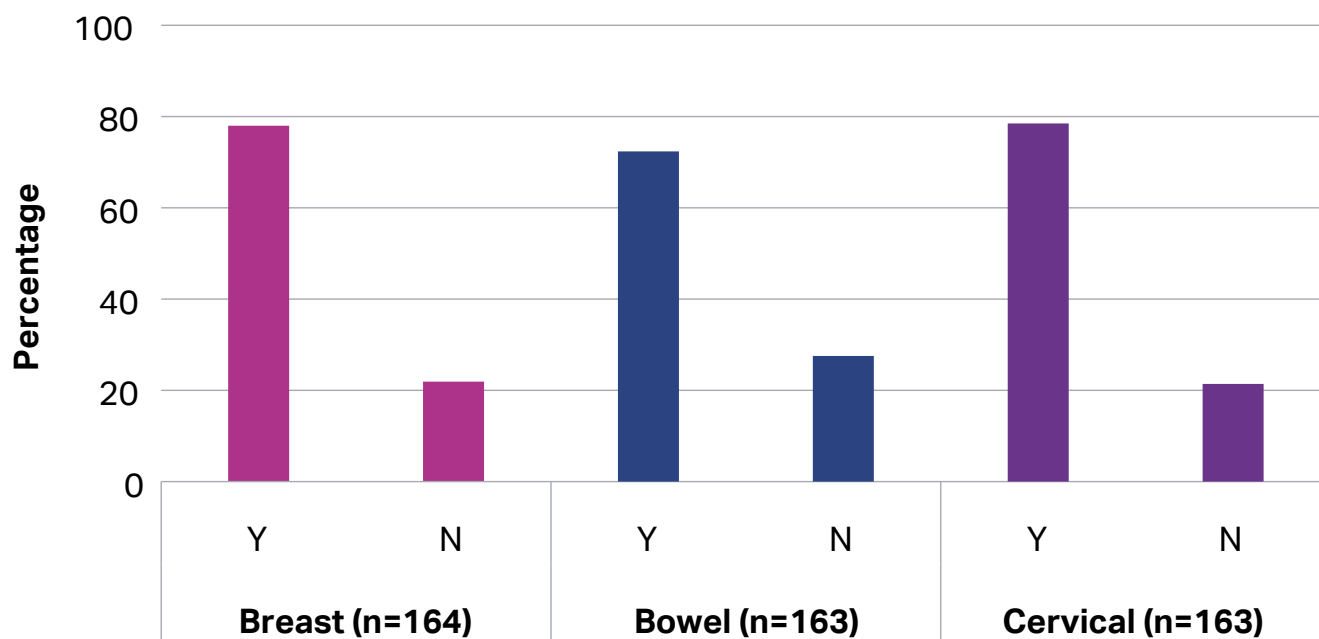
Health advocacy

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. It was also difficult for participants to advocate for their needs if English was their second language.

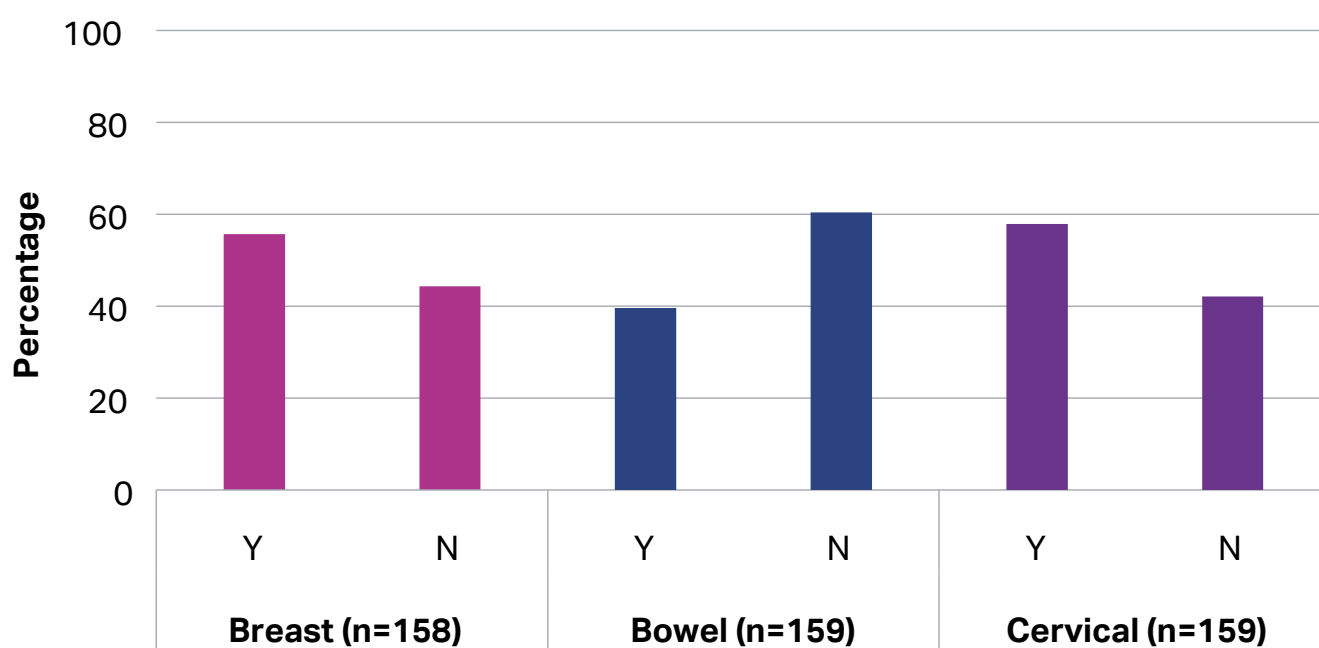
Cancer screening awareness and participation

Participants were asked if they were aware of and had used any national cancer screening programs.

Awareness of cancer screening programs



Participation in cancer screening programs



How to improve cancer screening participation

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



General practitioners to promote screening

Many participants believed that GPs could tell patients about screening programs and the benefits of detecting cancer early. Having resources at GP clinics can also help encourage participation in cancer screening.

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



Clearer messaging for symptoms, eligibility, and cost

Confusion around eligibility and cost were barriers for participating in cancer screening. Participants said clearer messaging on symptoms, eligibility and costs for cancer screening could help increase participation.

'Don't wait until you have symptoms. You must get the screening, even if you have no symptoms.'



Use language that is culturally appropriate and easy to understand

Participants said it was important to use simple language and pictures to share 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.



Hold education sessions for CaLD communities

Participants suggested holding education sessions on cancer prevention and screening during cultural events and gatherings to help increase awareness. Multicultural networks can also help share information about cancer screening.

Summary of key findings

Recruitment strategies

Word of mouth and leveraging existing relationships were the most effective strategies to recruit participants for the project. Establishing trusted relationships with CaLD people was also important, especially for CaLD men and those that lived in regional in WA.

Engagement strategies

It was important to be flexible and offer a range of consultation methods for participants, such as group discussions or interviews, and to offer them online or in-person. Providing project information and discussion questions upfront and examples during discussions helped participants answer the questions during consultation.

How participants accessed cancer information

Participants accessed information through a range of channels, including health professionals, family and carers, interpreters, and online information. Family members played an important role in interpreting information.

How participants liked to receive cancer information

Information that is person-centred, easy to understand and provided in stages helped participants to absorb the information and avoid feeling overwhelmed.

Types of cancer information important to participants

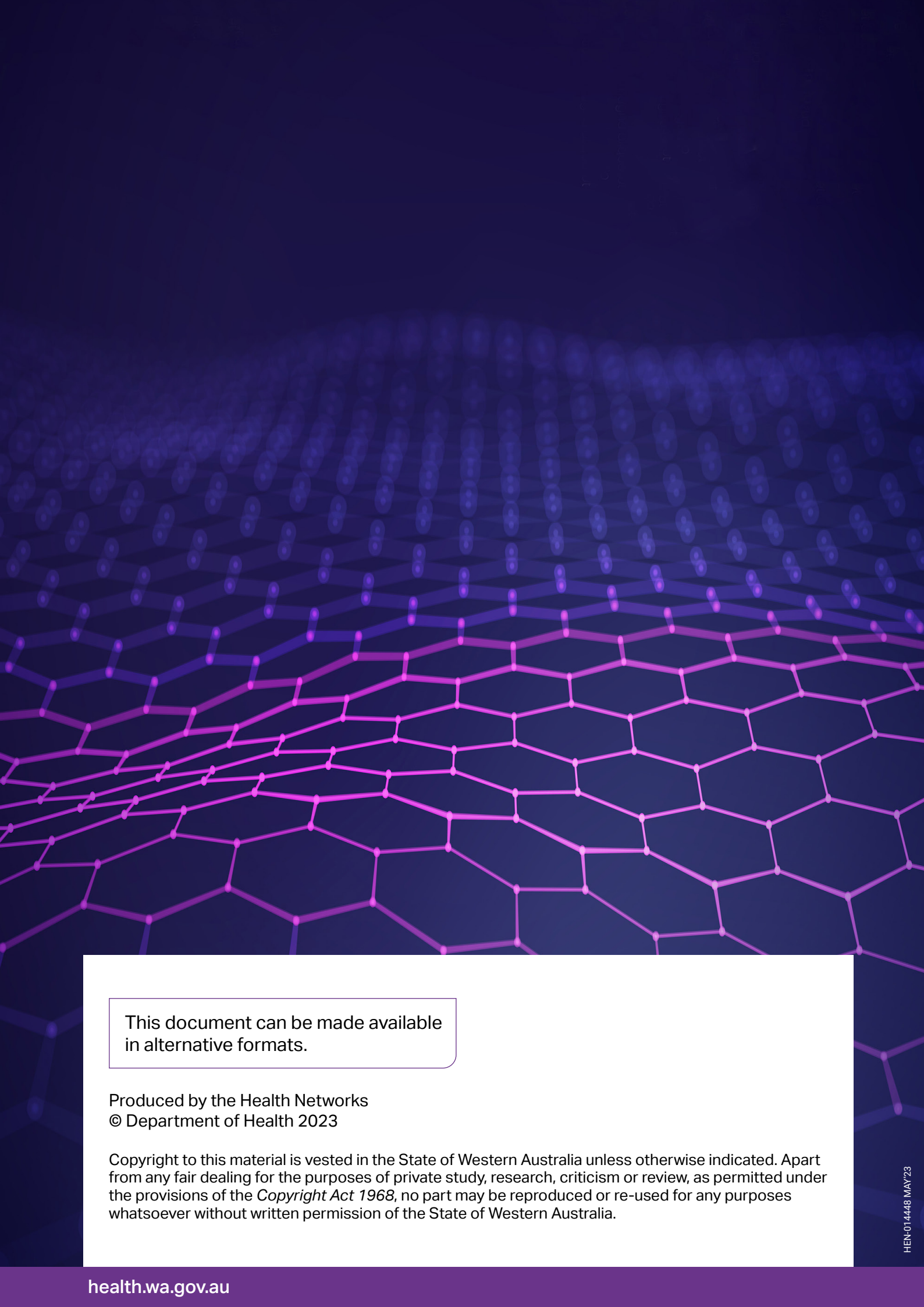
Information about diagnosis, making an informed decision on treatment, treatment costs, lifestyle changes, and how the Australian health system works were important to participants. Participants also would have liked more information about financial supports and services.

Cultural needs

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 family, and empowering CaLD people to advocate for their healthcare needs.

Cancer screening awareness and participation

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.



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