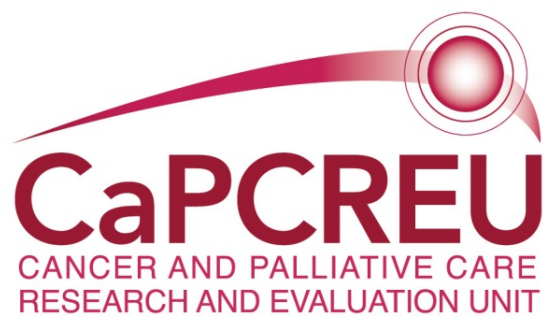


Understanding Consumers' Needs for Cancer Information

CaPCREU
CANCER AND PALLIATIVE CARE
RESEARCH AND EVALUATION UNIT



The Cancer and Palliative Care Research and Evaluation Unit (CaPCREU)
was established with funding from
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ABBREVIATIONS

AYA	Adolescents and Young Adults
CALD	Culturally and Linguistically Diverse
CaPCREU	Cancer and Palliative Care Research Evaluation Unit
CCWA	Cancer Council Western Australia
CIC Cancer	Continuous Improvement in Care – Cancer Project
DoH CN	Department of Health Cancer Network
DoH WA	Department of Health WA
PWG	Project Working Group
UWA	The University of Western Australia
WA	Western Australia
WACPCN CIU	WA Cancer and Palliative Care Network Clinical Implementation Unit

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EXECUTIVE SUMMARY

PURPOSE

This project provides an overview of cancer information currently available to consumers and explores whether this information is accessible and of value to consumers and meets their needs. Information obtained from this project has been used to make recommendations to support decision-making for improvements in patients' experience with, and understanding of, their cancer care, greater involvement in their cancer care and treatment options, and clarity of information surrounding their cancer diagnosis, diagnostics, and treatment plan.

METHODS

To identify consumers' needs for cancer information, the project was undertaken across 3 phases:

- Phase A: A desktop review was conducted to map the information resources available to cancer patients in Western Australia.
- Phase B: A jurisdictional assessment was undertaken to identify local, national, and international cancer information delivery models available to consumers. This included information available to consumers both in an online format and other modalities such as phone information service, print handouts, cancer support services, and peer support.
- Phase C: A consumer survey was developed, and data was collected to better understand what consumer information needs are, when they wanted to receive the information, whether the information was available and how they would like to access the information.

Cancer information themes identified by DoH WA were categorised into ten information types, and explored across all three phases of the project:

1. Cancer-specific types/conditions and diagnosis
2. Prognosis and/or survivorship including survival statistics, e.g., cancer-specific survival, relative survival, overall survival and disease-free survival rates
3. Treatment options by provider, location and patient insurance status
4. Associated costs specific to diagnostic tests and/or treatments (chemotherapy, radiotherapy, targeted therapy, immunotherapy and surgery; and direct and hidden expenses of cancer care)
5. Provision of a navigation tool/guideline/referral pathways
6. Wait-list information and times for diagnostic tests, treatments and supportive care
7. Clinical trial
8. Complementary care options (e.g. exercise, yoga, massage and reiki)
9. Performance and safety rating of medical providers, surgeons, unit and treatments
10. Services and groups which provide financial, practical and emotional support

RESULTS

Consultation with the Project Working Group identified health-related organisations and cancer organisations for review during Phase A and B of the project, respectively. Of the ten identified cancer information types, eight were available across the 17 health-related organisations assessed, either in its entirety or with limitations. Just over half of the health-related organisations providing resources specifically developed for Aboriginal and Torres Strait Islander peoples, however, no organisation provided resources developed for Culturally and Linguistically Diverse (CALD) communities.

Of the 11 cancer organisations assessed, Cancer Council WA had the largest range of accumulated patient information resources across print, verbal and audio-visual formats. Cancer helplines and

specialist cancer nurses were common models used to deliver cancer information and were employed across four cancer organisations. Of the cancer organisations that provided translated resources, the most common languages that cancer information was translated into were Chinese, Italian, Vietnamese, Greek and Arabic.

The Consumers' Needs survey explored consumers' experiences with seeking and obtaining cancer information, with consideration for their perceived importance on identified cancer information types. The survey was targeted at adult consumers of cancer information, with 222 surveys completed. The information type that respondents perceived of highest importance were diagnostics tests, treatment options, treatment access and prognosis. Consumers placed greater importance on cancer information when it was received at preferred points during their cancer journey. Most consumers surveyed sought cancer information online, with an equally high preference for receiving information verbally or through print materials. Information sought from health professionals were commonly provided by their treating doctor or oncology nurse.

RECOMMENDATIONS

Based on the findings, implementation of the following three recommendations are suggested:

Recommendation 1:

Collaborate with, support and promote local cancer information hubs/organisations already in place such as Cancer Council WA and Breast Cancer Care WA, and leverage on their key position within the cancer community.

Recommendation 2:

Further explore consumers needs for cancer information in groups that don't access the internet or have culturally or linguistically different needs such as CaLD and A populations.

Recommendation 3:

Develop a navigation system which can support and provide information to cancer patients and their carers at the rights times during their cancer journey.

1 INTRODUCTION

Cancer remains the leading cause of disease burden in Western Australia (WA) in terms of years lost due to disability (YLD) and years of life lost (YLL). ⁽¹⁾ In 2017, 13,346 Western Australians were diagnosed with cancer and 4,142 died from the disease. ^(2; 3) Age is a significant contributor to one's chance of developing cancer, with the specific risk being projected to increase by 50 per cent in the next 10 years among individuals aged 65 years and above in WA. ⁽⁴⁾ With an ageing baby-boom population, it is predicted that the number of Western Australians diagnosed with cancer will surpass 17,000 by 2025. ⁽²⁾ Nonetheless, cancer survival in WA has shown encouraging results over the past 30 years. ⁽²⁾

Between 1988 and 1992 to 2013 and 2017, the five-year survival rate for cancer in WA grew by 17 per cent (from 55 to 72 per cent), ⁽²⁾ thanks to improvements in early cancer detections and advances in medical treatments. ⁽⁵⁾ The growing number of people surviving and/or living with cancer denotes success in medicine while posing a challenge to the healthcare system, which will require holistic and innovative models of cancer care and support.

The cancer control system is characterised by high levels of complexity – as it traverses disciplines, organisations, and health service providers. ⁽⁶⁾ Cancer patients have reported wanting an increasing amount of cancer information – ranging from diagnosis, treatment options (symptoms and side effects), and prognosis, to signs and symptoms of potential recurrence, and peer-support groups. ⁽⁷⁾ Furthermore, improved cancer survivorship means more individuals are being confronted with issues associated with survivorship, such as psychological illnesses (anxiety and depression), fertility and difficulty with concentration and memory. ⁽⁸⁾ As a result, there is a need, and expectation, for reputable, accurate and up-to-date information on cancer, to assist patients navigate through their cancer trajectory. ⁽⁹⁾

The past decade has witnessed a shift in consumer behaviour in seeking health information, particularly their primary information resource – from health professionals to the internet. ^(10; 11) Individuals are prompted to seek cancer information online after learning about cancer symptoms, tests and diagnosis. ⁽¹²⁾ Cancer patients are also more likely to turn to the internet for information when their supportive care needs are not met – this suggests information seeking is driven by a need to obtain knowledge to resolve a specific issue or problem. ⁽¹¹⁾

Recognising consumers' rising demand for cancer information, the Department of Health Western Australia (DoH WA) identified a need to 'provide patients and carers with reliable information about their cancer, treatment pathway and potential costs' as a key strategy in improving cancer care outcomes in the WA Cancer Plan 2020-2025. ⁽⁶⁾ To assist in the delivery of this strategy, the Cancer Network at the DoH WA commissioned the Cancer Palliative Care Research and Evaluation Unit (CaPCREU) at the University of Western Australia (UWA) to explore consumers' needs for cancer information in WA.

2 BACKGROUND

In recent years, a growing number of patients have sought health information on the internet.⁽¹³⁾ Ease of access to new and emerging tests, greater and more advanced treatment options, and the ability to interact with peers and access cancer support have all contributed to this growth in utilising the internet as a source of cancer information.^(13; 14) The delivery of cancer information in different formats and resource types has enabled access to a wider range of cancer information, provided in ways to better support patient and consumer understanding of the information they are seeking.⁽¹⁵⁾ Understanding the types of information that cancer patients and consumers seek, and the formats that they prefer will enable more effective use of the available cancer information and resources.

CANCER INFORMATION PROVISION

Cancer information is delivered through a range of resources to suit patients, ranging from verbally through peers and health professionals, to print materials and written content, to multimedia and audio-visual formats such as radio and video.⁽¹⁵⁾ The internet is commonly used as a source for cancer information and support.⁽¹⁴⁾ With online technological advancements, cancer organisations can provide greater access to a wide range of resources via their websites, enhancing their ability to deliver cancer information to consumers through this online platform.⁽¹⁵⁾

SEEKING CANCER INFORMATION

There are many reasons that lead patients to seek cancer information online, from compensating for the lack of information provided by health professionals, to seeking greater detail and volume of cancer information.^(14; 16) Common types of cancer information sought online range from cancer types, treatment options and side effects, to staging, complementary therapies and clinical trials.⁽¹⁴⁾ Patients and consumers will also seek information relating to cancer support and services such as online support, peer support, emotional support, financial assistance, and insurance coverage.^(13; 14)

CANCER INFORMATION FOR DIFFERENT POPULATION GROUPS

Challenges are encountered by some minority population groups when seeking appropriate cancer information.⁽¹⁷⁾ Population groups including people of Culturally and Linguistically Diverse (CaLD) backgrounds, Aboriginal and Torres Strait Islander peoples and Adolescents and Young Adults (AYA) each require tailored and/or culturally appropriate cancer information resources that have been developed specifically for the needs of these population groups.^(17; 18; 19)

UNDERSTANDING CONSUMERS' NEEDS FOR CANCER INFORMATION PROJECT

To better understand consumers needs for cancer information, the Department of Health, Cancer Networks (DoH CN) sought an external consultancy service to map available cancer information to the information needs of consumers and recommend solutions to address the gaps

The resultant project sought to provide an overview of cancer information currently available to consumers and explore whether this information is accessible and of value to consumers, and meets their needs. Information obtained from this project was used to make recommendations to support decision-making for improvements in patients' experience with, and understanding of, their cancer care, greater involvement in their cancer care and treatment options, and clarity of information surrounding their cancer diagnosis, diagnostics and treatment plan.

3 METHODOLOGY

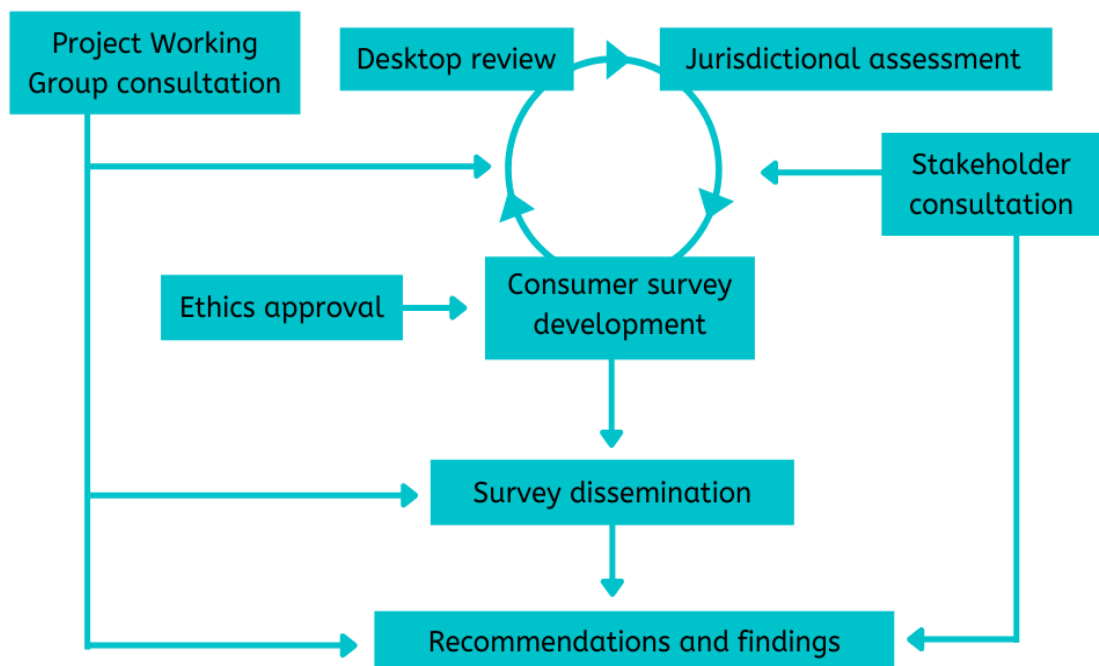
3.1 PROJECT PHASES

To identify consumers' needs for cancer information, the project was undertaken across 3 phases:

- Phase A – Desktop review
A desktop review was conducted to map the information resources available to cancer patients in Western Australia.
- Phase B – Assessment of cancer information models
A jurisdictional assessment was undertaken to identify local, national, and international cancer information provision models available to consumers. This included information available to consumers both in an online format and other modalities such as phone information service, print handouts, cancer support services, and peer support.
- Phase C – Consumers' Needs survey
A consumer survey was developed, and data will be collected to better understand what consumer information needs are, when they want to receive the information, whether the information is available and how they would like to access the information.

A flowchart of project activities is provided below.

Figure 1 - Project activities flowchart



3.2 CANCER INFORMATION THEMES AND TYPES

Cancer information sought by consumers were broadly categorised as related to cancer diagnosis, cancer treatment, or supportive cancer care. To expand on these categories, the following cancer information themes were identified by DoH WA for further exploration:

- Evidence-based and quality-assured information regarding cancer conditions and prognosis; ⁽²⁰⁾
- Information regarding treatment options ⁽¹⁴⁾, including by provider, location and health insurance status;
- Transparent and reliable information regarding associated costs of cancer care; ⁽²¹⁾
- Information regarding how to navigate known complex referral pathways; ⁽²²⁾
- Wait-list information and times for diagnostic, treatment and supportive care; ⁽²³⁾
- Information regarding eligible clinical trials and complementary care options; ⁽¹⁴⁾
- Performance and safety rates of medical providers, surgeons, units and treatments; ⁽²⁴⁾ and
- Information regarding where financial, practical, and emotional support services and groups can be accessed, including those in regional areas. ⁽¹⁴⁾

For ease of classification, these themes were categorised into the following cancer information types:

1. Cancer-specific types/conditions and diagnosis
2. Prognosis and/or survivorship including survival statistics, e.g., cancer-specific survival, relative survival, overall survival and disease-free survival rates
3. Treatment options by provider, location and patient insurance status
4. Associated costs specific to diagnostic tests and/or treatments (chemotherapy, radiotherapy, targeted therapy, immunotherapy and surgery; and direct and hidden expenses of cancer care)
5. Provision of a navigation tool/guideline/referral pathways
6. Wait-list information and times for diagnostic tests, treatments and supportive care
7. Clinical trial
8. Complementary care options (e.g. exercise, yoga, massage and reiki)
9. Performance and safety rating of medical providers, surgeons, unit and treatments
10. Services and groups which provide financial, practical and emotional support

These cancer information types were explored across all three phases of the project.

4 PHASE A – DESKTOP REVIEW

Phase A involved undertaking a desktop review of cancer information available to consumers in WA to understand the types of information currently available to those affected by cancer. Establishing this review was necessary to enable a comparison to be drawn when assessing whether the information currently available meets the needs of those that seek it – as was explored in Phase C.

A matrix was developed to review key health organisations – selected by the project team and guided by the Project Working Group (PWG) – that included consumer representatives, health professionals and allied health staff working in cancer care in WA (Appendix A – Desktop Review Matrix). Key cancer information types were derived from identified cancer information themes and used as a baseline in determining whether each organisational website provided the cancer information type specified. Development of appropriate resources for Aboriginal and Torres Strait Islander and CaLD groups were also noted.

4.1 MATRIX DEVELOPMENT

To develop the matrix, a desktop review was undertaken to assess select local, national and international ‘health’ related organisations that provide cancer information to consumers in WA through an online platform. These organisations were identified by the project team and reviewed by the PWG to ensure that the organisations selected were an accurate representation of the information sources most commonly available to cancer patients and consumers, and commonly referred to by health professionals working in the cancer sector in WA.

Organisations were classified as either:

- Local - WA-based organisations;
- National - Australian-based organisations that were located outside WA; or
- International - organisations that were based outside Australia;

based on the services that they provided within their local community, and/or their target audience. These organisational websites were then assessed against the identified cancer information themes and ten key information types.

To review each website, relevant tabs and webpages within the site that related to the identified cancer information types were scanned to seek out keywords relevant to the information themes. The search function within each website was also utilised, with keywords within each information type entered into the websites’ search function to seek the required cancer information. Examples of key search terms used include cancer type, diagnosis, prognosis, survival, treatment, insurance, diagnostic costs, wait-times, and clinical trials.

To ensure that the cancer information provided on each website satisfied the needs of the review, each website was assessed based on the availability of identified cancer information type provided, ensuring that all keywords within that type were discussed. Availability of cancer information was categorised as either:

- Available – organisational websites provided this information in its entirety
- Limited – limited information about this information type was available on the website. Information provided within the website did not cover the full scope of the informational need identified.
- Not Available – no information was provided about this information type on this organisational website.

To identify the availability of cancer information developed for different cultural groups, cancer organisations that had developed resources specifically targeted for, and tailored to, Aboriginal and Torres Strait Islander and CaLD populations were noted. These resources were generally identifiable by the differences in language used and the types of services referenced were culturally appropriate.

4.2 RESULTS

Following consultation with the PWG, 17 health-related organisations were selected for review (Table 1). Most of these organisations were targeted at audiences located across Australia, and/or at people residing in states outside of WA (national = 11), with two health-related organisations focusing their cancer information and services towards WA residents.

Most organisations reviewed had a key focus on cancer, with only two organisations providing a more generalised overview of health and or/patient support (Choosing Wisely and Health Direct).

Table 1 - Health-related organisations, by location

Health-related organisations	
Local	2
Breast Cancer Care WA Cancer Council WA	
National	11
Breast Cancer Network Australia Cancer Australia Cancer Council Australia Cancer Institute NSW Choosing Wisely Australia Health Direct Leukemia Foundation Lung Foundation Australia Peter MacCallum Cancer Support (Peter Mac) Prostate Cancer Foundation of Australia Rare Cancers Australia	
International	4
American Cancer Society (US) Cancer.Net (US) MacMillan Cancer Support (UK) OncoLink (US)	
Total	17

PROVISION OF IDENTIFIED CANCER INFORMATION TYPES

Widely available

Health-related organisations were assessed against the ten key information types (Table 2). Of the 17 reviewed organisational websites, the most widely available type of cancer information provided was *Type 1* - cancer-specific types/conditions and diagnosis (available = 16), followed by *Type 5* - navigation tool/guide/referral pathway and *Type 7* – clinical trials (available = 14).

Limited availability

Information was most limited when searching through organisational websites for cancer information about *Type 3* - treatment options by provider, location, and patient insurance status (limited = 17). The review found that information was available about cancer treatment types, and occasionally available for treatment options by provider and location. However, no information was available on treatment options by patient insurance status. This was followed by *Type 4* - associated costs specifically for tests/treatments/direct or indirect expenses (limited = 15). For this information type, information about general costs of cancer care, where costs may be incurred, and access to support to assist with costs were provided, yet no specific information or monetary amount was provided about the costs of potential diagnostic tests and treatments.

Not available

Cancer information that was consistently difficult to source or was not available on any of the organisational websites reviewed were *Type 6* – waitlist information/times for test and treatment, and *Type 9* - performance and safety rates of service providers and cancer units (not available = 17).

Table 2 - Availability of cancer information, by type

Cancer information type	Available	Organisations	
		Limited	Not available
1. Cancer-specific types/conditions and diagnosis	16	0	1
2. Prognosis and/or survivorship	12	4	1
3. Treatment options by provider, location and patient insurance status	0	17	0
4. Associated costs specifically to diagnostic tests/treatments/direct or indirect expenses	0	15	2
5. Navigation tool/guide/referral pathways	14	1	2
6. Waitlist information/times for test and treatment	0	0	17
7. Clinical trials	14	0	3
8. Complementary therapies	12	2	3
9. Performance and safety rating of service providers and cancer units	0	0	17
10. Support services and groups	11	3	3

Each organisational website was individually reviewed to determine its provision of information across the cancer information types identified. Of the 17 organisational websites reviewed, each organisation that had cancer as its key focus provided at least four types of cancer information on their website.

As displayed in Table 3, the organisational websites that provided the most types of identified cancer information were Breast Cancer Network Australia, Cancer Council Australia, Cancer Council WA, American Cancer Society (US), and MacMillan Cancer Support (UK), with each organisation providing six types of cancer information and limited information for two cancer information types.

This was followed by Cancer Institute NSW, Peter MacCallum Cancer Support (Peter Mac) and Cancer.Net (US), with each of these organisations providing five types of cancer information in its entirety and limited information for three cancer information types.

Table 3 - Availability of cancer information, by organisation

Health-related organisations	Cancer information types		
	Available	Limited	Not available
Breast Cancer Network Australia	6	2	2
Cancer Council Australia	6	2	2
Cancer Council WA	6	2	2
American Cancer Society (US)	6	2	2
MacMillan Cancer Support (UK)	6	2	2
Cancer Institute NSW	5	3	2
Peter MacCallum Cancer Support (Peter Mac)	5	3	2
Cancer.Net (US)	5	3	2
Lung Foundation Australia	5	2	3
Prostate Cancer Foundation of Australia	5	2	3
Rare Cancers Australia	5	2	3
Breast Cancer Care WA	4	1	5
Cancer Australia	4	3	3
Leukemia Foundation	4	4	2
OncoLink (US)	4	3	3
Health Direct	3	3	4
Choosing Wisely Australia	0	3	7

PROVISION OF TARGETED CANCER INFORMATION

Of the 17 cancer organisations reviewed, seven organisations provided cancer information resources targeted or tailored to audiences of Aboriginal and Torres Strait Islander background, with four of these organisations excluded from review due to their focus on international audiences (Table 4). Although translated resources were identified, resources developed and targeted for CaLD audiences were not available on any organisational website reviewed.

It should be noted that Breast Cancer Network Australia (national) and MacMillan Cancer Support (international) had developed 'easy read' cancer information resources, aimed at consumers with mental disabilities or those with low literacy levels. Materials specifically developed for AYA populations was provided by one international organisation (OncoLink).

Table 4 - Development of resources for specific population groups

Specific population groups	Organisations		
	Available	Not available	Not applicable
Resource for Aboriginal and Torres Strait Islander populations	7	6	4
Resource for people with low literacy levels	2	15	0
Resource for AYA populations	1	16	0
Resource for Culturally and Linguistically Diverse groups	0	17	0

5 PHASE B – JURISDICTIONAL ASSESSMENT

Phase B involved conducting a jurisdictional assessment to identify cancer information delivery methods and models that service local, national and international populations. Undertaking this assessment aimed to provide a better understanding of how cancer information is currently delivered to consumers, and enable a comparison to be drawn when assessing whether the delivery of cancer information meets the needs of consumers – for further exploration in Phase C.

To conduct this review, key cancer organisations were selected for assessment of their methods and models for delivery of cancer information to patients and consumers (Appendix B – Jurisdictional assessment matrix). Cancer information resource types and sub-types were identified to understand the most prevalent delivery modes of cancer information. Availability of translated cancer information resources and references to external cancer information sources were also noted.

5.1 MATRIX DEVELOPMENT

To develop the matrix, key cancer organisations were reviewed against the following select criteria:

- Type of cancer information resource – cancer information categorised by resource type and sub-type;
- Resource translation – the number of languages that cancer information was translated into; and
- Referrals to external sources – identification of whether cancer organisations provided the cancer information directly on their website, or if they referred users to external information sources.

The matrix was developed in a similar way to Phase A, organisations were classified as either local (serviced the WA population), national (serviced Australian populations but based outside of WA) or international providers.

5.2 RESULTS

Following consultation with the PWG, 11 cancer organisations were selected for review (Table 5). Most of these cancer organisations were targeted at audiences located across Australia, and/or residing in states outside of WA (national = 7), with two organisations focusing their cancer information and services towards WA residents.

Table 5 - Cancer organisations, by location serviced

Cancer organisations	
Local	2
Breast Cancer Care WA	
Cancer Council WA	
National	7
Breast Cancer Network Australia	
Cancer Australia	
Cancer Council Australia	
Cancer Institute NSW	
Lung Foundation Australia	

Ovarian Cancer Australia	
Prostate Cancer Foundation of Australia	
International	2
MacMillan Cancer Support (UK)	
OncoLink (US)	
Total	11

CANCER INFORMATION RESOURCE

Each cancer organisation was assessed based on their provision of cancer information through one of three resource types: print/written, audio-visual and verbally/in-person (Table 6). Print/written resources were the most common type of resource available across all models reviewed (n=54), followed by verbal/in person (n=25) and audio-visual resources (n=21).

Of the 11 cancer organisations reviewed, Cancer Council WA had the largest range of accumulated resource types (n=18), followed by Ovarian Cancer Australia (n=14), and Lung Foundation Australia (n=12).

Upon evaluating each resource type, Ovarian Cancer Australia provided the largest print/written range of resources (n=10), followed by Lung Foundation Australia (n=7) and Cancer Council WA (n=6). For audio-visual resources, Cancer Council WA provided the largest range (n=4), followed by Breast Cancer Network Australia and Lung Foundation Australia, both providing three audio-visual resources each. Cancer Council WA provided the largest range of verbal/in-person resources (n=8), followed by Breast Cancer Care WA, Cancer Council Australia, Ovarian Cancer Australia and Prostate Cancer Foundation Australia, each providing three resources within this type.

Table 6 - Cancer information resources, by organisation

Cancer organisation	Resource type			Total
	Print/ written	Audio-visual	Verbal/ in-person	
Cancer Council WA	6	4	8	18
Ovarian Cancer Australia	10	1	3	14
Lung Foundation Australia	7	3	2	12
Cancer Council Australia	5	2	3	10
Breast Cancer Network Australia	5	3	1	9
Breast Cancer Care WA	4	1	3	8
Prostate Cancer Foundation of Australia	4	1	3	8
MacMillan Cancer Support (UK)	3	2	2	7
Cancer Australia	4	2	0	6
Cancer Institute NSW	4	1	0	5
OncoLink (US)	2	1	0	3
Total	54	21	25	100

When assessing the cancer information resource types identified across all cancer organisations reviewed, each of the resources were further categorised by resource sub-type (Table 7).

The most common type of print/written resources available was web content (provided by all cancer organisations, n=11), followed by booklets and factsheets (n=7). Videos/webcast was the most common form of audio-visual resource found across all cancer organisations (n=11), followed by podcasts (n=5). Specialist cancer nurses and helplines were equally the most common forms of verbal/in-person

resources and were found across four cancer organisations, followed by webinars (n=3) and information support centres (n=3).

Table 7 - Cancer information resources, sub-types

Cancer information resources, sub-types	Cancer organisations
Audio-visual	
Video/webcasts	11
Podcasts	5
CDs	1
DVDs	1
Virtual conference	1
Audiobooks	1
Read speaker function	1
Verbal/in-person	
Helplines	4
Webinars	3
Information and support centres	3
Workshops	2
Support coordinators/officer	2
Forums	1
Counsellors	1
Education	1
Regional education officers	1
Seminars	1
Online community	1
PCFA Ambassador Program	1
Print/written	
Web content	11
Booklets	7
Fact sheets	7
Stories	5
Blogs	4
Magazine/newsletter	3
Flyers	3
Guides	2
Brochures	2
Posters	2
Infographics	2
Symptom diary	1
Protocols	1
Online app	1
Resilience Kit	1
eLearning	1
Bookmarks	1

PROVISION OF CANCER INFORMATION IN LANGUAGES OTHER THAN ENGLISH

The most common languages that cancer information was translated into were Chinese, Italian, Vietnamese, Greek and Arabic, with six organisations providing cancer information translated into these languages (Table 8). This was followed by Spanish (n=5), Hindi (n=3) and Punjabi (n=3).

It is important to note that the different languages cancer information resources were translated into varied depending on the location and target group of the cancer organisation. This was most evident when comparing local (WA) and national (Australian) cancer organisations with international organisations.

Table 8 - Translated cancer resources

Languages	Cancer organisations
Chinese	6
Italian	6
Vietnamese	6
Greek	6
Arabic	6
Spanish	5
Hindi	3
Punjabi	3
Dari	2
Sinhalese	2
Korean	2
Tagalog	1
Gujarati	1
Romanian	1
Urdu	1
Welsh	1
Bengali	1
Portuguese	1
Russian	1
Polish	1

CANCER INFORMATION MODELS

Some of the resources identified in Table 7 were also considered cancer information delivery models, due to their ability to further assist consumers by providing additional information, resources and/or support. As listed in Table 9, the most common types of cancer information delivery models were Helplines (telephone support services) and Specialist Cancer Nurses, with each of these models provided across four cancer organisations. Helplines were provided by one local organisation (Cancer Council WA), two national organisations (Breast Cancer Network Australia and Cancer Council Australia) and one international organisation (MacMillan Cancer Support (UK).

Specialist Cancer Nurses provide patients with nursing care and support specific to their cancer and was available through one local organisation (Breast Cancer Care WA) and three national organisations (Lung Foundation Australia, Ovarian Cancer Australia, and Prostate Cancer Foundation of Australia).

Table 9 - Cancer information models

Cancer information models	Delivery models
Helplines	4
Breast Cancer Network Australia	1
Cancer Council Australia	1
Cancer Council WA	1
MacMillan Cancer Support (UK)	1
Information and Support Centres	3
Cancer Council WA	2
MacMillan Cancer Support (UK)	1
Online Community	1
Ovarian Cancer Australia	1
Ambassador Program	1
Prostate Cancer Foundation of Australia	1
Regional Education Officers	1
Cancer Council WA	1
Specialist Cancer Nurses	4
Breast Cancer Care WA	1
Lung Foundation Australia	1
Ovarian Cancer Australia	1
Prostate Cancer Foundation of Australia	1
Support Coordinators/Officers	2
Breast Cancer Care WA	1
Cancer Council WA	1
Total	16

REFERRALS TO EXTERNAL CANCER INFORMATION SOURCES

Cancer organisations were reviewed based on their provision of cancer information themes and types, as identified in the project methodology. Reviewed organisations would refer consumers to external sources in instances where they were unable to provide identified cancer information. Of the 11 cancer organisations reviewed, 325 instances of referrals to 172 external websites/ sources were noted.

The website/source that was most often referred to for additional cancer information was Cancer Council Australia (n=15), followed by Cancer Council NSW (n=14) and Cancer Australia (n=10). It is interesting to note that four Cancer Council websites (the national site and three state sites) were in the top 10 most referred websites amongst all the organisations reviewed in Table 10.

Table 10 – Referrals to external cancer information sources

External sources/organisations	Instances referred to external source
Cancer Council Australia	15
Cancer Council NSW	14
Cancer Australia	10
Cancer Council VIC	8
MacMillan Cancer Support	7
American Society of Clinical Oncology	5
Breast Cancer Network Australia	5
Australian Government - Department of Health	5
Cancer Council WA	5
US National Institute of Health - National Cancer Institute	5
Other (n=162)	246
Total	325

These instances were also categorised according to the type of additional cancer information that was being sought (Table 11). Of all the instances of referrals to external sources for additional identified cancer information, 110 of these instances were for support services and groups, followed by cancer-specific types/conditions and diagnosis (n=67) and treatment options by provider, location and patient insurance status (n=62).

Table 11 - Types of cancer information requiring external sourcing

Cancer information type	Instances referred to external source
Support services and groups	110
Cancer-specific types/conditions and diagnosis	67
Treatment options by provider, location and patient insurance status	62
Clinical trials	29
Complementary therapies	21
Associated costs specifically to diagnostic tests/treatments/direct or indirect expenses	20
Prognosis and/or survivorship	12
Navigation tool/guide/referral pathways	4
Total	325

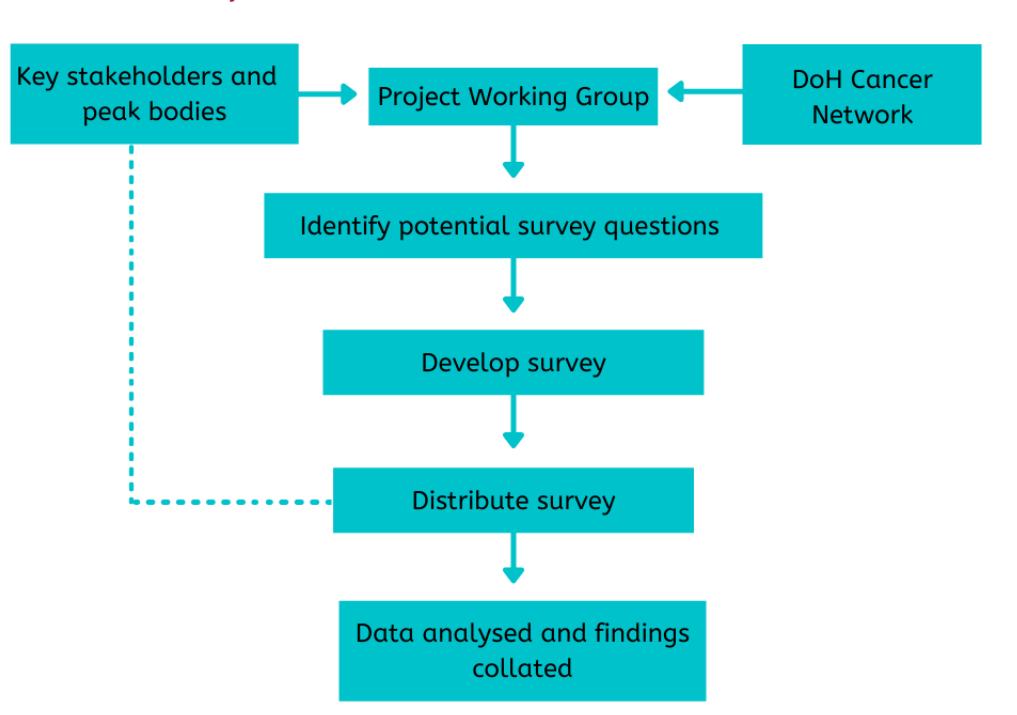
6 PHASE C – CONSUMERS’ NEEDS SURVEY

6.1 SURVEY DEVELOPMENT

The project team developed an online consumer survey to explore the informational needs of cancer patients (Appendix C – Consumers’ needs survey). The survey tool considered various themes based on consumers’ use of information, reported needs, perceived priority and importance of these needs, and perceived accessibility. Survey questions explored the importance of cancer information across the cancer pathways at specific time points and patients’ experiences with obtaining relevant cancer information, with a key focus on the 10 cancer information types identified.

The online survey consisted of 32 open ended and closed questions including multiple choice, Likert scale and matrix style questions. The survey was developed in consultation with the PWG and was designed using RedCap™ software. Consent for participation was collected prior to commencing the survey.

Figure 2 - Consumer survey activities flowchart



The survey was split into the following key sections:

- About you
- About your cancer journey
- What cancer information matters to you
- Your experiences with getting cancer information
- Looking for cancer information online
- Looking for extra cancer information
- Feedback

ETHICS APPROVAL

Ethics and governance approval was granted by the Human Ethics Research Committee (HREC) at The University of Western Australia, prior to distributing the survey.

PARTICIPANTS

The primary target audience of the survey were adult cancer consumers (cancer patients of all cancer types, aged ≥ 18 years), currently located in WA. Consumers who identified as Aboriginal or CALD were also captured. This was to provide an understanding of whether they would complete online surveys and assist in identifying a need for other ways of approaching Aboriginal or CALD people to better understand their specific cancer information needs, and where they would choose to seek that information.

6.2 SURVEY DISTRIBUTION

To assist in widespread distribution of the consumer survey, already existing networking channels were utilised. Survey promotional materials were provided to stakeholders/stakeholder groups (n=12), who had previous contact with the project team and confirmed their support for the survey:

- Aboriginal hospital liaison officers
- Arche Health
- Breast Cancer Care WA
- Cancer Council WA
- CIC Cancer Project Consumer Reference group
- Consumer and Community Involvement Network
- Health Consumer Council WA
- Department of Health Cancer Network
- Ovarian Cancer Nurses
- Prostate Cancer Foundation Australia
- Solaris Cancer Care
- WA Cancer and Palliative Care Network Clinical Implementation Unit

Each stakeholder was provided with a Participant Invitation Form which included the survey link (Appendix D – Consumers’ Needs survey – Participant information form). Additional promotional content was developed for use in newsletters, social media, etc (Appendix E – Consumers’ Needs survey – Samples of promotional materials). A flyer was also developed for those seeking to promote the online survey in a different setting (Appendix F – Consumers’ Needs survey – Flyer).

The survey was open for completion for a total of 6 weeks from 24 January 2022.

6.3 SURVEY RESULTS

RESPONSE RATE

The survey received 377 responses with 222 surveys completed to a minimum of 50% of the survey questions, resulting in a 59% completion rate. This report provides an overview of the results obtained from the 222 respondents who completed the survey (Appendix G – Consumers’ Needs Survey – Survey results).

DEMOGRAPHICS

Of those who completed the survey, 89% (n=198) of respondents were cancer patients, 88% (n=190) were females and 87% (n=188) live in the Perth Metropolitan area, and these respondents were evenly spread across the three Perth Metropolitan Health Service catchment areas. Of those who resided in a regional centre (12%, n=25), most respondents were from the South West (36%, n=9), followed by respondents from the Goldfields (24%, n=6).

The majority of consumers who completed the survey were over the age of 45 years (84%, n=185), with the largest age bracket of respondents aged between 55 and 64 years (31%, n=68, Table 12).

Table 12 - Age range of responders

Age range	Count	Percentage (%)
18-24 years	5	2
25-34 years	8	4
35-44 years	21	10
45-54 years	55	25
55-64 years	68	31
65 years or above	62	28
Total	219	100

When asked about their ethnicity, more than half of respondents identified as non-Indigenous Australians (55%, n=104), and more than a quarter identified as European (28%, n=53). Consumers who identified as Aboriginal or Torres Strait Islander made up 3% (n=6) of those surveyed, whilst those who identified as either Asian, North American or African had the lowest representation in the survey, accounting for 2% (n=2), 2% (n=4) and 1% (n=1) of responses respectively. When asked about language spoken at home, most respondents stated that English was their primary language (98%, n=212). Other primary languages spoken included Cantonese, Hungarian, Spanish and Tagalog (2%, n=5).

Table 13 - Ethnicity of responders

Ethnicity	Count	Percentage (%)
Non-Indigenous Australian	104	55
European (including UK)	53	28
Other	9	5
South Pacific nations (including New Zealand)	8	4
Aboriginal or Torres Strait Islander	6	3
North American	4	2
Asian	2	2
African	1	1
Total	189	100

CANCER JOURNEY

Respondents were surveyed about their cancer journey and their diagnosis. As shown in Table 14, 73% of respondents were diagnosed with breast cancer (n=160), followed by other cancers (6%, n=13) and prostate cancer (4%, n=9).

Table 14 - Cancer diagnosis

Cancer diagnosis	Responses	Percentage (%)
Breast	160	73
Male reproductive (Prostate/Testicular)	10 (9/1)	5
Rare cancer	7	3
Lung	6	3
Lymphoma	6	3
Colorectal/bowel	6	3
Melanoma/skin cancers	4	2
Urological	4	2
Brain/central nervous system	3	1
Endocrine	3	1
Leukaemia	3	1
Pancreas	3	1
Gynaecological	2	1
Ovarian	2	1
Head and neck	1	1
Total	220	100

Of those surveyed about their cancer journey, most patients reported being diagnosed between 2019 and 2021 (61%, n=126). Many consumers reported that their cancer was diagnosed early (70%, n=151), while a significant proportion noted that they had either finished their treatment and were living cancer free (40%, n=87), or were having ongoing treatment after completing surgical, chemotherapy and/or radiotherapy treatment (35%, n=78).

Of those who had either commenced or finished treatment, more than a third had received their treatment in the public health care system (39%, n=85). Similar proportions of respondents were found to have accessed private cancer care services (29%, n=63) and a mix of both private and public sectors (30%, n=66) (Table 15). Most respondents were made aware of the treatment services that they would receive (86%, n=191) and informed of where their treatment would be delivered (86%, n=189).

Table 15 - Sector of cancer care provision

Sector	Count	Percentage (%)
Public only	85	39
Private only	63	29
Both public and private	66	30
Other	5	2
Total	219	100

When asked an open-ended question about their biggest informational need post diagnosis, the variation in responses required categorisation into 15 key themes (Table 16). The most common theme was treatment options and side effects (33%, n=108), followed by cancer-specific information and diagnosis (13%, n=44), prognosis and survivorship (12%, n=41), and navigator/plan through cancer journey (9%, n=29).

Table 16 - Biggest informational need, by theme*

Biggest informational need (theme)	Responses
Treatment options and side effects	108
Cancer-specific information and diagnosis	44

Prognosis and survivorship	41
Navigator/plan through cancer journey	29
Cancer support/services	26
Information is clearly explained and willingly provided by health professional	14
Financial and practical advice/support	13
Providers of cancer care	12
Complementary therapies/support and modifiable lifestyle changes	10
Emotional/psychological advice and support	9
Cancer information/support for family	9
No informational need identified	7
Follow up by cancer nurse/health professional	5
Everything	2
Abundance of information was overwhelming	1
Total	330

* Please note that some responses identified with more than one theme.

IMPORTANCE OF CANCER INFORMATION

Information type

Consumers were surveyed on their perceived importance of the 10 cancer information types identified and explored in both Phase A and Phase B. Cancer information types that were of greatest importance amongst respondents were diagnostic tests (99%), treatment options (98%), treatment access (96%) and prognosis (96%). It was interesting to note that consumers also highly ranked information about understanding the health system (92%) and wait times for diagnostic tests and treatments (92%) (Table 17).

Table 17 - Importance of cancer information type*

Cancer information type	Strongly agree (%)	Agree (%)	Total (%)
Diagnostic tests	15	84	99
Prognosis (likely progression of the cancer)	86	10	96
Treatment options	89	9	98
Where to access treatment	69	26	96
Understanding the health system and referral pathways for my cancer care	64	29	92
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy or surgery)	69	23	92
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	61	28	89
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	56	31	87
Understanding how my treatment will be organised when health services are provided at different health sites	60	25	86
Personal financial costs of diagnostic tests, cancer treatment and care	52	32	84
Support services for patients and carers (including financial, practical and emotional support services and groups)	64	18	82
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	43	36	79

Clinical trials	34	37	71
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* This question allowed for multiple responses

Key results are noted in bold and underlined.

Timing of access

The importance of obtaining cancer information at specific points during the cancer journey was also ascertained from the survey responses (Table 18).

- Respondents greatly valued the importance of obtaining the following types of cancer information at diagnosis: diagnostic tests (85%), prognosis (67%), treatment options (70%), treatment access (59%) and wait times for tests and treatments (63%).
- Receiving cancer information was preferred before treatment for: financial costs of treatment (63%), understanding how treatment will be organised (69%), performance and safety ratings (60%), and clinical trials (44%).
- Information about insurance cover for treatment (54-55%) and support services for patients (50-53%) were equally preferred, both at diagnosis and before treatment.
- Information regarding understanding the health system (59-60%) and complementary therapies (43-44%) were both equally preferred to be received during and after cancer treatment.

Table 18 - Importance of cancer information, by specific time point*

Cancer information type	At time of diagnosis (%)	Before treatment (%)	During treatment (%)	After treatment (%)
Diagnostic tests	<u>85</u>	29	17	14
Prognosis (likely progression of the cancer)	<u>67</u>	29	19	24
Treatment options	<u>70</u>	45	12	6
Where to access treatment	<u>59</u>	55	10	4
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	<u>54</u>	<u>55</u>	7	4
Personal financial costs of diagnostic tests, cancer treatment and care	44	<u>63</u>	10	5
Understanding the health system and referral pathways for my cancer care	52	<u>60</u>	<u>59</u>	19
Understanding how my treatment will be organised when health services are provided at different health sites	36	<u>69</u>	17	7
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy or surgery)	<u>63</u>	45	19	6
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	42	<u>60</u>	14	6
Support services for patients and carers (including financial, practical and emotional support services and groups)	<u>53</u>	<u>50</u>	35	23
Clinical trials	32	<u>44</u>	21	16
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	25	<u>43</u>	<u>44</u>	30

* This question allowed for multiple responses

Key results are noted in bold and underlined.

EXPERIENCES OBTAINING CANCER INFORMATION

Timing of access

The survey further explored consumers' experiences with obtaining cancer information. When asked about obtaining information along the cancer journey, a significant proportion of consumers reported either seeking or receiving cancer information about diagnostic tests (74%) and prognosis (46%) at time of diagnosis (Table 19). Approximately half of respondents reported obtaining information about treatment options either at time of diagnosis (51%) or before treatment (49%), while a third of consumers sought information about the health system and referral pathways either at diagnosis (32%) or before treatment (36%). Information about access to treatment (53%), insurance cover of treatment (46%), financial costs of treatment (41%), wait times for tests and treatments (46%) and performance of care providers (33%) were most often acquired before treatment. Support services and clinical trials were most often obtained before treatment (32% and 18% respectively) or during treatment (35% and 14% respectively). Only a quarter of consumers obtained information about complementary therapies, and this was most often sought during treatment (27%) or after treatment (24%).

Table 19 - Obtaining cancer information, by specific point in time*

Cancer information type	At time of diagnosis (%)	Before treatment (%)	During treatment (%)	After treatment (%)
Diagnostic tests	<u>74</u>	31	17	10
Prognosis (likely progression of the cancer)	<u>46</u>	31	28	16
Treatment options	<u>51</u>	<u>49</u>	14	4
Where to access treatment	46	<u>53</u>	11	4
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	29	<u>46</u>	19	2
Personal financial costs of diagnostic tests, cancer treatment and care	24	<u>41</u>	24	5
Understanding the health system and referral pathways for my cancer care	<u>32</u>	<u>36</u>	26	10
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy or surgery)	32	<u>46</u>	22	6
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	26	<u>33</u>	15	9
Support services for patients and carers (including financial, practical and emotional support services and groups)	27	<u>32</u>	<u>35</u>	19
Clinical trials	10	<u>18</u>	<u>14</u>	8
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	10	21	<u>27</u>	<u>25</u>

* This question allowed for multiple responses

Key results are noted in bold and underlined.

Sufficiency of information

Almost half of consumers (46%) stated that the information provided was sufficient and delivered in a way that they could understand, while almost a quarter of respondents (24%) stated that although they were provided with enough cancer information, they were unable to process the information at the time of delivery (Table 20).

Table 20 - Understanding cancer information provided

Understanding cancer information provided	Responses	Percentage (%)
Yes	90	46
I was given information, but could not understand it	8	4
I was given information, but I was not ready to process it at the time it was given	46	24
I was given information, but it didn't suit my needs at the time	13	7
No. I was not given enough information	35	18
Don't know/can't remember	3	1
Total	195	100

Despite this, 61% (n=116) of consumers reported that they were successful in seeking and obtaining cancer information in their preferred formats, at relevant points in their cancer journey (Table 21).

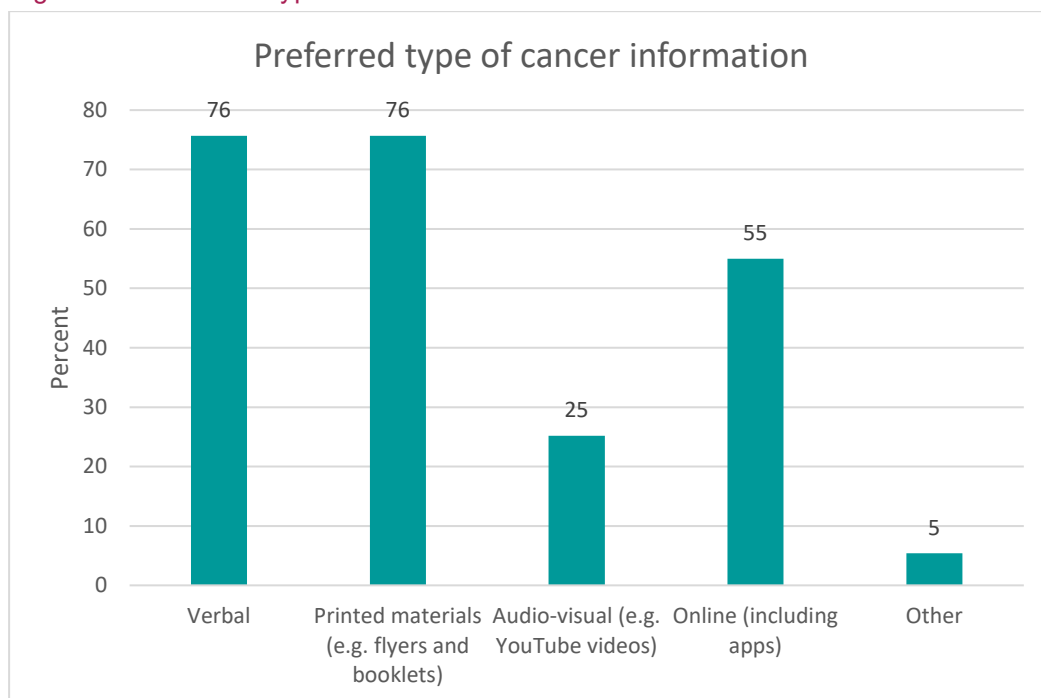
Table 21 - Obtaining cancer information in timely manner

Obtaining cancer information in preferred format, in timely manner	Responses	Percentage (%)
Yes	116	61
No	56	30
Don't know/can't remember	17	9
Total	189	100

Preference for information resource

Most respondents equally preferred their cancer information verbally or as print materials (76%) (Figure 3).

Figure 3 - Preferred type of cancer information



* This question allowed for multiple responses

Source of access – health professionals

A significant proportion of respondents received most of their cancer information from their treating doctors, while information about cancer support services and complementary therapies were more often provided by oncology nurses (Table 22).

Table 22 - Receiving cancer information from a health professional*

Cancer information type	GP (%)	Treating doctors (%)	Oncology nurses (%)	Social worker (%)	Other health professionals (%)
Diagnostic tests	45	<u>72</u>	26	2	10
Prognosis (likely progression of the cancer)	11	<u>76</u>	19	-	3
Treatment options	10	<u>79</u>	22	1	5
Where to access treatment	14	<u>69</u>	24	2	8
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	13	<u>46</u>	18	4	14
Personal financial costs of diagnostic tests, cancer treatment and care	5	<u>40</u>	18	6	17
Understanding the health system and referral pathways for my cancer care	15	<u>40</u>	29	7	18
Understanding how my treatment will be organised when health services are provided at different health sites	8	<u>45</u>	33	3	14
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy or surgery)	9	<u>59</u>	27	1	10
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	12	<u>31</u>	19	4	14
Support services for patients and carers (including financial, practical and emotional support services and groups)	10	20	<u>35</u>	18	25
Clinical trials	1	<u>30</u>	8	1	15
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	6	17	<u>24</u>	13	31

* This question allowed for multiple responses

Key results are noted in bold and underlined.

Of those who received cancer information from a health professional, most respondents were **given** cancer information verbally through discussions with their health professional (76%, n=168), followed by provision of print materials (53%, n=118).

Source of access - other

When asked about their experiences with **seeking** cancer information, 87% of respondents reported seeking cancer information online, noting that cancer diagnostics, prognosis, treatment options, ratings of care providers and clinical trials were information types most commonly sought through this platform. Of those who looked for cancer information online, 26% of consumers reported that they had used social media platforms to obtain additional cancer information. Most consumers reported that they had no

issues getting cancer information online (82%) and most of the information was easy to understand (86%).

As shown in Table 23, the types of websites most commonly used by consumers to seek cancer information were Australian cancer websites (48%, n=107), followed by Government websites (47%, n=104) and online support groups and forums (34%, n=75). When asked to elaborate on specific websites used to seek cancer information, Cancer Council was the most common website utilised (23%, n = 37), followed by Breast Cancer Network Australia (10%, n = 16) and Breast Cancer Care WA (8%, n = 23). It is interesting to note that these websites were also more likely to be recommended by health professionals, with the websites most recommended including Cancer Council (29%, n=8), followed by Breast Cancer Network Australia (21%, n=6) and Breast Cancer Care WA (18%, n=5).

Table 23 - Common websites for seeking cancer information, by type*

Website type	Responses	Percentage (%)
Australian cancer websites (general) e.g. Cancer Council	107	48
Government websites (cancer specific) e.g. Cancer Australia	104	47
Online support groups and forums	75	34
Australian cancer websites (cancer-type specific) e.g. Rare Cancer Australia, Prostate Cancer Foundation	64	29
International cancer websites e.g. MacMillan (UK)	63	28
Professional medical association websites	55	25
Government website (General) e.g. WA Health	42	19
Academic journals and bibliographic databases	40	18
News websites	10	5
Other	9	4
Alternative and complementary therapy websites	0	0
Total	589	100

* This question allowed for multiple responses

Additional information types

Aside from the key cancer information themes that were addressed throughout the survey, consumers were also asked if they looked for additional cancer information that wasn't covered in the questionnaire. Approximately a quarter of consumers (26%, n=47) sought further cancer information outside of the themes covered in the questionnaire, with over a third of respondents (38%, n=50) finding the additional cancer information that they were looking for.

Consumer feedback

The following responses provide some insight into key cancer information types and issues that patients felt most strongly about during their cancer journey:

- *“If I had been reporting on my 1st diagnosis, the answers would have been quite different especially navigating the health care system private vs Medicare but having been through it before that wasn't an issue. I think for those in the serious health system for the first time, this is very difficult.”*
- *“Having a cancer nurse specific to your cancer has been one of the most helpful things in navigating the medical world. Having her support with a quick phone call or email and her being able to access specialists etc makes dealing with problems/questions so much simpler and less stressful. This is an amazing service for us.”*
- *“Information needs to be provided in stages as appropriate. Overloading patients at diagnosis just adds to the emotional and psychological impact of that diagnosis.”*

- *“I felt very overwhelmed by the amount of verbal information I received while undergoing treatment as my brain was not functioning properly. I often thought if we could have had a flow chart or something to help navigate it all of this information it would have been very helpful.”*
- *“The problem is that when you are first diagnosed (especially) it is all a little overwhelming. There is multiple moving parts and there is huge amounts of information thrown at you or available. You have no idea how busy you will become with specialist appointments, diagnostic tests and decision making.”*
- *“A lot of information provided at first visit with surgeon by Breast Nurse. I didn't read it all immediately. The volume of information but also the significance of the diagnosis was a bit overwhelming at the beginning. However I believe the information needs to be given at the beginning and further discussion along the treatment journey.”*

7 DISCUSSION

7.1 KEY FINDINGS

To understand the complexities around consumers' needs for cancer information, all three phases were reviewed, compared and analysed to form the following findings.

AVAILABILITY AND PERCEIVED VALUE OF CANCER INFORMATION

The desktop review of cancer information undertaken in Phase A provided an understanding of the types of cancer information currently available to consumers. Using the cancer information types identified in the methodology, the reviewed information was assessed against the cancer information types identified in the methodology, and was further compared with the responses collected from the consumer survey undertaken in Phase C.

Of the ten cancer information types identified in the methodology, eight are available to WA consumers of cancer information – a reflection of current literature about the types of cancer information available online.^(7; 8; 9; 13; 14) Results from the review undertaken in Phase A found that the most widely available type of cancer information was *Type 1* - cancer-specific types/conditions and diagnosis. The availability of this information type positively aligns with the survey results from Phase C, with respondents ranking this information type as highest importance and as their biggest informational need, post cancer diagnosis.

The two information types that were unobtainable during the desktop review were *Type 6* - wait-list information and times for diagnostic tests, treatments and supportive care and *Type 9* - performance and safety rates of medical providers, surgeons, unit and treatments. Despite the impact these information types can have on cancer outcomes and patient satisfaction,^(23; 24) it was found that this information could not be located across the local, national and international organisations reviewed in Phase A. Although these two information types were moderately ranked by consumers when prompted about their perceived importance, each of these types were not automatically offered by consumers when they were surveyed about their 'biggest informational need', post cancer diagnosis. The difficulty in sourcing these information types combined with the consumers' inability to recall these as a 'biggest informational need' suggests that, although it would be ideal to have access to this information, the feasibility of providing these information types would require in-depth exploration, particularly if resources are limited.

Consumers placed relatively high importance on information regarding navigators and greatly valued understanding how the health system works. This was evident when consumers were asked about their 'biggest informational need' and the importance that they placed on navigation information. Consumer feedback provided in the survey also suggests that the provision of a navigator or assistance with navigating the health system was beneficial along their cancer journey, with praise shown for the health system by those who received navigational support and negativity by those who did not. These survey findings support current literature which encourages the implementation of navigators in cancer care, due to its ability to improve cost-effectiveness, efficiency and quality of care ^(25; 26).

The desktop review identified five key organisations that provided eight out of the ten cancer information types identified for investigation:

- Breast Cancer Network Australia (National - Australia)
- Cancer Council Australia (National - Australia)
- Cancer Council WA (State - WA)
- American Cancer Society (International - US)

- MacMillan Cancer Support (International - UK)

This was compared to the data collected from the Consumers' Needs survey where patients were asked about their cancer-information seeking behaviours. Similarities can be drawn between the organisations identified in the desktop review as key providers of identified cancer information, and the responses from consumers about their use of these organisations when seeking cancer information. Responses from the survey found that consumers were more likely to seek cancer information from Australian cancer websites. When asked to elaborate about specific websites, Cancer Council was the most common website utilised, followed by Breast Cancer Network Australia and Breast Cancer Care WA. This supports the notion that organisations who are currently providing a wide range of identified cancer information types are also widely utilised by consumers and cancer patients in WA.

Survey respondents also placed significant importance on information about cancer treatment options and where to access treatment, which aligns with *Type 3* - treatment options by provider, location and patient insurance status in Phase A. Although information about treatment options were widely available, information regarding access to treatment including treatment providers' locations and associated insurances were difficult to obtain, demonstrating a gap in availability of this type of cancer information.

CANCER INFORMATION FOR CALD AND ABORIGINAL AND TORRES STRAIT ISLANDER POPULATIONS

Cancer information targeted towards CaLD and Aboriginal and Torres Strait Islander communities were also considered to identify whether currently available cancer information meets their needs. In Western Australia, people who identify as Aboriginal make up 3.9% of the population⁽²⁷⁾ while those who are defined as CaLD represent approximately 17% (dependent on the definition of CaLD).⁽²⁸⁾ It has been reported that those who identify as Aboriginal or Torres Strait Islander have higher rates of cancer incidence and mortality, with many patients often diagnosed at a cancer stage more consistent with higher morbidity and mortality.^(6; 27) Although lower rates of cancer diagnosis are experienced in those defined as CaLD, factors that may contribute to this include lower rates of participation in national cancer screening due to language barriers, capacity to attend screening, and attitudes towards national screening programs.⁽²⁹⁾ Although this project does not have a key focus on understanding the informational needs of these specific groups, identifying whether they engaged with the survey undertaken in Phase C was beneficial.

Of those who completed the Consumers' Needs survey, almost half the respondents identified as either Aboriginal (3%) or stated that their ethnicity was neither Australian and Indigenous Australian (42%), yet the majority of respondents (98%) stated that English was their primary language spoken at home. With the delivery of the survey as an online tool and only available in English, it was anticipated that a significant proportion of consumers would select English as their primary language. The desktop review found that the resources available to those who identified as Aboriginal and Torres Strait Islander was limited, with just over half the organisations reviewed providing cancer information developed specifically for this community group. Development of resources specifically for those who identify as CaLD, however, was not available across any organisation reviewed in Phase A. This can be expected when taking into consideration the complexities of developing resources specifically targeted to diverse communities with differing backgrounds.⁽³⁰⁾

Despite the lack of targeted cancer information developed specifically for the CaLD community, cancer information translated into other languages were identified during Phase B of the project. This found that the most commonly available languages for cancer information resources were Chinese, Italian, Vietnamese, Greek and Arabic, consistent with the literature that indicates that Mandarin, Italian and Vietnamese are the most common languages primarily spoken at home in WA in 2016.⁽³¹⁾

Results from the Consumers' Needs survey found that 2% of respondents spoke a language other than English at home. Of these five respondents, the languages spoken included Cantonese, Hungarian, Spanish and Tagalog. Although the languages provided were inconsistent with the findings from current literature, it still supports the need for translated resources in languages commonly spoken and used

within the local community. With extremely low representation from people who speak a primary language other than English, it would be beneficial to engage this community using more targeted strategies, to better understand their needs for cancer information.

CANCER INFORMATION DELIVERY

Consumers' understanding of cancer information can vary, depending on the way the information is provided and delivered.⁽³²⁾ This can range from the use of different formats for presentation to delivery through different channels and various models. To understand how cancer information is currently delivered and provided to WA consumers of cancer information, a jurisdictional assessment of cancer information delivery was undertaken in Phase B. Although used to a lesser extent in this phase, cancer information types identified in the methodology were referenced to ensure consistency across the project, and comparisons were made with the responses collected from the consumer survey undertaken in Phase C.

Phase B involved assessing 11 cancer organisations on their provision of cancer information, taking into consideration resource types, information delivery, and referrals to external sources. Resources were categorised into three types: audio-visual, print and verbal/in-person. Results from Phase B found that the most commonly available resource type were print resources. When compared to the responses collected from the Consumers' Needs survey undertaken in Phase C, this fared favourably with most respondents stating that print and verbal resources were equally their preferred channels for receiving cancer information. These results support consumers' preferences for cancer information delivered verbally, particularly from their health care provider, and through tailored print materials.⁽¹⁶⁾

Of the 11 organisations reviewed in Phase B, Cancer Council WA provided the largest range of cancer information resources, providing 18 resource types across written, audio-visual and verbal formats. Again, this compared well with the survey as respondents cited Australian cancer websites (general) e.g. Cancer Council as their most frequently used online source of information. Cancer Council was also one of the organisations referred to most by health professionals when consumers are seeking additional information. Whilst Ovarian Cancer Australia was found to be the cancer organisation which provided the largest range of print/written resources, they provided very limited resources in other formats. In addition, given the specificity of the cancer type, this organisation was not as highly rated by survey respondents.

Organisations were assessed for the models utilised to distribute and deliver cancer information. Phase B found that specialist cancer nurses and helplines were equally the most common type of cancer delivery models, with each model adopted by four different organisations. Of these, five were national organisations, one was international and two were local organisations - Cancer Council WA and Breast Cancer Care WA. This review also found that Cancer Council WA disseminated cancer information through five information delivery models - the highest number of models by organisations assessed. Furthermore, Cancer Council was most often referred to by other organisations for additional cancer information, in instances when those organisations were unable to provide identified cancer information to their consumer. The integration of these organisations within the cancer community was also evident in survey results, which found Cancer Council and Breast Cancer Care WA both cited by survey respondents as websites highly frequented for cancer information.

EXPERIENCES SEEKING CANCER INFORMATION

Consumers' needs for cancer information can vary greatly depending on the amount of information they seek, the type of information required, the source of information and their ability to understand and absorb this information.⁽³³⁾ To better understand consumers' needs for cancer information in a WA setting, an online survey was undertaken in Phase C to explore consumers' experiences with seeking and obtaining cancer information.

Consumers were surveyed about their **perceived importance on obtaining** cancer information at specific points during their cancer journey. This was directly compared to survey responses on **when they received** this information during their cancer journey (Table 24).

The following information types were not received at a time point that was deemed most important:

- Where to access treatment
- Wait times for diagnostic tests and treatments (e.g. chemotherapy/radiotherapy/surgery)

While the following information types were deemed important at two time points, but not obtained at both time points:

- Whether the diagnostic tests and treatment were covered by private health insurance or Medicare
- Understanding the health system and referral pathways for my cancer care
- Support services for patients and carers (including financial, practical and emotional support services and groups)
- Complementary therapy options (e.g. exercise, yoga, massage, reiki)

Table 24 - Information received at time points - importance vs obtained

Cancer information type	At diagnosis		Before treatment		During treatment		After treatment	
	I*	O**	I*	O**	I*	O**	I*	O**
Diagnostic tests	✓	✓						
Prognosis (likely progression of the cancer)	✓	✓						
Treatment options	✓	✓		✓				
Where to access treatment	✓			✓				
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	✓		✓	✓				
Personal financial costs of diagnostic tests, cancer treatment and care			✓	✓				
Understanding the health system and referral pathways for my cancer care		✓	✓	✓	✓			
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy or surgery)	✓			✓				
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)			✓	✓				
Support services for patients and carers (including financial, practical and emotional support services and groups)	✓		✓	✓		✓		
Clinical trials			✓	✓		✓		
Complementary therapy options (e.g. exercise, yoga, massage, reiki)			✓		✓	✓		✓

* Importance of obtaining information

** Obtained information

Survey results also indicated that 46% of respondents received enough information from their health professional and understood the information they were provided, with a higher number of responses (90%) recorded for a similar question in preliminary data collected from the CaPES study.⁽²⁶⁾ Just under a quarter of respondents stated that although they were provided with enough cancer information, they

were unable to process the information at the time of delivery (24%) or it didn't suit their needs at the time (7%). This supports the notion that cancer information provided by health professionals is generally easy to understand, however the value of the information can also vary, depending on when they receive it.

Despite the slight differences found above, overall findings showed that most consumers obtained the identified cancer information at specific time points that they perceived important. Some of the discrepancy in findings may lie in the respondent's inability to recall this information to the specific details asked of them in the survey, or it may reflect that although they may not have received some information at specific time points, they were generally satisfied with the information they received at points across their cancer journey.

Consumers' sources of cancer information were also identified. Most respondents equally preferred their cancer information verbally or as print material. For those who preferred their information verbally, a significant proportion obtained most of their cancer information from their treating doctor or oncology nurse. This is in line with current research which has shown that consumers prefer to receive cancer information from a health professional and are more accepting of recommendations made by their treating doctor when seeking further cancer information.^(15; 16)

A significantly large proportion of surveyed respondents reported seeking cancer information online (87%), with more than a quarter of these respondents seeking additional information on social media platforms. Research has shown that although there has been an increasing trend in consumers seeking cancer information online,⁽¹³⁾ the proportions seen in the survey data may not be an accurate representation of all consumers. Preliminary results from the comprehensive CAPES study reported a more modest 9% of consumers seek cancer information online.⁽²⁶⁾ However, emerging evidence suggests the need to acknowledge the evolving use of social media in the provision of cancer information.⁽³⁴⁾

7.2 LIMITATIONS

Limited survey response

The survey was accessible for a period of 6 weeks between 24/1/22 and 7/3/22. This was later than anticipated, this was a result of delays with ethics approvals. These delays impacted on both the timing of the survey and the period it was open for completion. The holiday period prior to the survey opening also reduced opportunities for stakeholder promotion of the survey.

Online distribution of survey

Many consumers chose not to access the internet for cancer information for a myriad of reasons. These included, unfamiliarity with internet use, no access to the internet, lack of tools and/or skills to navigate information online; these consumers will not be captured in this project.⁽³³⁾ Hence this project may not reflect all consumers' needs, particularly those who are not accustomed, or comfortable with seeking cancer information online.

Online nature of cancer information provision

The project predominantly explores online sources of information, but as the evidence suggests, consumers seek information from a range of sources, and at different stages during their cancer journey.^(33; 26) At diagnosis, patients don't always turn to the internet for their initial source of cancer information. Thus, informational needs for cancer patients may not be met online as patients may not naturally seek information online at that time. Results from this survey should only be applied to consumers who currently utilise the internet to seek cancer information as they may not be applicable to the wider cancer community. Further exploration into initial cancer seeking behaviours of consumers in WA should be investigated.

Representation of consumer groups

This survey strongly represents those with a breast cancer diagnosis. Breast cancer is the most common cancer in females in WA and accounts for 30% of cancer in this cohort. ⁽³⁵⁾ With 73% of survey respondents reporting a breast cancer diagnosis and 89% of respondents were female, this accurately reflects current literature. However, it is less representative of males, or people diagnosed with other cancer types.

It is important to acknowledge the challenges that some minority populations encounter when seeking appropriate cancer information.⁽³⁶⁾ This survey was only available in English as this is the primary language spoken and written in WA. ⁽³¹⁾ With the diversity of cultures and backgrounds evident in WA, people who speak languages other than English may not have the language skills to have completed this survey and their representation will be limited. Further research using different methodologies is needed to ensure true representation of all cancer patients including those from Aboriginal and Torres Strait Islander peoples and CaLD communities.

This project has only reviewed adult consumers of cancer information. Research shows that those diagnosed with cancer when aged less than 18 years have very specific needs when it comes to cancer information. ⁽¹⁹⁾ Time, budget and resource constraints for this specific project would not allow for a thorough investigation of this cohort.

8 RECOMMENDATIONS

To better meet the needs of consumers of cancer information in WA, implementation of the following three recommendations are suggested:

Recommendation 1:

Collaborate with, support and promote local cancer information hubs/organisations already in place such as Cancer Council WA and Breast Cancer Care WA, and leverage on their key position within the cancer community.

Recommendation 2:

Further explore consumers needs for cancer information in groups that don't access the internet or have culturally or linguistically different needs such as CaLD and Aboriginal and Torres Strait Islander populations

Recommendation 3:

Develop a navigation system which can support and provide information to cancer patients and their carers at the rights times during their cancer journey.

9 CONCLUSION

Improvements in cancer screening and technological advances in cancer care have resulted in a growing number of people surviving and living with cancer. ⁽⁵⁾ There has been an increasing number of people seeking information from online sources to alleviate their cancer concerns. ⁽¹³⁾ Key cancer information types that consumers are seeking (and deem important) are available to WA consumers through reputable, health-related and cancer organisations. Despite this, consumers may not be aware of these resources or have access to these at essential time points during their cancer trajectory. Exploring patients' past experiences with seeking and obtaining cancer information has offered great insight toward better understanding consumers' needs for information. This report will provide a solid base to inform DoH WA's decision making regarding effective utilisation of available cancer information resources to better service the WA cancer community.

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APPENDIX A – DESKTOP REVIEW MATRIX

Please see Appendix A – Desktop Review Matrix

APPENDIX B – JURISDICTIONAL ASSESSMENT MATRIX

Please see Appendix B- Jurisdictional Assessment Matrix

APPENDIX C – CONSUMERS’ NEEDS SURVEY



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

Consumers’
 **THE UNIVERSITY OF
WESTERN
AUSTRALIA**
Needs for Cancer Information Survey

ABOUT YOU

1. Are you responding to the following questions as a cancer patient, or as a carer on behalf of a patient diagnosed with cancer?
 - Patient
 - Carer

- 2a. What is your age range? **Skip logic will be used here. People selecting ‘patient’ in question 1 will only see question 2a.**
 - 18-24 years
 - 25-34 years
 - 35-44 years
 - 45-54 years
 - 55-64 years
 - 65 years or above

- 2b. What is the age range of the person you are the carer for? **Skip logic will be used here. People selecting ‘carer’ in question 1 will see question 2a and 2b.**
 - Less than 17
 - 18-24 years
 - 25-34 years
 - 35-44 years
 - 45-54 years
 - 55-64 years
 - 65 years or above

If you are a carer, please respond to the rest of the survey on behalf of the person you care for.

3. Which ethnic group do you identify with?
 - Aboriginal or Torres Strait Islander
 - Non-Indigenous Australian

- Asian
- South Pacific nations (including New Zealand)
- Middle Eastern
- European (including UK)
- North American
- South American
- African
- Other – please specify below

4. Is English your primary language spoken at home? If no, please specify the language spoken.

- Yes
- No

5. Do you identify as?

- Male
- Female
- Other
- Prefer not to say

6. What is your postcode (or the person you care for)?

ABOUT YOUR CANCER JOURNEY

If you are a carer, please answer the questions on behalf of the person you care for.

7. Which of the following applies to you?

- Recently diagnosed with cancer and have not started treatment
- Undergoing surgical, chemotherapy or radiotherapy treatment
- Having continuing treatment after finishing surgery, chemotherapy, or radiotherapy
- Finished treatment and living cancer free
- Finished treatment and living with cancer
- Receiving palliative care
- Other – please specify below

8a. What type of cancer were you first diagnosed with?

- Brain/central nervous system
- Breast
- Colorectal/bowel
- Digestive (e.g. Oesophageal, Stomach, Bile duct)
- Endocrine
- Gynaecological
- Head and neck
- Leukaemia
- Lung
- Lymphoma
- Melanoma/Skin cancers
- Mesothelioma
- Myeloma
- Ovarian
- Prostate
- Rare cancer
- Other – please specify below

8b. Have you had a further diagnosis of cancer? If yes, please provide details. **Skip logic will be used here. People selecting 'No' in question 8b will skip to question 9a.**

- Yes
- No

8c. Are you answering this survey based on your experiences of the first or further diagnosis? **Skip logic will be used here. People selecting 'further diagnosis' will skip to question 9b.**

- First diagnosis
- Further diagnosis

9a. In what year were you first diagnosed with cancer? **Skip logic will be used here. People who answer question 9a will not see question 9b.**

9b. In what year were you further diagnosed with cancer?

9c. What was the cancer stage at this diagnosis?

- Early/localised
- Advanced/distant spread/spread to other parts of the body
- Don't know/can't remember
- Other - please specify below

10. What was your biggest information need after receiving your cancer diagnosis?

11. Where did the cancer care take place?

- Public only
- Private only
- Both public and private
- Waiting for treatment
- Other – please specify below

12. Were you made aware of the treatment services you would need? If no, please provide details.

- Yes
- No
- Don't know/can't remember

13. Were you informed of where all aspects of your treatment would be delivered?

- Yes
- No
- Don't know/can't remember

WHAT CANCER INFORMATION MATTERS TO YOU

If you are a carer, please answer the questions on behalf of the person you care for.

For the questions in this section, please respond to each of the statements provided for the different points along the cancer care pathway, as they apply to you.

14. The following cancer information is/was important to me:

	Strongly agree	Agree	Disagree	Strongly disagree	N/A
Diagnostic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Prognosis (likely progression of the cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to access treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal financial costs of diagnostic tests, cancer treatment and care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the health system and referral pathways for my cancer care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding how my treatment will be organised when health services are provided at different health sites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy surgery or support services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support services for patients and carers (including financial, practical and emotional support services and groups)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. At which points in the cancer journey do you feel it is important for the following cancer information to be provided? Select all that apply.

Please note: Not all columns will be relevant to all rows

	At time of diagnosis	Before treatment	During treatment	After treatment	N/A
Diagnostic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Prognosis (likely progression of the cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to access treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal financial costs of diagnostic tests, cancer treatment and care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the health system and referral pathways for my cancer care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding how my treatment will be organised when health services are provided at different health sites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy surgery or support services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support services for patients and carers (including financial, practical and emotional support services and groups)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. Which format do you prefer cancer information to be provided to you? Select all that apply.

- Verbal
- Printed materials (e.g. flyers, booklets)
- Audio-visual (e.g. YouTube)
- Online (including apps)
- Other – please specify below

YOUR EXPERIENCES WITH GETTING CANCER INFORMATION

If you are a carer, please answer the questions on behalf of the person you care for.

In this section, respond to each of the statements provided as these apply to you.

17. When in the cancer journey did you seek or receive the following cancer information?

Select all that apply.

Please note: not all columns will be relevant to all rows.

	At time of diagnosis	Before treatment	During treatment	After treatment	N/A
Diagnostic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prognosis (likely progression of the cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to access treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal financial costs of diagnostic tests, cancer treatment and care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the health system and referral pathways for my cancer care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding how my treatment will be organised when health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

services are provided at different health sites					
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy surgery or support services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support services for patients and carers (including financial, practical and emotional support services and groups)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. Did you seek or receive information from the following health professionals? Select all that apply.

	GP	Treating doctors	Oncology nurses	Social worker	Other health professional
Diagnostic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prognosis (likely progression of the cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to access treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Personal financial costs of diagnostic tests, cancer treatment and care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the health system and referral pathways for my cancer care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding how my treatment will be organised when health services are provided at different health sites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy surgery or support services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support services for patients and carers (including financial, practical and emotional support services and groups)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please provide details about **other** health professionals you sought information from:

19. If you were given information from a health professional, how was this provided?

- Discussion with the health professional
- Flyer/pamphlet/other written information
- Other - please specify below

20. Were you given enough information by health professionals about your cancer care and support, in a way that you could understand?

- Yes
- I was given information, but could not understand it
- I was given information, but I was not ready to process it at the time it was given
- I was given information, but it didn't suit my needs at the time
- No. I was not given enough information
- Don't know/can't remember

21. From what **other** sources have you sought or received information about your cancer? Select all that apply.

- *Personal contacts (e.g. family, friends, colleagues, someone you know that has experience with cancer)*
- *Cancer information helpline (e.g. Cancer Council 13 11 20, Breast Cancer Network Australia Helpline, Prostate Cancer Specialist Telenursing Service)*
- *Support groups (e.g. face to face meetings, online forums)*
- *Print information (e.g. flyers, pamphlets, posters, booklets)*

	Online	Personal contact	Cancer information helpline	Support groups	Print information	Other sources	N/A
Diagnostic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prognosis (likely progression of the cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where to access treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whether the diagnostic tests and treatment were covered by private health insurance or Medicare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal financial costs of diagnostic tests,	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

cancer treatment and care							
Understanding the health system and referral pathways for my cancer care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding how my treatment will be organised when health services are provided at different health sites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Wait times for diagnostic tests and treatments (e.g. chemotherapy, radiotherapy surgery or support services)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Performance and safety ratings of care providers (e.g. treating surgeons, health service providers, cancer treatment centres)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Support services for patients and carers (including financial, practical and emotional support services and groups)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Complementary therapy options (e.g. exercise, yoga, massage, reiki)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please provide details about **other** information sources you may have used (e.g. apps):

22. If you obtained information from a support group, in what format/s was the support group made available? Select all that apply.

- Face-to-face/workshop
- Online/video
- Social media
- Don't know/can't remember
- Other – please specify below

23. Thinking about the way you prefer to be provided with information (Q16) and when you sought information (Q17). Did you find the information you were looking for and at the right time? If no, please provide details.

- Yes
- No
- Don't know/can't remember

LOOKING FOR CANCER INFORMATION ONLINE

If you are a carer, please answer the questions on behalf of the person you care for.

24. Have you been **advised** by a healthcare professional/s (e.g. GP, surgeon, oncology nurse, etc) to seek additional cancer information online? If yes, please provide details about the options suggested.

- Yes
- No

25. Have you **searched** for cancer information online? If no, please provide details.

- Yes
- No

26. What types of websites do you most commonly use to look for cancer information? Select all that apply.

- Government websites (general) e.g. WA Health and Indigenous Health InfoNet
- Government websites (cancer specific) e.g. Cancer Australia

- Australian cancer websites (general) e.g. Cancer Council and Peter MacCallum Cancer Centre
- Australian cancer websites (cancer-type specific) e.g. Rare Cancer Australia, Prostate Cancer Foundation Australia
- International cancer websites e.g. MacMillan (UK), Cancer.Net (US) and Johns Hopkins (US), Mayo Clinic (US)
- News websites
- Online support groups and forums
- Professional medical association websites e.g. WebMD
- Alternative and complementary therapy websites
- Academic journals and bibliographic databases
- Other – please specify below

27. Among the websites you visited, which were your 'go-to' sites, and why?

28. What **other** online resources have you used to look for cancer information? Select all that apply.

- Social media platforms
- YouTube
- Apps (e.g. My Journey)
- Other – please specify below

29. Did you have any difficulties **understanding** the cancer information available online? If yes, please provide details below.

- Yes
- No

30. Did you have any difficulties **getting** the cancer information available online? If yes, please provide details below.

- Yes
- No

LOOKING FOR EXTRA CANCER INFORMATION

If you are a carer, please answer the questions on behalf of the person you care for.

31. Did you look for any other cancer information that is not included in the questions you have already answered? If yes, please provide details about the **type** of information you were looking for and **where** you looked for that information. **Skip logic will be used here.**
People selecting 'No' in question 31 will skip to 'Feedback' section

- Yes
- No

32. Were you able to find this additional cancer information? If yes and you can recall this, please provide details on where you found it.

- Yes
- No

FEEDBACK

If you are a carer, please provide your feedback on behalf of the person you care for.

If you have any additional feedback or comments, please provide below.

Thank you for taking the time to complete the survey.

APPENDIX D – CONSUMERS’ NEEDS SURVEY – PARTICIPANT INFORMATION FORM



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



Subject: Invitation to participate in the

'Understanding Consumers' Needs for Cancer Information' project

Hi,

You are invited to help us identify what, and how best, to provide cancer information to Western Australians

The WA Department of Health Cancer Network, in partnership with the University of Western Australia's (UWA) Cancer and Palliative Care Research and Evaluation Unit are undertaking a project to better understand the information needs of people affected by cancer. WA Health are keen to learn about what type of cancer information people need, where they look for it, where they find it, how they want to receive the information, and when they need it.

What are we looking for?

The project seeks your views and experiences on looking for cancer information during your cancer journey. This will help WA Health to provide cancer information in the best way possible for people diagnosed with cancer in the future. This research study has UWA Human Research Ethics approval.

How can you help?

Complete our online survey (it should take about 20-30 minutes to complete)

Start survey (please click link): <https://redcap.link/cancerinformationsurvey>

Kind regards,

Dr Angela Ives (Project Lead)

Research Fellow

Cancer and Palliative Care Research and Evaluation Unit (CaPCREU)

UWA Medical School (Fiona Stanley Hospital)

Faculty of Health and Medical Sciences

☎: +61 8 6151 1124 ✉: angela.ives@uwa.edu.au

APPENDIX E – CONSUMERS’ NEEDS SURVEY – SAMPLES OF PROMOTIONAL MATERIALS

Breast Cancer Care WA

Social media - Facebook

Breast Cancer Care WA
 Charity Organization · Nonprofit Organization
 Privacy Policy
 breastcancercarewa

Photos See all

Videos See all

You are so brave.
 Today is Metastatic Breast Cancer Aware...
 110 likes
 3.4K views · 19 weeks ago

Upcoming events See all

TUE, MAR 29 AT 11 AM

Breast Cancer Care WA
 February 22 at 4:27 PM · 🌐

Share your experiences of searching for cancer information! WA Health in partnership with The University of Western Australia are keen to hear about what type of cancer information people need, where they look for it, where they find it, how they want to receive the information, and when they need it. Sharing your views and experiences about looking for cancer information will help guide the provision of information for people diagnosed with cancer in future. If you have undergone treatment or are living with breast cancer and would like to share your experiences, please complete our online survey by following this link -> <https://bit.ly/3f5RhgI> The survey closes on 28 February 2022.

#research #cancerinfo #breastcancer #breastfriends #breastcancercarewa

You, Chandrika Gibson and 13 others
 2 Shares

Like Comment Share

Write a comment...

Cancer Council WA

Social media -
Facebook

Cancer Council Western Aust... Learn more Liked Message

When the UV level is at 3 or above it can...
180 views · a week ago

Page transparency See all
Facebook is showing information to help you better understand the purpose of a Page. See actions taken by the people who manage and post content.
Page created - January 10, 2011

Related Pages

- Cancer Council WA Relay...
Jo Jones likes this
Charity Organization Like
- Relay For Life Australia
Jo Jones likes this
Nonprofit organization Like
- Investor Insight
Consulting agency Like

Add your business to Facebook
Showcase your work, create ads and connect with customers or supporters.
Create Page

WA HEALTH AND UWA WOULD LIKE YOU TO SHARE YOUR EXPERIENCE

You, Ann Trumble, Hayley Clarke and 7 others
Like Comment Share

Write a comment...

Cancer Council WA

Social media -
Instagram

cancercouncilwa

WA HEALTH AND UWA WOULD LIKE YOU TO SHARE YOUR EXPERIENCE

12 likes

cancercouncilwa WA Health in partnership with The University of Western Australia are keen to hear about what type of cancer information people need, where they look for it, where they find it, how they want to receive the information, and when they need it.

Sharing your views and experiences on looking for cancer information during your cancer journey will help provide cancer information in the best way possible for people diagnosed with cancer in the future. To share your experiences, please complete...

Home Search Post Add Profile

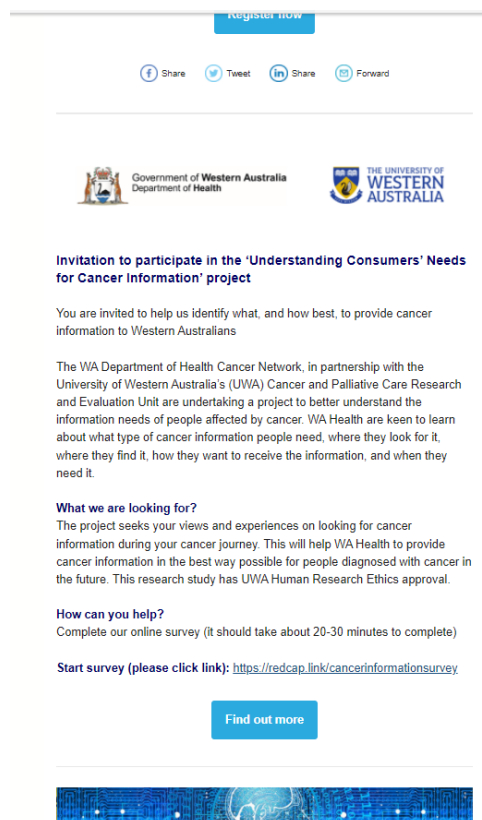
Breast Cancer Care WA

Social media - Instagram



Consumer and Community Involvement Program

E-Newsletter - Research Involvement newsletter



Prostate Cancer Foundation of Australia

Online Community

The screenshot shows a forum post titled "Share your experience (Survey)" by Chris McNamara, a Community Manager. The post is dated 4 weeks ago and has 42 likes. It features logos for the Government of Western Australia Department of Health and The University of Western Australia. The text of the post describes a survey project aimed at understanding the information needs of people affected by cancer. It includes details about the target group (people living in WA diagnosed with cancer, aged 18+), survey distribution (online only), completion time (20-30 minutes), and availability period (January 24 to February 28, 2022). A survey link is provided: <https://redcap.link/cancerinformationsurvey>. There is also a link to a participant invitation email document. On the right side of the post, there are "House Rules" which outline guidelines for respectful and helpful interactions, including a prohibition on commercial or promotional activity and a request for members to be kind to each other.

Department of Health Cancer Network

E-Newsletter – Health Happenings on HealthPoint

The screenshot shows a weekly news digest titled "Health Happenings" for Thursday, 3 February 2022. The digest is from the Government of Western Australia Department of Health. It contains several announcements:

- Announcement: The WA Department of Health Churchill Fellowship** - In 2022 WA Health is sponsoring a Churchill Fellowship for travel commencing February 2023.
- Call for applications: Research Excellence Awards 2022** - Applications are invited for the Research Excellence Awards (REA) 2022 Program.
- COVID-19 staff update webinar** - WA Health staff are invited to join a COVID-19 webinar on Tuesday 8 February which will provide staff with a general update on COVID-19 in WA from the DG, CHO and senior health executives.
- Share your experiences searching for cancer information** - WA Health is interested in hearing about what type of cancer information people need, where they look for it, where they find it, how they want to receive the information, and when they need it.
- Reminder: Aboriginal Mental Health Research Scholarship** - East Metropolitan Health Service is offering a 'top up' scholarship to support an Aboriginal Master of Research or PhD candidate who is conducting research into Aboriginal mental health.
- Nominations open for the 2022 Shaping Health Systems Program** - Nominations are now being sought from staff interested in participating in the inaugural 2022 Shaping Health Systems Program.

Department of
Health Cancer
Network

E-Newsletter
Health Networks

- [Journal of the Australian Indigenous HealthInfonet - Volume 3, Issue 1 2022](#)

Have Your Say



Consumer's Needs For Cancer Information Survey

Please help us by sharing your experiences searching for cancer information.

The WA Department of Health Cancer Network (WA Health), in partnership with the University of Western Australia's (UWA) Cancer and Palliative Care Research and Evaluation Unit are undertaking a project to better understand the information needs of people affected by cancer. WA Health is keen to hear about what type of cancer information people need, where they look for it, where they find it, how they want to receive the information, and when they need it.

Sharing your views and experiences on looking for cancer information during your cancer journey will help provide cancer information in the best way possible for people diagnosed with cancer in the future.

To share your experiences, please complete our [online survey](#).

Private Hospitals and Health Services Act and Regulations surveys

The *Private Hospitals and Health Services Act 1927* and the *Hospitals (Licensing and Conduct of Private Hospitals) Regulations 1987* and the *Private Hospitals (Licensing and Conduct of Private Psychiatric Hostels) Regulations 1997* govern 121 private hospitals and private psychiatric hostels in Western Australia at which over 6,000 patients and 700 hostel residents are cared for at any one time. There is a need for contemporary legislation to:

- meet contemporary and future regulatory practices
- meet government and community expectations
- allow for flexibility with regulations, guidelines and standards.

Health Consumers Council

E-Newsletter - Health Consumers' Council

E-news

Australia and its translation into benefits for all, by fostering leadership within our sector, providing expert advice to decision makers, and engaging patients and the public.

Consumer's Needs For Cancer Information Survey

The WA Department of Health Cancer Network (WA Health), in partnership with the University of Western Australia's (UWA) Cancer and Palliative Care Research and Evaluation Unit are undertaking a project to better understand the information needs of people affected by cancer. WA Health is keen to hear about what type of cancer information people need, where they look for it, where they find it, how they want to receive the information, and when they need it.

Sharing your views and experiences on looking for cancer information during your cancer journey will help provide cancer information in the best way possible for people diagnosed with cancer in the future.

To share your experiences, please complete the [online survey](#).

Mental Health Act – input from the City of Gosnells

The City of Gosnells is seeking expressions of interest from people from culturally and linguistically diverse (CALD) backgrounds who have received treatment in public mental health settings in the last five years, to provide their feedback on their experience and share recommendations that will assist the Mental Health Commission in reviewing the Mental Health Act 2014. The Act is a legal document that guides mental treatment and supports people who have mental illness and their families or carers in Western Australia. Feedback and

APPENDIX F – CONSUMERS’ NEEDS SURVEY – FLYER



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



Please help us by sharing your experiences of searching for cancer information!

The WA Department of Health Cancer Network (WA Health), in partnership with the University of Western Australia’s (UWA) Cancer and Palliative Care Research and Evaluation Unit, are undertaking a project to better understand the information needs of people affected by cancer. WA Health is keen to hear about what type of cancer information people need, where they look for it, where they find it, how they want to receive the information, and when they need it.

Sharing your views and experiences about looking for cancer information during your cancer journey will help provide cancer information in the best way possible for people diagnosed with cancer in the future.

To share your experiences, please complete our online survey by following this link:

<https://redcap.link/cancerinformationsurvey>

APPENDIX G – CONSUMERS’ NEEDS SURVEY – SURVEY RESULTS

Please see Phase C – Consumers’ Needs Survey data