

# Cancer healthcare in WA

**Consumer insights – June 2019**



HEALTH CONSUMERS'  
COUNCIL  
YOUR VOICE ON HEALTH

# Working in partnership

- Department of Health commissioned Health Consumers' Council to carry out a survey of consumers and carers with experience of cancer service in WA
- This work was done in partnership with Cancer Council WA and the Consumer and Community Health Research Network.



# Acknowledgement of Traditional Owners



We acknowledge the Whadjuk Noongar people who are the Traditional Owners of this Land and pay respect to all Elders past, present and future. We extend our respect to all other Aboriginal and Torres Strait Islander Cultures.

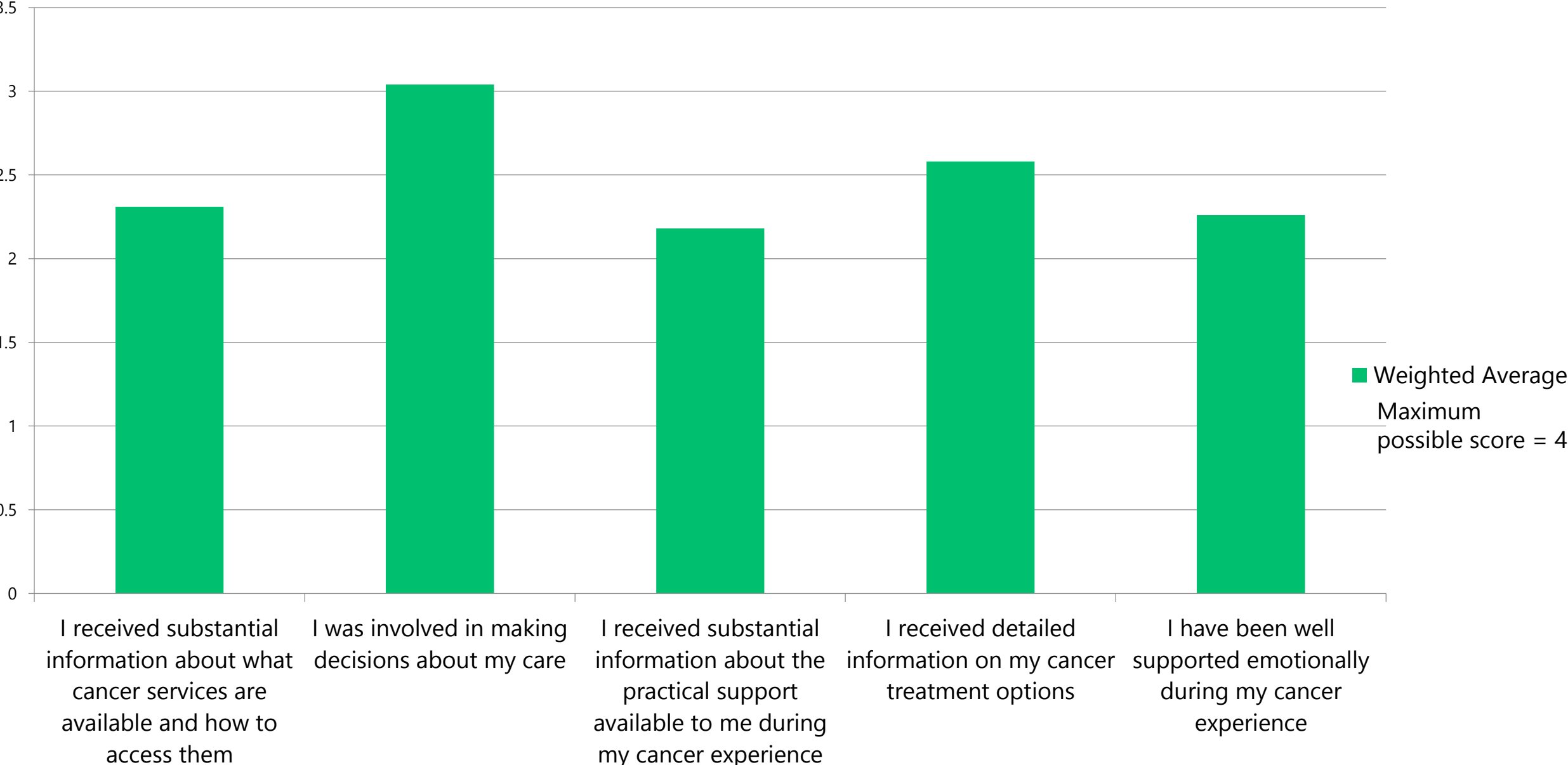
# Key takeaways

- There are **many strengths to build on** - areas identified for improvement by some are already being experienced by others
- Receiving a cancer diagnosis can be a turbulent time – people need to navigate **a high volume of information** as well as the **mental/emotional impact**, the **financial impact** and the **physical health** issues
- People value having **one person to turn to** – for information, support and continuity/coordination – who can help them navigate the wide range of options and make the best decision for themselves. There's a desire for **someone to talk to**, not just access to information to read.
- Many people experience **uncoordinated and fragmented care**.
- People want to be **treated as 'whole'** and not just a body part or a diagnosis.
- People want to be supported and **involved in decisions** about their care, not 'dictated' to.
- People would value more **mental and emotional support**
- There's a desire for a **broader range of support and for longer** – up to 5 years after treatment
- The **financial impact of cancer is significant** including the cost of care, as well as the loss of income.

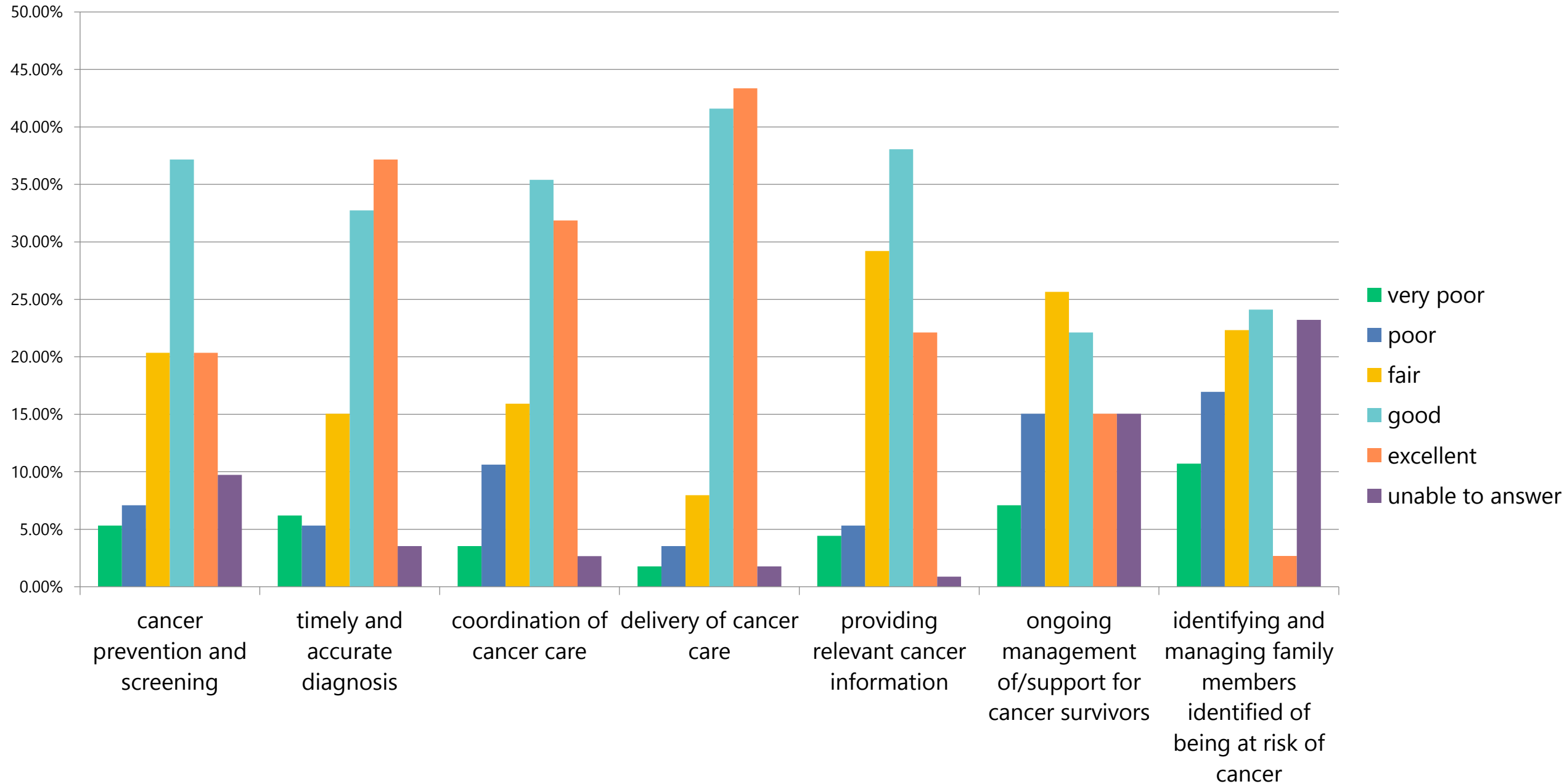
# Demographics

- Survey open from [Natasha to add dates] until 26 June
- Survey distributed via
  - HCC membership and networks
  - HCC social media
  - Targetted Facebook groups
  - Cancer Council WA
  - Consumer and Community Health Research Network
- 183 responses
  - Over 81% had personal experience of cancer
  - 13% had cared for someone with cancer
  - 44% had been involved in cancer research in some way

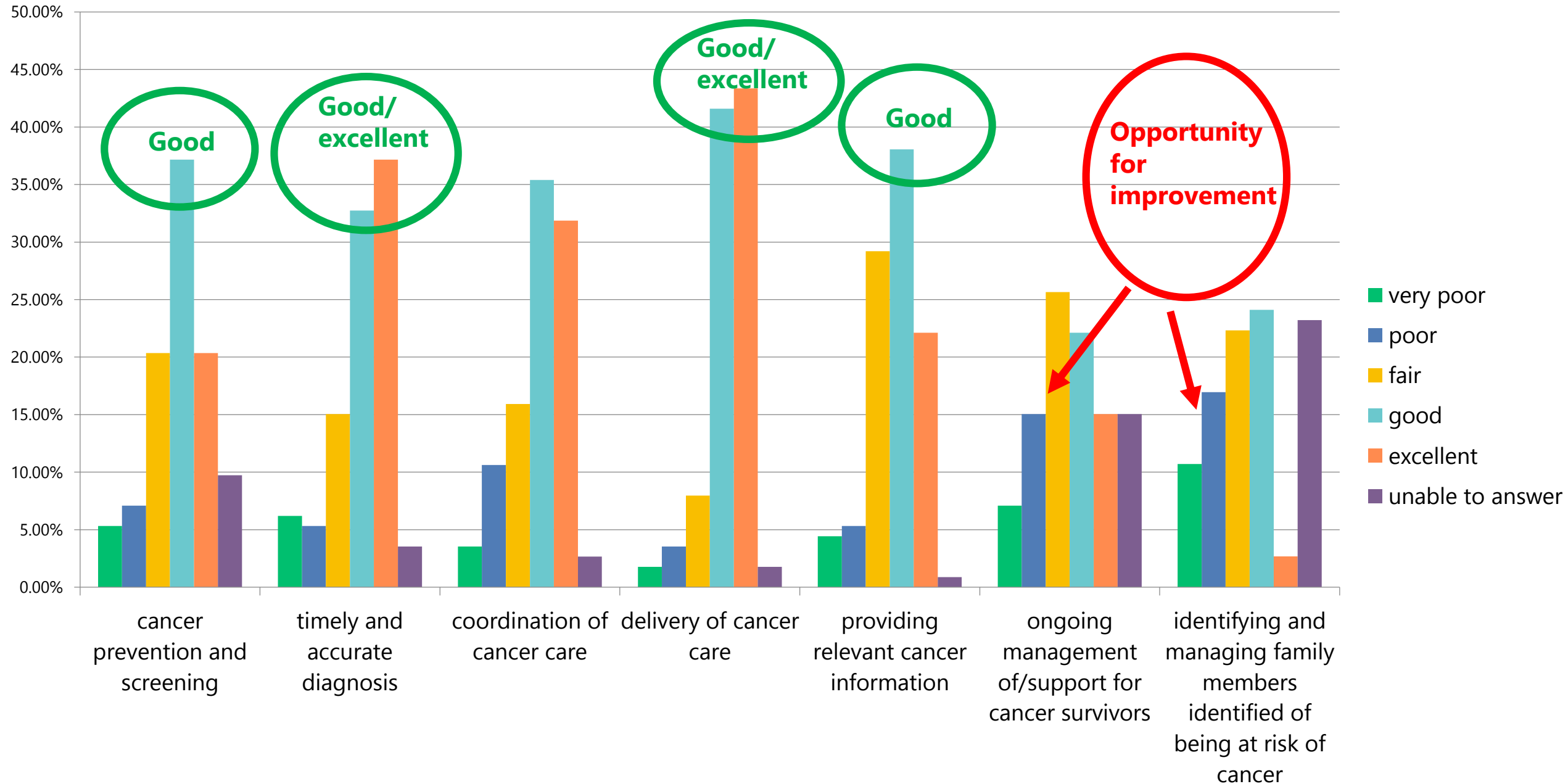
Please indicate the level of frequency with which you were supported whilst accessing cancer healthcare services in Western Australia.



Based on your personal experience and knowledge, please rate the quality of the following elements of cancer healthcare services in Western Australia.



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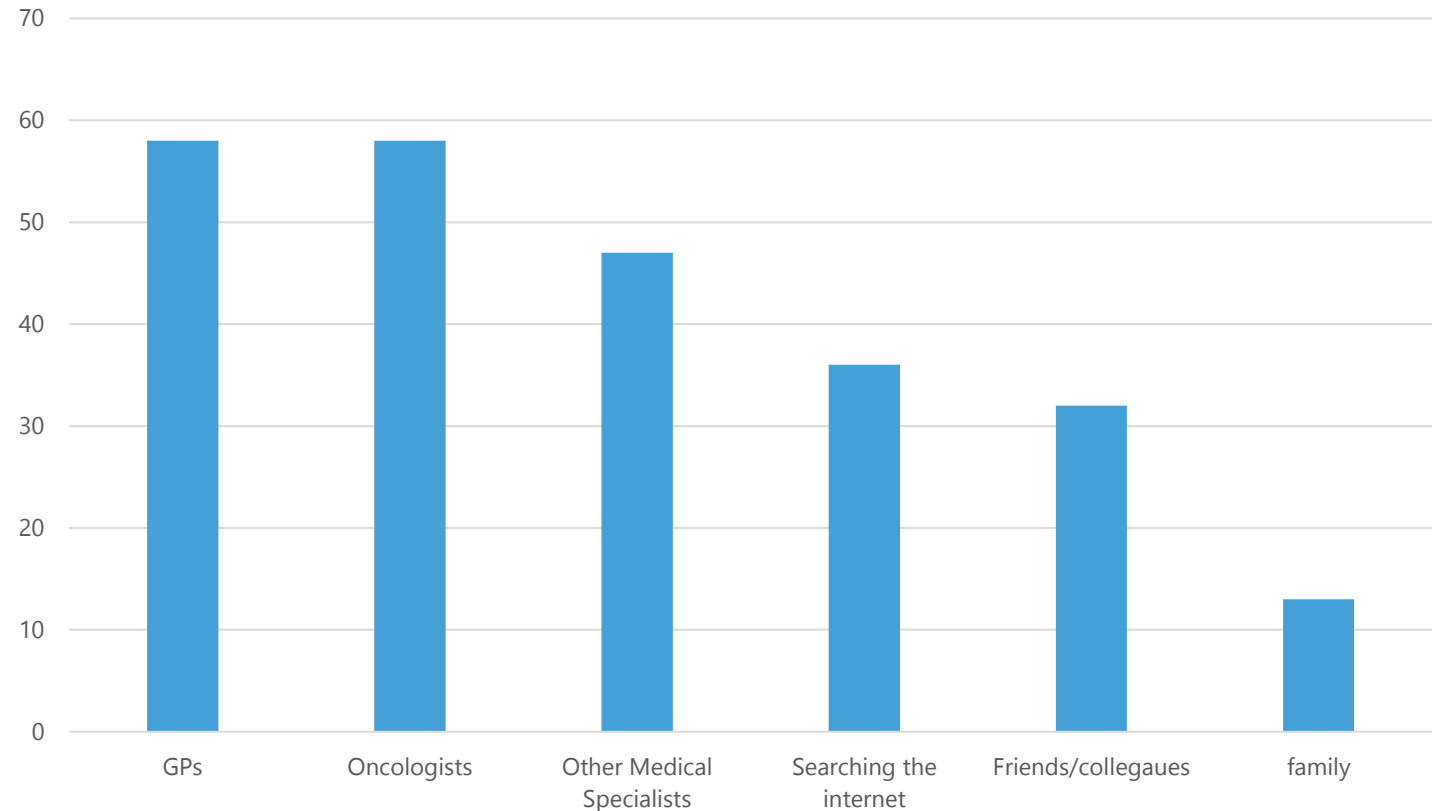


# Who helped you find out about the cancer healthcare services that were available?

A majority of cancer consumers found out about the services available through GPs & Oncologists.

The most common response in "Other medical specialists" Breast Cancer Nurses, followed by through Support Groups.

Who helped you find out about the cancer healthcare services that were available?





# Working well

- Speed of treatment
- Skilled well-informed staff in particular
  - Oncologists
  - The care and support from breast cancer nurses was mentioned by many people
- Having someone to coordinate your care, with your involvement
- Caring, kind, compassionate staff treating people with respect – being heard
- Availability of support services and groups, in particular
  - Breast Cancer Care WA
  - Cancer Council WA

# What needs to improve? (1)

- Communication and information
  - Between members of the clinical team
  - Between the consumer and the clinical team
  - Improve knowledge and information from GPs about the whole range of options available
- Currently many people experience fragmented and uncoordinated care
  - A desire for one person who has the “big picture” of someone’s care – not the GP as they’re not specialist in cancer
  - Several people commenting about “too many doctors” and not clear what they all do and if they talk to each other
- Staff
  - People experienced a lack of continuity of care
  - Attitudes of some

*“The [staff] deal with [cancer] all the time but need to remember for the patient it is our first and hopefully only time!”*

*“Multidisciplinary meetings without the consumer present. I found that amazingly short-sighted. This was my cancer.”*

*“I had to do a lot of chasing up constantly.”*

*“With numerous specialists involved – who knew the whole picture and looked at the whole person so as to avoid the (obvious in hindsight) pitfalls. It... fell back on his GP who whilst terrific is not a cancer specialist. The onus on follow-up is also very much on him.”*

# What needs to improve? (2)

- Need for more follow up care and support
  - Broader range of support including mental/emotional
  - More care and diagnosis support for younger people (both younger adults and children)
- Costs – lots of comments about high costs
  - Of diagnostics
  - To manage side effects
  - Of medications
  - Of parking when attending many appointments and also when appointments over-run
- Reducing waiting times
  - From diagnosis to treatment
  - In the clinics
- Access to services and support in regional areas

*“Everything. [I’m a] single person, no support, regionally based, financially drained from leave without pay and mortgage and rent... Everything which will impact and cause stress, needs to be addressed.”*

*“The cost of care. I had all initial surgery and follow up chemo at private hospitals. Despite having top table... insurance the gap for imaging, cost of drugs, cost of being a country patient, hospital gap fees and doctors Medicare gap fees added up to over \$45,000...”*

# What would ideal cancer care look like?

- Coordinated and standardised
- Information about care pathways available **to the patient** in one centralised place
  - including information about complementary therapies
- Delivered in a “one stop shop” with multiple services and care providers under one roof to minimise the stress and hassle
- Extended support including mental and emotional support, practical support, financial support, support for families, children and partners
  - ...for up to 5 years after treatment
- More low cost or free services
- That patients are treated with care, compassion, respect and kindness – and treated as whole people, not a body part or diagnosis
- Timely - access to care with no waiting times

*“Good communication between patients and teams. To feel well informed and less like you are just sitting on a rollercoaster with lots of other people.”*

*“Offer more free services, mentors when diagnosed, to know that someone “cares” not to be left to own devices to seek help. Planning with someone...”*

*“... a central updated portal where all information regarding WA wide cancer supports can be accessed. It’s very hard to know where to go for support and seems to be luck if you happen to find something that works for you.”*

*“What I had – involvement in treatment decisions, care delivery at home, rapid access to diagnosis and treatment.”*

# Suggestions for new approaches

- Free Oncotype tests
- Detailed website for cancer specialists, surgeons, oncologists, support services
- Inclusion of complementary therapies
- “Cancer hotline for mental health and information that patients can call when feeling down or overwhelmed”
- “Support right from the start... an assigned cancer coordinator/nurse who can help navigate/explain and “tailor make” treatments... including coordinating psychological help and physio...”
- Support for cancer sufferers in the workplace

# What services must continue?

## Services mentioned several times

- Most common response: “all”
- Prevention, including screening
- Others mentioned multiple times include (in no particular order):
  - Psychological/mental health services
  - Chemotherapy
  - Radiation
  - Surgery
  - Specialist nurses including breast nurses

## • Others (continued)

- Cancer Council WA
- Breast Cancer Care WA
- Solaris
- Support groups
- Chemotherapy at home
- Support for families
- Complementary and well-being services
- Regional services



# Key takeaways



## KEY NEEDS

Many have expressed the need for more support in the early stages after a diagnosis in order to:

- Navigate the vast array of information handed to them
- Find out about support services and help in selecting what ones are right for them at the time.
- Find peer support groups to discuss with others who have had similar diagnosis.

opportunity


This could help individuals feel empowered and more in control of their situation.



## MENTORSHIP

Respondents have suggested the need for a a “mentor” a “co ordinator” to be allocated when first diagnosed to assist them on their cancer journey.

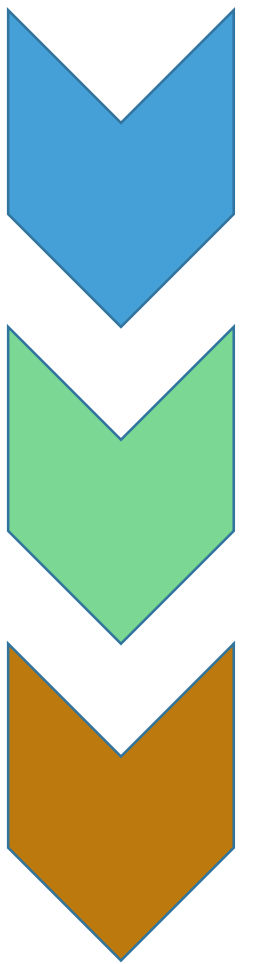
Someone who is available whenever the person needs support and to whom the patient can ask all the questions they have about their care



Where multi-disciplinary team members work with and advise the individual throughout the process of treatment.

## ONE STOP SHOP

“**One stop shop**” – this phrase was used by a lot of people. There is interest in having multiple services and care providers under one roof, in a timely manner to minimise the stress and hassle of having to navigate between different buildings (and car parks)



# PSYCHO SOCIAL SUPPORT

Individuals have expressed the need for more personalized care highlighting 'compassion' and 'respect'.

Mental health support for patients and their families.

Counselling services.

**Compassionate** care to alleviate fear of patients and their families.



# In summary – cancer healthcare feedback

- There are **many strengths to build on** - areas identified for improvement by some are already being experienced by others
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# WA Cancer Healthcare & Research Sample

The study had 106 respondents in total

- 56% had not been involved with cancer research
- 18% had been involved in clinical trials
- 26% in collection samples
- 17% as a research participant
- 3% (n=3) as a researcher themselves
- 3.4% (n=4) in an exercise cancer trial

70 respondents registered their interest in being kept informed about this work

*“[I] have been involved in assessing research grant applications and encouraging researchers to involve consumers in their research”*


# Opportunity to engage more with the community on cancer research

Most people agree or strongly agree that cancer research is important for improving health care (over 91%)

Most people agree or strongly agree that Western Australia is supporting relevant cancer research (68%)

Many people felt unable to answer a number of the questions which could suggest there are more opportunities to communicate regularly about issues relating to cancer research. For example:

- 30% unable to answer whether Western Australia has sufficient cancer research expertise
- 39% unable to answer whether there is sufficient access to clinical trials in Western Australia
- 42% unable to answer whether researchers appropriately involve people with cancer when developing research activities
- 35% unable to answer whether researchers clearly communicate the results and outcomes of research activities to people with experience of cancer



## Cancer research priorities – everything is important

- new possible cancer treatments and cures (93%)
  - while all were high priority, most respondents identified this as a high priority
- improve accuracy and speed of cancer diagnosis (85%)
- research how best to deliver cancer healthcare services that are suitable for cancer patients and their carers (82%)
- cancer prevention and screening programs (82%)
- Provide and communicate access to clinical trials (78%)



# Other priorities for cancer research?

- Wide range of answers
- Some mentioned more than once:
  - Children and young people
  - Cancer recovery and following up with people after care
  - Consumers are interested in being involved in research
  - It's important to learn and apply research findings from overseas – WA shouldn't "go it alone"

*"People die from cancer every day, how can I say which is more important. My cancer is rare so any research breakthrough will only help a small number of people. To say focus on the majority thereby saving more lives discounts me as a minority."*

# Thank you

- To the people with experience of living with cancer and their families who put their trust in us and took the time to share their feedback so that cancer services and research can be better in future for others in WA



Photo by [McKenna Phillips](#) on [Unsplash](#)