

Cancer Patient Experience Survey (CaPES) in WA

Angela Ives¹, Lesley Millar¹, Kathleen O'Connor², Karen Taylor² Christobel Saunders^{1,3}
¹ The University of Western Australia, ² Cancer Network WA, ³ University of Melbourne
Contact: ciccancer-smed@uwa.edu.au; www.ciccancer.com

Background:

- Understanding the patient experience across the pathway of care helps health services and health care professionals improve ways in which care is resourced and delivered.
- Efficiency in health services should be captured through appropriate allocation of resources to things that matter to patients.

Aim:

This project aimed to identify areas in cancer care that are important to patients, through determining health service gaps and variations in patient experience across their cancer journey.

Methodology:

The All.Can International patient experience survey, co-designed by researchers, health professionals and consumers (www.all-can.org), was adapted for use in this project.

Data collected reflected various patient experiences, from cancer diagnosis, care and treatment to the continuing support and financial impacts of cancer on patient quality of life.

Potential participants were people aged 18 years or over identified from the WA Cancer Registry, diagnosed with a primary cancer between 1 January and 31 December 2019. Participants were given the option to complete the survey on paper or online.



Results:

Demographics	Where respondents thought care could be improved		
<ul style="list-style-type: none">10,348 surveys were mailed and 3238 (31.3%) completed (or returned as completed) were received.Only 26 (0.8%) identified as Aboriginal or Torres Strait Islander. <p>Respondents were representative of WA people diagnosed with cancer in 2019:</p> <ul style="list-style-type: none">Age - median 66.4 years - SD 11.8 (range 18 to 95 years)Sex - men (n-1736, 53.6%) vs women (n-1450, 44.8%)Most common cancer - prostate (23.3%), breast (19.1%), melanoma (11.5%) and colorectal/bowel cancer (9.9%).Residence - metropolitan area (n-2496, 77.1%), rural (n-597, 18.4%) and remote patients (n-67, 2.1%)Treatment setting: private (n-1295, 40.0%), public (n-1123, 34.7%) and both public and private 742 (22.9%).	<p>Communication by health care professionals e.g. lack of empathy, explanations of care, inability to manage expectations, poor continuity of care.</p> <p><i>'I was told I had cancer over the phone...[they] didn't ask if anyone was home before telling me about my diagnosis...'</i> (Endocrine – #1)</p> <p><i>'You need to ask specific questions to get information otherwise you're told nothing at all. It's like a secret.'</i> (Digestive - #1374)</p>	<p>Better organisation of appointments, less delays in being seen, better follow-up care, and getting the right information and communication.</p> <p><i>'The Oncologist is always so busy, 40-minute drive, 30-minute + wait (or more), 5-minute talk, then 40-minute back home...more phone conversations would be better.'</i> (Rare cancer - #3061)</p> <p><i>'...If I had more than one treatment would be good to have them the same day e.g. Dentist/check-ups' (Head and neck - #851)</i></p> <p><i>'When having to fly to Perth on PATS arranging other appointments while in Perth at same time' (Multiple - #1370)</i></p>	<p>Coordination between different elements of the healthcare system e.g. general practice, social services and hospital.</p> <p><i>'This is a really bad system, with your GP NOT INVOLVED! No information gets to your doctor or you. No one knows what is going on, and you can't get the information as you don't know who is involved...'</i> (Digestive - #1727)</p> <p><i>'I just graduated uni and had little funds. After treatment I was too unwell to work for 6 months after. I attempted to seek Centrelink...they did not want to help at all. All they did was put me on job keeper and said it was my problem to deal with...'</i> (Colorectal/Bowel - #2055)</p>
<p>Most people could not find fault with the system and how resources were used</p>	<p>A 'go to' person to talk through issues or the opportunity to talk to other people who had been through similar experiences and thus identify issues early.</p> <p><i>'Better communication & knowledge of what different parts of health service can offer: [private hospital/tertiary hospital]/Silver Chain etc'</i> (Colorectal/Bowel – #108)</p> <p><i>'A road map of the process from diagnosis to rehab would have been most helpful. The first 4 months were very confusing and stressful.'</i> (Prostate - #2527)</p>	<p>Rural/remote respondents who lived away from home during treatment needed additional resources to keep a home/house presentable or care for animals.</p> <p><i>'Finding people to do gardening lawns and general household duties' (Colorectal/Bowel - #975)</i></p> <p><i>'Putting beloved dogs in the Kennel, \$25/day each' (Brain/CNS - #3119)</i></p>	

Key 'Takeaway' Messages

- Most people could not find fault with the system and how resources were used
- Communication and continuity of care were reported by respondents as areas 'where resources could be better used'
- Knowing how to navigate the health system and being an advocate for yourself was also an issue

Conclusion:

Overall, respondents to the survey believed the cancer treatment and support services provided to them in the WA public and private setting are very good and better than reported from other countries in the All.Can International survey. Many of the issues that were identified could be rectified by:

- better communication between all levels of healthcare, the patient, and their family;
- improved continuity of care; access to information that better meets the patient needs and ensuring that they understand the information they receive; and
- improved management of patient's expectations of their care.

The introduction of a central navigator/contact system for information and support, and the instigation of further one-stop diagnostic services and follow up clinics, would improve patient care, service provision and efficiencies whilst providing a more positive experience for both patients and providers.