

Priorities for Cancer Survivorship Research

Set by people with living- or lived-experience of cancer and carers

In October 2025, people with lived- or living-experience of cancer or carers led, and took part in, a workshop to set priorities for cancer survivorship research. Together, we aimed to:

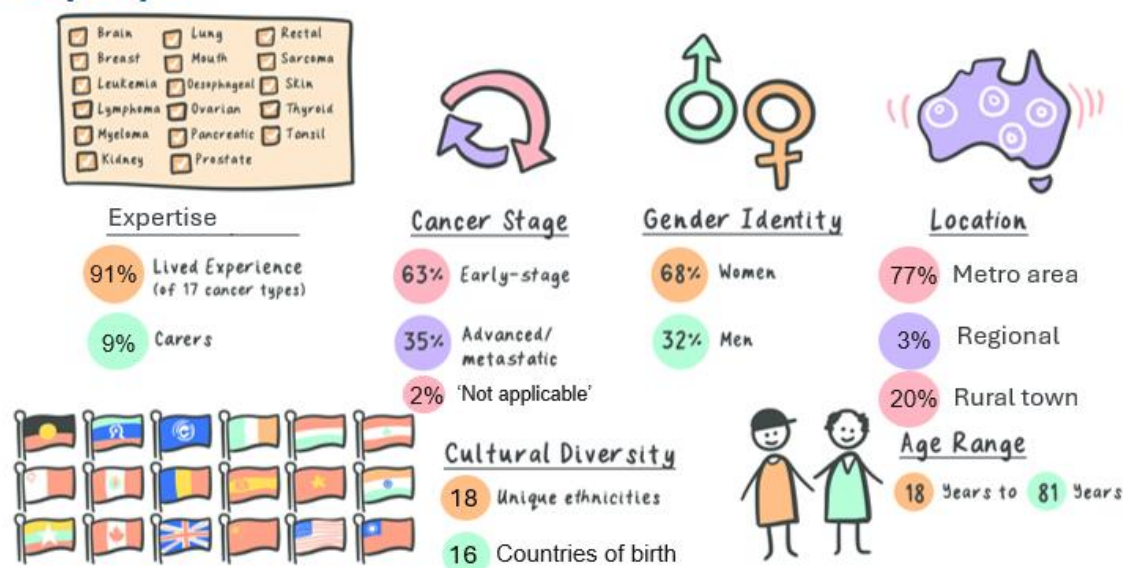
- 1) **Find a new way to set research priorities** that was designed WITH people with living or lived-experience of cancer and carers and;
- 2) **Create a list of highly-rated cancer survivorship priorities** that were set BY people living with and beyond cancer and carers
- 3) **Understand if this new way was acceptable, useful or could be improved**

This document explains what we did, what you told us and why it's meaningful.

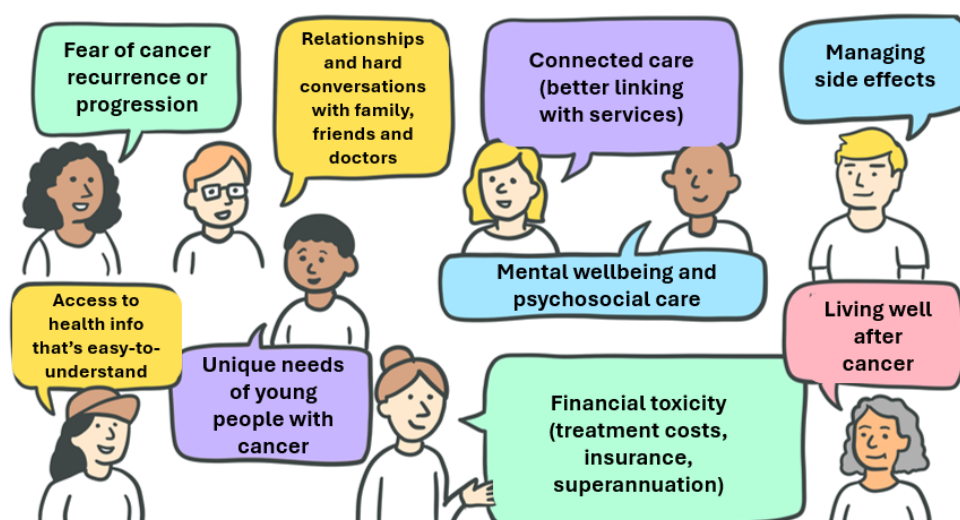
Step 1: Pre-workshop survey

The group filled in a survey about themselves. The group represented **56 diverse people**, including men and women who had or have cancer, or carers across NSW.

56 people



The group told us 3 things they wanted to talk about during the workshop. They wrote a total of 2914 words (average=49 words per person, minimum 3 words to maximum 225 words). We grouped their words into **9 topics**:

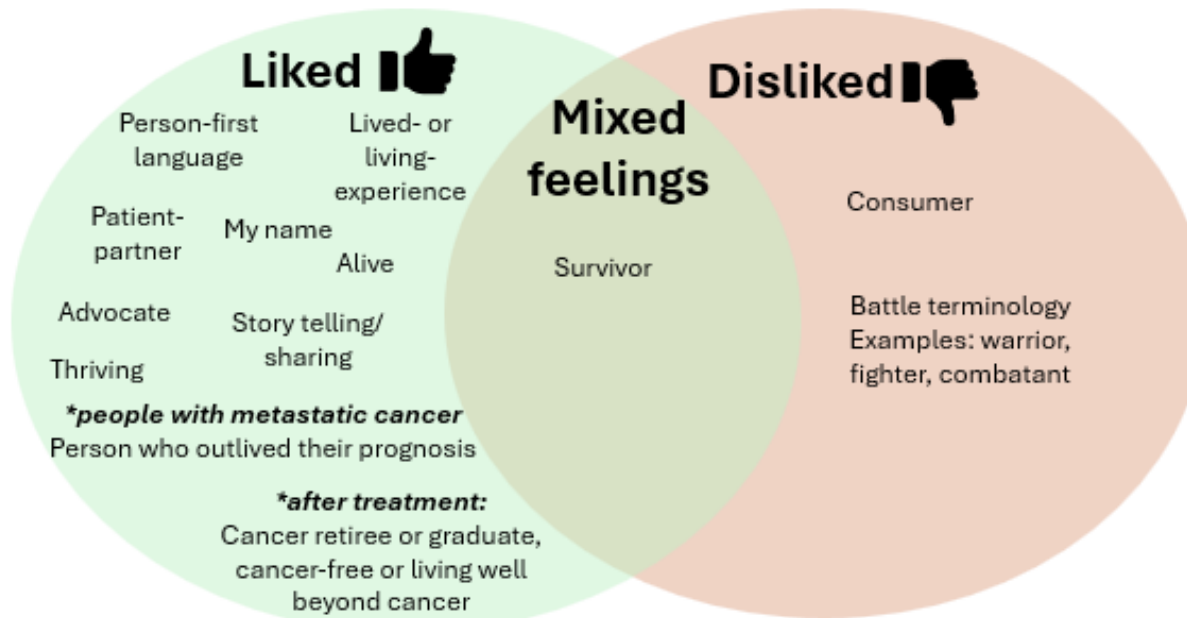


Step 2: The Workshop

On October 30th 2025, the group attended an in-person workshop with 4 activities:

Activity #1: What is in a word? Reimagining the term ‘Cancer Survivor’

The group shared why they liked or disliked certain words to represent them as a person who has had or has cancer or carer. They told us 85 words, that we grouped together:



The group **liked** words that focus on the person, personal expertise, story-telling and quality of life instead of cancer because ‘I am more than my cancer experience’. For people finished treatment, surgery, chemotherapy or radiation therapy, they liked words that focused on leaving cancer in the past (e.g. *cancer graduate* or *successor*, *living well* or *breathing beyond cancer*). For people with metastatic cancer *person who outlived their prognosis* was seen as inclusive and hopeful.

The group **disliked** words that suggested being a customer of the hospital (e.g. ‘consumer’) or soldier in a war.

The group had **mixed-feelings** about the term *survivor*, especially when definition included diagnosis to end-of-life. The positives included it’s easy to use (one word), widely known and has traction in the media. Some people liked it because “I survived!!” and felt like they were part of a community. The negatives are that it can imply that the cancer experience is complete or behind them, which is not the case for people on treatment, living with metastatic or advanced cancer, on active surveillance (e.g. prostate cancer) or living with ongoing health issues or side effects after treatment. For people who had completed active treatment, it did not feel like they did anything ‘heroic’, only what was necessary.

Importantly, the group told us that their feelings about which words they like or dislike can change over time and experiences. For example, a person who completed treatment for early-stage cancer disliked *survivor* and wanted to ‘leave cancer behind’ but was later diagnosed with metastatic cancer and embraced the term *survivor*.

Activity #2: Voting on the top priorities for Cancer Survivorship Research

Each person had 100 points to allocate to research topics they wanted to talk about more. There were lots of topics to choose from. Here's the graph the group saw during the workshop, that shows the average percentage of points given to each topic:



In a whole-room discussion, the group told us 'care navigation' and 'knowing where to go and what to do' were similar topics, so we combined them.

Next, each person had 100 points to allocate to the topic you felt was **most important** to talk about in Activity #3. The average percentage of points given to each topic were:



Activity #3: Defining the top 7 priorities and voting for consensus

We did a 'World Café', where everyone chose 1 priority to discuss at their table, and then switched tables 2 times. Each table talked about the types of research that could address the priority, who would benefit and what success would look like.

One person at the table took notes ('scribe') on butcher paper. We then talked about each priority with the whole room, in case anyone wanted to add ideas.

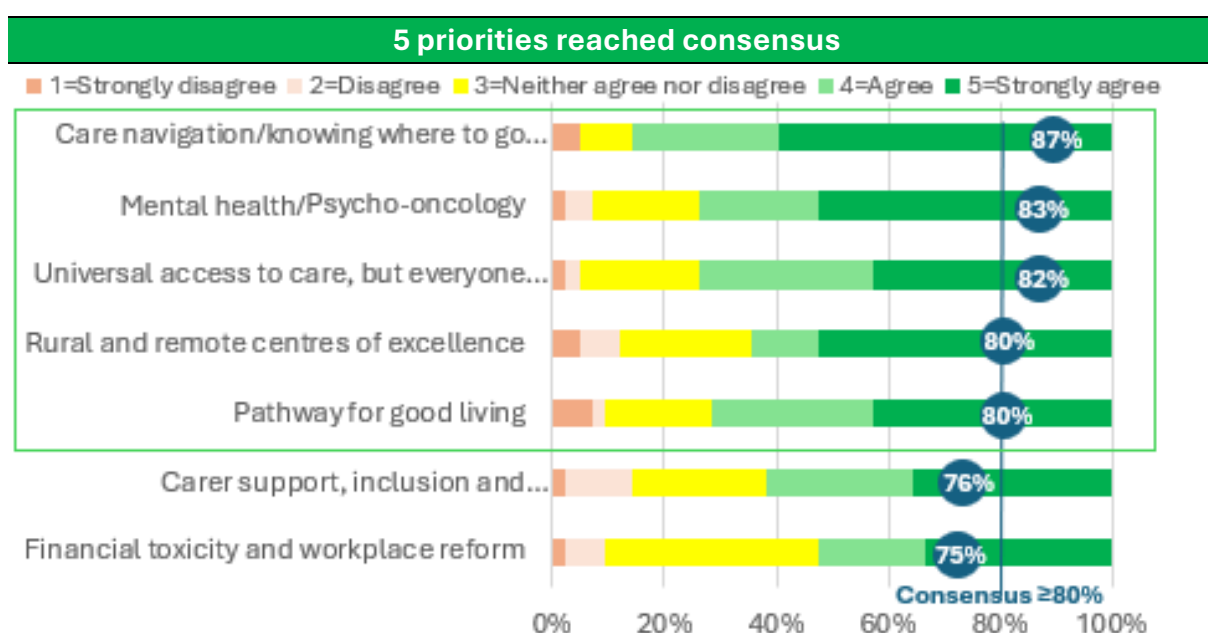
After the workshop, the research team combined similar topics.

'Universal access to care, but everyone's unique' became a 'cross-cutting theme', because these topics apply to all priorities:

Mental health/ Psycho-oncology	Care navigation and coordination	Improved access in rural/remote areas	Pathway for good living	Support for carers, families & loved-ones	Financial toxicity/workplace reform
• Support options (peer-, allied health, specialist) • Culturally-safe • Anxiety/Fear of recurrence/progression	• Better integration between hospitals, GPs, community services • Employed navigators • Survivorship care plans	• Travel support • Outreach services • Regional centres of excellence • Culturally-safe services • Strategies that overcome resource constraints (e.g. limited internet)	• Recognise survivorship as a lifelong experience • Support people to live well physically, emotionally, socially and practically	• Burnout • Inclusive models of care and care plans • Peer-support	• Costs beyond treatment (meds, travel, allied health) • Loss of income • Return-to-work and workplace rights • Insurance • Family impacts
Universal access to care, but everyone is unique Person-centred and tailored care that empowers agency with health decisions and considers people of all ages, cancer types and stages Harness digital health and artificial intelligence, when possible, with online resources/care plans, tele-health					

Next, each person voted on how much they agreed with each of the top 7 priorities on a 5-point scale, from 1 (strongly disagree) to 5 (strongly agree). The image below shows the average score for each priority, ranked from highest to lowest.

When the group's average score for a priority was between 4 and 5 (i.e. 80% 'agreement' or higher), the priority was accepted as consensus.



Activity #4: Deciding the next steps for involving people with living- or lived-experience of cancer and carers in research prioritisation

The group's ideas:

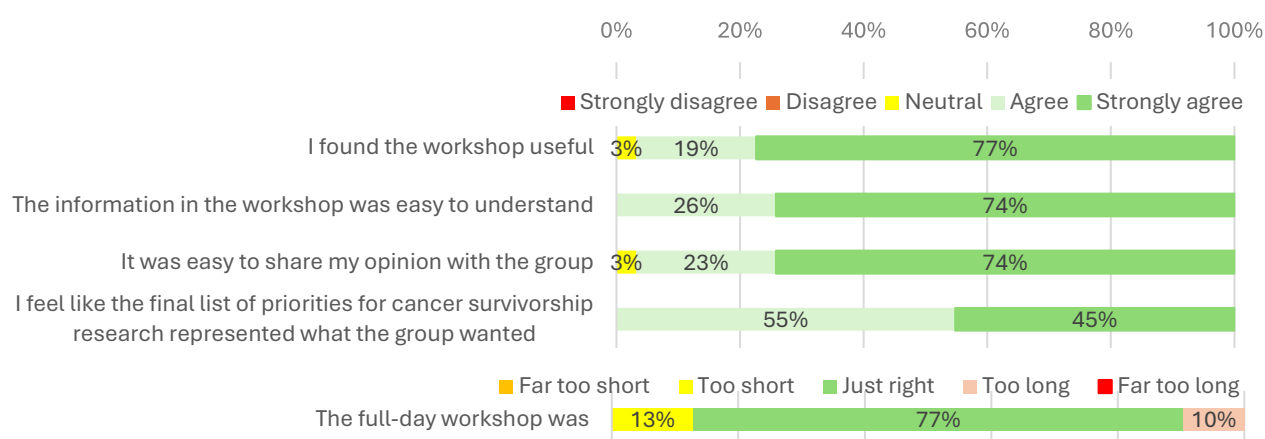
- Send regular updates about this study and new studies via e-newsletter
- Offer training to be a peer-facilitator at future workshops
- Create working groups, so people can work on research they are passionate about

Our team members from Cancer Voices NSW provide a free Consumers in Research training program and a Consumer-Researcher matching program. Here's the website, if you're interested: <https://www.cancervoices.org.au/consumer-training/>

Step 3: Feedback about the workshop

The group could fill in a feedback survey either at the end of the workshop or via email within the 2 weeks after the workshop. Thirty-one people filled in the feedback survey.

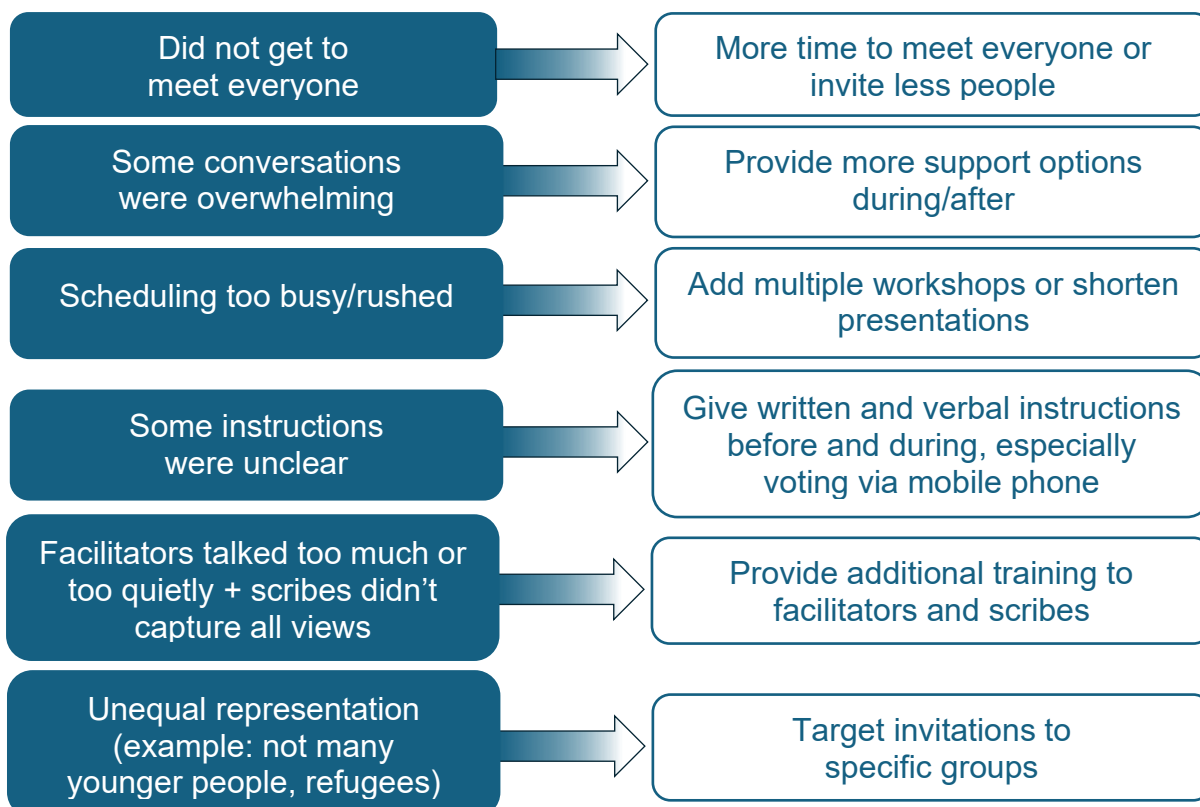
Most people 'agreed' or 'strongly agreed' that the workshop was useful (96%), easy-to-understand (100%), easy to share their opinion (97%) and the final list of priorities for cancer survivorship research represented what the group wanted (100%). Most participants felt the length of the workshop (full-day, 9-4pm) was 'just right' (77%), but some felt it was too short (13%) or too long (10%).



What the group liked about the workshop:

- ✓ **Hearing and sharing experiences with others**, especially the breadth of experiences with cancer types, stages and cultural background
- ✓ **The workshop structure**, including the:
 - Intention to uplift voices of people living with/beyond cancer and carers
 - Balance of presentations and conversations
 - Flow between activities
 - Friendly facilitators
 - Many opportunities to feel heard (conversations at tables and full room)
 - Graphic artist and real-time summaries of your conversations
- ✓ **Contributing meaningfully to research about you and future patients**

What the group disliked about the workshop and suggestions to improve:



Summary of what we achieved

This workshop showed that **our new way to set priorities, that was led by people with living- or lived-experience of cancer and carers, created priorities for cancer survivorship research that were meaningful and agreed on.**

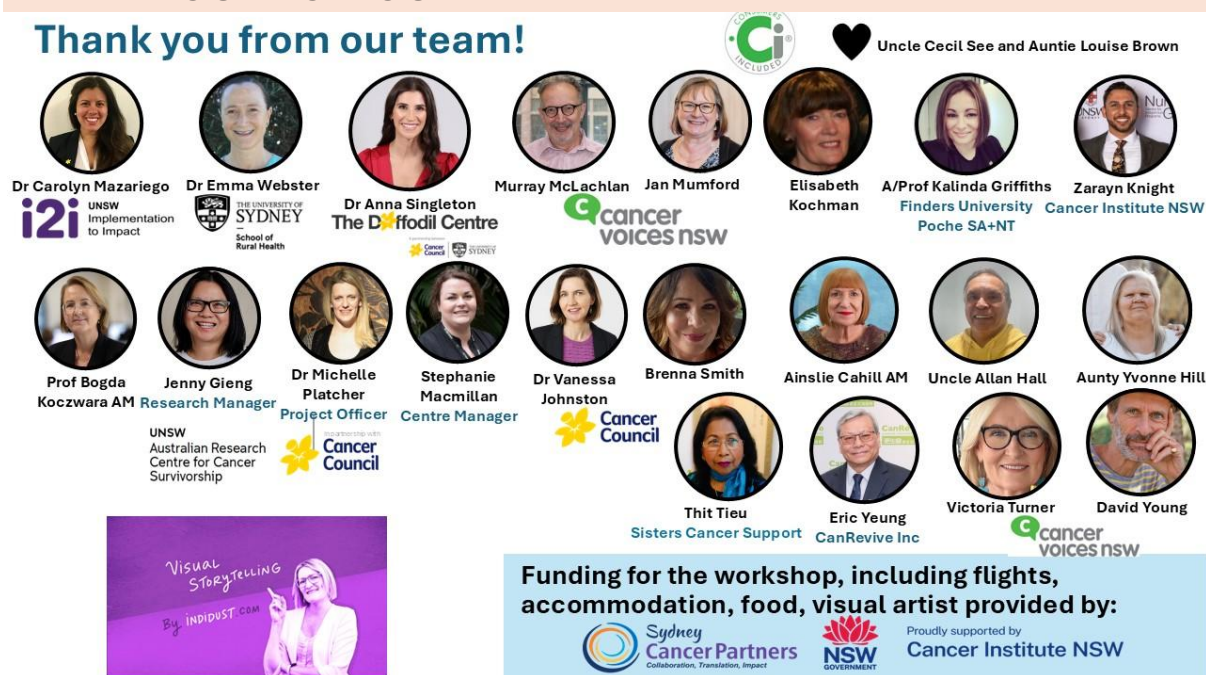
The group told us **this way of setting priorities was acceptable**, but can still be improved. The group's feedback will be used to make this process better and easier. We can now advocate for these priorities and this way of setting priorities to policy makers and other researchers.

ACKNOWLEDGEMENTS

Our team would like to express our deepest gratitude and respect for Uncle Cecil See (Wiradjuri) and Aunty Louise Brown. The idea for this study arose in discussions with Uncle Cecil and Aunty Louise at the 2023 NSW Cancer Conference where they pointed out that cancer survivors were only included in research after all the 'big' decisions had been made. Whilst cancer has claimed the lives of both these generous and dedicated people, the proposed research is one of the important legacies they leave behind. We would also like to acknowledge the people living with and beyond cancer and carers who contributed to this research. Moreover, we would like to thank the amazing team at the Australia Research Centre for Cancer Survivorship, including Jenny Gieng, Michelle Platcher and Stephanie Macmillan for their support, coordination and organisation of the workshop. We could not have achieved this successful workshop without them.

THANK YOU FROM OUR TEAM

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ETHICS

This research was approved by the University of Sydney Human Research Ethics Committee (Approval No: 2024/HE000738) and was conducted in accordance with the relevant guidelines and regulations, including the “Declaration of Helsinki” and the National Health and Medical Research Council (NHMRC) of Australia’s National Statement on Ethical Conduct in Human Research (2007). All participants will provide informed e-consent.

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COMPETING INTERESTS

Authors have no competing interests to disclose.