CANCER SURVIVORSHIP RESEARCH PRIORITIES IN AUSTRALIA



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The number of cancer survivors, defined as people living with and beyond a diagnosis of cancer, continues to grow. Research plays an integral role in providing the evidence to support best practice cancer survivorship care.

In 2020, the Clinical Oncology Society of Australia's Survivorship Group undertook a research study to establish expert consensus on the key priorities for cancer survivorship research in Australia.

Background

Australian and international literature was reviewed to identify existing research priority items and research gaps relevant to cancer survivorship^{1,2,3,4}. Items were mapped across five distinct categories adapted from the Quality of Cancer Survivorship Care Framework⁵ and National Institutes of Health focus areas of grant funding⁶. These included four research categories: physiological outcomes; psychosocial outcomes; population groups; and health services, and one category regarding priorities around research infrastructure.

Methods

A two-round online, modified-Delphi study was conducted between November 2020 and February 2021. The panel of experts included cancer survivors, academic researchers, health professionals, advocacy organisations, and policymakers. In round one, participants ranked the importance of 77 items on a five-point scale, could make comments on wording and relevance, and suggest additional items. In round two, participants ranked the top five priorities within each category. The type of research needed for each priority, such as biological, exploratory,

intervention development, or implementation, was also selected.

Results

Response rates were 76% (63/82) and 82% (68/82) for rounds one and two, respectively. Participants were predominantly female (74%) and had been working in cancer survivorship for an average of 15 years. After round one, 12 items were added, and 16 items combined or reworded. The top five priorities from each category and corresponding types of research required are shown below.

CANCER SURVIVORSHIP RESEARCH PRIORITIES

Physiological Outcome Priorities		Psychosocial Outcome Priorities		Population Group Priorities		Health Services Priorities	
1	Cancer progression or recurrence	1	Fear of cancer recurrence	1	Rare or under-represented cancers	1	Quality of care
2	Management of comorbidities	2	Economic issues	2	Advanced or recurrent disease	2	Models of care
3	Fatigue	3	Distress, anxiety and depression	3	Rural, regional, remote populations	3	Self-management
4	Exercise and physical activity	4	Adaptation and adjustment	4 F	Paediatric and childhood cancer survivors	4	Communication
5	Cognitive function	5	Work and study issues	5 9	Survivors with lower socio-economic status	5	Patient navigation

Research Infrastructure Priorities

1. Data availability and data linkage

2. Rigorous reporting standards

3. Collaborative research

4. Funding opportunities

5. Investment in researchers

Legend – Types of research



= Biological/aetiological





= Intervention development



Implementation and dissemination

- 1. Jacobsen, P.B., et al., Identification of key gaps in cancer survivorship research: findings from the American Society of Clinical Oncology Survey.
- 2. Lagergren, P., et al., Cancer survivorship: an integral part of Europe's research agenda
- 3. Takahashi, M., Cancer survivorship: current status of research, care, and policy in Japan

- 4. Urguhart, R., et al., A Pan-Canadian Framework for Cancer Survivorship Research
- 5. Nekhlyudov, L., et al., Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research, and Policy.
- 6. Rowland, J.H., et al., Survivorship science at the NIH: lessons learned from grants funded in fiscal year 2016.