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ORIGINAL ARTICLE

Defining research and infrastructure priorities for cancer survivorship in Australia: a modified Delphi study

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Abstract

Purpose The aim of this study was to establish research and infrastructure priorities for cancer survivorship.

Methods A two-round modified online Delphi study was completed by Australian experts in cancer survivorship. Initial priorities were generated from the literature and organized into four research categories: physiological outcomes, psychosocial outcomes, population groups, and health services; and one research infrastructure category. In round 1 (R1), panelists ranked the importance of 77 items on a five-point scale (not at all important to very important). In round 2 (R2), panelists ranked their top 5 priorities within each category. Panelists also specified the type of research needed, such as biological, exploratory, intervention development, or implementation, for the items within each research category.

Results Response rates were 76% (63/82) and 82% (68/82) respectively. After R1, 12 items were added, and 16 items combined or reworded. In R2, the highest prioritized research topics and the preferred type of research in each category were: biological research in cancer progression and recurrence; implementation and dissemination research for fear of recurrence; exploratory research for rare cancer types; and implementation research for quality of care topics. Data availability was listed as the most important priority for research infrastructure.

Conclusions This study has defined priorities that can be used to support coordinated action between researchers, funding bodies, and other key stakeholders. Designing future research which addresses these priorities will expand our ability to meet survivors' diverse needs and lead to improved outcomes.

Keywords Cancer survivorship · Cancer research · Research prioritization · Delphi study

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The number of survivors living with and beyond a diagnosis of cancer continues to grow [1, 2]. Despite ongoing improvement in life-saving treatments, cancer continues to have substantial and long-term impacts [3, 4]. In 2006, the Institute of Medicine's (IOM) landmark report *From Cancer Patient to Cancer Survivor: Lost in Transition* highlighted the importance of cancer survivorship care and provided ten recommendations to ensure the best possible outcomes for cancer survivors [5]. One recommendation was that funding agencies should increase their support of survivorship-focused research and research programs focused on cancer follow-up care [5]. Following this, the American Society of Clinical Oncology (ASCO) released a statement in 2013 recommending that cancer survivorship research be increased in order to guide quality care, and emphasized identifying knowledge gaps, auditing current research activities, and promoting innovative research methods [6]. Consistent with these statements, cancer survivorship research has been a growing field for the last 15 years; however, evidence gaps remain in addressing needs for particular cancer types, population groups and survivor outcomes [7, 8].

Cancer survivorship research plays an integral role in providing the evidence to support best practice. However, funding and resources for research in cancer survivorship are limited compared to many other areas of cancer research [9, 10]. There is a pragmatic need to identify cancer survivorship research priorities which can help select where and why resources should be allocated. Cancer survivorship research includes a wide range of issues, populations, and settings; future research needs to ensure it addresses gaps in existing knowledge, that it reflects the needs of stakeholders, and it is effectively implemented into unique healthcare systems and health policy [11]. Australia has major strengths in cancer survivorship research, making significant contributions to the research literature globally; thus, priorities developed internationally may not be relevant to the advanced research field in Australia [12]. Thus, it is important that research priorities consider current research activity, build on existing strengths and continue to advance the field.

Internationally, cancer survivorship research priorities have highlighted the importance of opportunities for the translation of research into practice and policy and enabling interventions for improved survivorship care for all cancer patients across different population groups [7, 8, 13–17]. The recommendations produced internationally have often been developed with specific healthcare systems in mind, while other research priority statements have focused on specific cancer types or stages [18, 19]. To date, cancer survivorship research priorities in the Australian context have not been formally identified. Although healthcare in Australia shares similarities with other universal healthcare systems, there are marked differences with a large portion of cancer care delivered through a private health system. As current survivorship care practices vary internationally, context is important when considering research priorities [20]. Additionally, previous research prioritization approaches have not systematically assessed the type of research designs required to address identified gaps and topics. Thus, the current study aims to investigate not only the research topics that need to be prioritized for cancer survivorship in Australia, but also the research designs, from biology to implementation science, that are required, as well as the infrastructure which is needed to conduct beneficial cancer survivorship research.

Comprehensively addressing concerns for cancer survivors requires international collaboration and coordination of research, Thus, in 2020 the Clinical Oncology Society of Australia (COSA)'s Survivorship Group Executive Committee developed a research study to establish expert consensus on the key priorities for cancer survivorship research in Australia. Establishing these research priorities will contribute to the global discussion, and help to advance research, practice, and policy in the field of cancer survivorship. Additionally, funding agencies in Australia may be directed by the development of Australian-specific cancer survivorship priorities.

Methods

This study involved scoping of relevant literature to identify potential research priority items, followed by a modified Delphi consensus process. The Delphi technique uses a structured process to establish consensus on a specific topic of interest with an invited panel of experts over a series of rounds [21], and is an appropriate method of identifying research priorities [22]. A modification to the traditional Delphi method involved beginning the process with purposely selected items based on existing literature rather than generating the items through the panel, a modification consistent with recommended methodologies [21].

The study was approved by the Peter MacCallum Cancer Centre Human Research Ethics Committee (HREC/69659/PMCC).

Generation of initial priorities

Searches were conducted in Google scholar, checking reference lists of relevant publications, and targeted searching on the websites of national cancer research institutions for literature that examined specific research priorities and research gaps relevant to cancer survivorship. Thirteen publications were selected which covered a range of different jurisdictions and methodologies [13–17, 19, 23–29]. Literature was searched from inception to 9th September 2020. The priority items listed within each publication were extracted and then mapped across five distinct categories adapted from Nekhlyudov and colleagues' Quality of Cancer Survivorship Care Framework [30] and National Institutes of Health focus areas of grant funding [16] and determined iteratively by the research team as those which best represented the items identified in the literature. Once similar items were combined, a total of 77 priority items arose across four categories of research: survivors' physiological outcomes; survivors' psychosocial outcomes; population groups; health services; and one category of priorities for research infrastructure.

Delphi consensus procedure

Panel recruitment

Potential participants were identified through survivorship-focused research output published between 2015 and 2020, including (i) first, last, and presenting authors of presentations at the COSA, Flinders-COSA Cancer Survivorship, and Victorian Cancer Survivorship scientific meetings; (ii) lead chief investigator recipients of grants awarded by the National Health and Medical Research Council, Australian Research Council, or Cancer Australia; (iii) principal investigators of Australian clinical trials registered on Australian New Zealand Clinical Trials Registry (ANZCTR); and (iv) first authors of peer-reviewed publications obtained through a PubMed search of Australian literature using a predefined search strategy ((cancer* OR tumor* OR neoplas* OR malignan* OR carcinoma*) AND (surviv* OR post-treatment) AND (Australia*)). To complement the clinical and academic participant group, cancer consumer and advocacy organizations, and health policy organizations were contacted and asked to nominate members who may be willing to participate. A range of professionals were invited to participate to ensure findings were not biased towards the perspective of particular groups.

The research team identified 153 potential participants including: cancer survivorship researchers; health professionals (oncologists, primary-care providers, cancer nurses, and allied health); cancer consumers; cancer advocacy representatives; and health policymakers. Individuals were eligible to participate if they: had been involved in cancer survivorship in the past 5 years; were aged 18 years or over; lived in Australia; and had a proficient level of written English. Although there is no set number of participants required for a Delphi study, the aim was to have 60–70 participants complete each round to allow for a diversity of views. Potential panelists were invited to participate in the two-round Delphi study via email through an opt-in process. Non-responders were sent a maximum of two reminders following the initial invitation. In total, 82 individuals agreed to participate and were sent a link to each of the survey rounds. The Delphi surveys were developed online using Qualtrics software. Panelists provided informed consent after reading an online participant information sheet and selecting to enter the survey on the following webpage. For each survey, up to two reminder emails were sent. Participants did not have to complete round 1 in order to complete round 2.

Round 1 procedure

In round 1, panelists were asked demographic questions including current role/profession, age, gender, and years in cancer survivorship. Secondly, panelists were asked to rate the importance of the 77 preliminary priority items. Each of the items were rated on a five-point Likert scale from (1) not at all important to (5) very important. Two optional open-ended questions were provided at the end of each category for comments on the wording or relevance of the items, as well as to contribute priorities deemed important that were not listed.

Round 2 procedure

Based on participant responses in round 1, a revised list of priorities was generated for consideration in round 2. Panelists were asked the demographic questions from round 1, and then asked to rank five of the most important priorities within each category, using a number rank system within Qualtrics. Panelists were asked to indicate the type of research needed for the five items they had ranked as the most important within the categories of physiological outcomes, psychosocial outcomes, population groups, and health services. For each item ranked in the top 5, panelists could select whether etiological/biological or exploratory research, intervention development, or implementation research was needed for that priority. Panelists could select multiple types of research for each priority item.

Round 1 data analysis

Quantitative data from round 1 were analyzed and summarized using descriptive statistics (frequency/percentages). Although there are no universally agreed consensus criteria in Delphi studies [21]; the following thresholds were applied: inclusion of items was set at 70% or more participants providing a positive result (Likert score 4–5) and exclusion less than 50% participants providing a positive result. Criteria that met more than 50% but less than 70% agreement was reviewed by the research team to decide if it would progress to the next round. Based on open-ended feedback from participants, research priority items were added, modified or combined to reduce redundancy and to improve clarity. Modifications to each item were discussed and finalized among the research team.

Round 2 data analysis

Quantitative data from round 2 were analyzed and summarized using descriptive statistics. Firstly, data was reverse scored so that an item which was ranked as the most important (1) was given a score of five, thus a 1st priority score yielded 5 points for that item, a 2nd priority score yielded 4 points, and so on. Each individual item score was then summed based on all responses and a summary score and respective ranking was developed. Mean scores were calculated for each item ranked by two or more panelists (with five being the highest score). Finally, the percentage of participants including each item within their top 5 was calculated, along with the percentage of participants who rated the item as the most important (scored as 5). Summary scores and rankings were initially compared between the researcher and health professional participants (researcher group) and all other participants including cancer survivors, advocacy, and policymakers (non-researcher group) to identify any noticeable differences between groups.

Results

Round 1 was completed by 63 experts (76.8% response rate) and round 2 by 68 experts (82.9% response rate). Panelist characteristics are summarized in Table 1.

Round 1—item modification

After rating the importance of items in round 1, one item (*complementary and alternative therapies*) was removed as less than 50% of participants rated this item important or very important. Panelists suggested 12 additional items, and 16 items were combined or reworded to clarify the meaning (Supplementary Table 1). Items were designed to be of similar sizes to ensure that items within each category were comparable to others. For instance, refugees, prisoners, and people subject to domestic violence were combined into one item of ‘vulnerable population groups’ to compare with other items such as ‘populations living in rural and remote areas’. Similarly, distress, anxiety, and depression were combined to be comparable with other items in the psychosocial category (refer to Supplementary Table 1 for further information).

Round 2—ranked importance of priorities

The research and infrastructure priorities ranked according to the summary score can be found in Supplementary Tables 2-11, presented separately for the total panel (*n* = 68), researcher/health professional participants (*n* = 47) and non-researcher participants (*n* = 21). Mean scores, standard deviation, and proportion of participants who included a priority item within the top 5 are also presented. While there were minor differences between groups in order of ranking, overall, the highest-ranked and lowest-ranked items were quite consistent, and ranked order was not dominated by any one

Table 1 Participant characteristics

	Round 1 (*n* = 63) ***N*** (%)	Round 2 (*n* = 68) ***N*** (%)
Gender:		
Female	47 (73.4%)	51 (75.0%)
Male	17 (26.6%)	17 (25.0%)
Age:		
25–34 years	4 (6.3%)	3 (4.4%)
35–44 years	13 (20.3%)	15 (22.1%)
45–54 years	16 (25.0%)	17 (25.0%)
55–64 years	23 (35.9%)	24 (35.3%)
65 years or over	8 (12.5%)	9 (13.2%)
Role:		
Researcher/academic	27 (42.9%)	29 (42.7%)
Cancer survivor	10 (15.9%)	10 (14.7%)
Health professional	16 (25.3%)	18 (26.5%)
Advocacy group (non-government organization)	8 (12.7%)	7 (10.3%)
Government/policymaker	1 (1.6%)	1 (1.5%)
Friend/family	1 (1.6%)	2 (2.9%)
Administrator/managerial staff	–	1 (1.5%)
Years in cancer survivorship:	Mean = 15 years Range = 3–36	Mean = 15 years Range = 2–36

participant group. Thus, it was decided that presenting the results of the total panel was the best way to represent the views of all stakeholders.

Table 2 lists the top 5 priorities within each of the four categories of research priorities and the research infrastructure priorities, ranked according to the summary scores. Table 2 also indicates the type of research required for each research priority item, as selected by the panelists. The type of research for all other research and infrastructure priority items can be found in Supplementary Tables 12 and 13. Figure 1 provides an overview of the highest-ranked research and infrastructure priorities.

Physiological outcomes

In the category of survivors' physiological outcomes, 22 research priorities were ranked. One item (urinary function) was deemed not an important priority for research as no participant included this in the top 5. The top 5 priorities and suggested type of research included: biological/etiological research for cancer progression and recurrence; intervention development research for the physical impacts of cancer or treatment such as fatigue; cognitive function; and the management of comorbidities; and implementation or dissemination research for exercise and physical activity (Table 2). Research priorities receiving lower rankings included side effects such as neuropathy, pain, sleep disturbances, and sexual functioning, as well as health behaviors such as smoking, alcohol consumption, and sun protection (Supplementary Tables 2 and 3).

Psychosocial outcomes

In the category of survivors' psychosocial outcomes, 15 research priorities were ranked. The top 5 priorities and suggested type of research included: implementation or dissemination research for fear of cancer recurrence; intervention development research for economic issues; adaptation and the transition back to daily life; and return to work or study issues; and implementation or dissemination research for distress, anxiety, and depression outcomes (Table 2). Research priorities receiving lower rankings included spiritual wellbeing, body image and identity issues, social support and interpersonal needs, and informational needs (Supplementary Tables 4 and 5).

Population groups

In the category of population groups, 17 research priorities were ranked. The top 5 priorities and suggested type of research included: exploratory research designs for cancer types that are rare or are under-represented in research; and intervention development research for cancer survivors with advanced or recurrent disease; those who live in rural, regional, and remote locations; survivors of pediatric and childhood cancers; and those with low socioeconomic status (Table 2). Research priorities receiving lower rankings included cancer survivors identifying as LGBTQI+, survivors with multiple malignancies or other comorbid conditions or disabilities, survivors less than 5 years post-diagnosis, and cancer survivors in vulnerable population groups (Supplementary Tables 6 and 7).

Health services

In the category of health services, 13 research priorities were ranked. The top 5 priorities and suggested type of research included a combination of implementation or dissemination research and intervention development research, for quality of care; models of care; self-management techniques and patient preferences; communication between healthcare providers and patients; and patient navigation tools or health literacy (Table 2). Research priorities receiving lower rankings included the provision of care by community services, healthcare workforce training, policy factors and regulation, communication between health services, and telehealth (Supplementary Tables 8 and 9).

Infrastructure priorities

In the research infrastructure category, eight priorities were ranked. The top 5 priorities for infrastructure required to advance research included: the availability of patient data and data linkage; collaborative or multi-disciplinary research; funding opportunities; rigorous reporting standards; and development of survivorship researchers. Infrastructure priorities receiving lower rankings included the engagement of patients and families in research, increasing the dissemination of research, and developing or facilitating access to appropriate research tools (Supplementary Tables 10 and 11).

Discussion

This study provides evidence to inform research priorities for cancer survivorship in Australia and builds on a growing agenda worldwide. The findings of this study highlight several physiological and psychosocial issues that are important to prioritize, including fatigue, cognitive function, fear of cancer recurrence, as well as economic and employment related concerns. Other priorities include understudied population groups, health system quality, and models of care. Furthermore, as survivorship research continues to increase, these findings highlight infrastructure requirements which will progress research activity efficiently and effectively,

Table 2 Top 5 priorities within each category ranked in order of importance

Research priorities	SUM	Included in top 5 N (%[a])	Mean (SD)	Type of research required[b] *N* (%[c])			
				Etiology/biology	Exploratory	Intervention development	Implementation/dissemination
Physiological outcomes							
Cancer progression or recurrence	220	51 (75.0%)	4.31 (1.24)	**31 (60.78%)d**	21 (41.18%)	29 (56.86%)	13 (25.49%)
The management of comorbidities (having one or more other illness or disease as well as cancer)	151	39 (57.35%)	3.87 (1.19)	8 (20.51%)	18 (46.15%)	**32 (82.05%)**	14 (35.90%)
Fatigue	105	35 (51.47%)	3.00 (1.35)	17 (48.57%)	15 (42.85%)	**27 (77.14%)**	14 (40.0%)
Exercise and physical activity	95	37 (54.41%)	2.57 (1.28)	6 (16.21%)	6 (16.21%)	23 (62.16%)	**28 (75.67%)**
Cognitive function (memory, concentration, and thinking)	69	27 (39.70%)	2.56 (1.09)	9 (33.33%)	13 (48.15%)	**18 (66.67%)**	10 (37.04%)
Psychosocial outcomes							
Fear of cancer recurrence	164	43 (63.23%)	3.81 (1.28)	9 (20.93%)	10 (23.26%)	30 (69.77%)	**31 (72.09%)**
Economic issues such as financial toxicity, medical costs, living expenses, and insurance	147	46 (67.64%)	3.20 (1.33)	6 (13.04%)	25 (54.35%)	**35 (76.09%)**	22 (47.83%)
Distress, anxiety and depression	132	38 (55.88%)	3.47 (1.45)	4 (10.53%)	7 (18.42%)	24 (63.16%)	**30 (78.95%)**
Adaptation, adjustment, and the transition back into daily life	130	41 (60.29%)	3.17 (1.73)	3 (7.32%)	19 (46.34%)	**33 (80.49%)**	23 (56.10%)
Work and study issues such as return to paid or unpaid work, work participation, self-employment, and academic outcomes	62	23 (33.82%)	2.70 (1.46)	1 (4.35%)	12 (52.17%)	**20 (86.96%)**	11 (47.83%)
Population groups							
Rare cancer types or cancer types that are under-represented in research	126	35 (51.47%)	3.60 (1.54)	23 (65.71%)	**28 (80.0%)**	21 (60.0%)	11 (31.43%)
Survivors with advanced disease (cancer which has spread) or recurrent disease (cancer which has come back)	119	34 (50.0%)	3.50 (1.46)	9 (26.47%)	23 (67.65%)	**27 (79.41%)**	17 (50.0%)
Populations living in rural, regional, and remote areas	107	38 (55.88%)	2.82 (1.16)	2 (5.26%)	17 (44.74%)	**30 (78.95%)**	25 (65.79%)
Survivors of pediatric and childhood cancers	103	28 (41.17%)	3.68 (1.42)	11 (39.29%)	17 (60.71%)	**21 (75.0%)**	14 (50.0%)
Cancer survivors with low socioeconomic status	81	25 (36.76%)	3.24 (1.39)	2 (8.0%)	15 (60.0%)	**22 (88.0%)**	14 (56.0%)
Health Services							
Quality of care (including cancer care delivery, care coordination, healthcare utilization, and survivorship care planning)	127	37 (54.41%)	3.43 (1.24)	NA	17 (45.95%)	23 (62.16%)	**26 (70.27%)**
Flexible, cost-effective, and equitable models of care	122	34 (50.0%)	3.59 (1.35)	NA	19 (55.88%)	**28 (82.35%)**	25 (73.53%)
Survivors self-management, patient preferences, and decision-making	118	37 (54.41%)	3.19 (1.60)	NA	19 (51.35%)	**28 (75.68%)**	**28 (75.68%)**
Communication between patients and healthcare providers	98	29 (42.64%)	3.38 (1.52)	NA	16 (55.17%)	**23 (79.31%)**	20 (68.96%)
Patient navigation tools, engagement in the health system, and health literacy	97	29 (42.64%)	3.34 (1.40)	NA	12 (41.38%)	**21 (72.41%)**	**21 (72.41%)**

Table 2 (continued)

Research priorities	SUM	Included in top 5 N (%[a])	Mean (SD)	Type of research required[b] *N* (%[c])			
				Etiology/biology	Exploratory	Intervention development	Implementation/dissemination
Research infrastructure priorities	SUM	Included in top 5 N (%a)	Mean (SD)				
Enhance the availability of patient records and data linkage, and unify existing datasets and data collection systems	191	56 (82.35%)	3.41 (1.38)				
Facilitate and increase cross-jurisdictional, multi-disciplinary, collaborative research	164	53 (77.94%)	3.09 (1.36)				
Provide funding opportunities for researchers	162	52 (76.47%)	3.12 (1.50)				
Utilize rigorous reporting standards to ensure that the collection of patient information is precise and equivalent	134	39 (57.35%)	3.44 (1.48)				
Invest in and develop survivorship researchers	129	43 (63.23%)	3.00 (1.31)				

[a] Percent of total participants calculated (n=68)

[b] Participants could select more than one type of research for each priority item

[c] Percent calculated based on number who selected this item in top 5

[d] Bolded options indicate highest % for each item

SD = standard deviation, *NA* = not applicable (option not provided for participants to select)

such as enhancing the availability of patient records for research and providing appropriate funding and development opportunities for researchers.

While international literature regarding research priorities for cancer survivorship is in line with the current priorities identified by Australian experts, the previous frameworks have often been broader and focus on the general identification, surveillance, and management of late and long-term physical and psychosocial effects, and prioritization of diverse population groups [7, 13–15, 19, 28]. On the other hand, the Australian findings have highlighted specific issues needing research attention such as cancer progression and recurrence, the management of comorbidities, fear of recurrence, and the transition back to daily life, as well as specific population groups which require additional attention. Furthermore, while the research topics prioritized are similar to those in other countries, in certain areas such as psychosocial outcomes and health behavior research, past international literature has suggested a focus on developing and evaluating interventions [13, 14, 17], whereas the current findings suggest that research may move beyond interventions and towards implementation and translation. This focus on implementation and translation likely comes as evidence of intervention efficacy has grown, as well as a greater awareness and appreciation of implementation science methodologies in cancer care research in recent years [7]. Panelists identified priorities that reflect the unmet needs of cancer survivors. This suggests that the panel may have prioritized aspects of the cancer survivorship experience where evidence concerning optimal or existing interventions is limited. Fatigue, cognitive impairment, and fear of cancer recurrence have been identified as some of the most pressing concerns for cancer survivors following treatment [3, 4]. Interventions to address these issues have been effective in small trials [31, 32], however; while these issues remain a priority for cancer survivors, there needs to be continued research focusing on interventions tailored to diverse population groups, sustainability of intervention outcomes, and implementation into routine care [7, 8, 13, 14]. Economic and employment issues have also been recognized as a significant unmet need among cancer survivors, and a priority for cancer survivorship research in the current study and internationally [7, 13, 15, 19]. Financial toxicity and return-to-work issues were identified as research priorities over 12 years ago [25], yet progress has been slow and work still needs to be done to meet patient needs [7, 8, 13–15, 19]. It is noteworthy that economic and employment issues continue to be identified as research priorities across developed countries despite differing health systems [33]. While Australia has a universal healthcare system that provides free inpatient care in public hospitals, access to most medical services and subsidy of many prescription drugs, out-of-pocket costs for

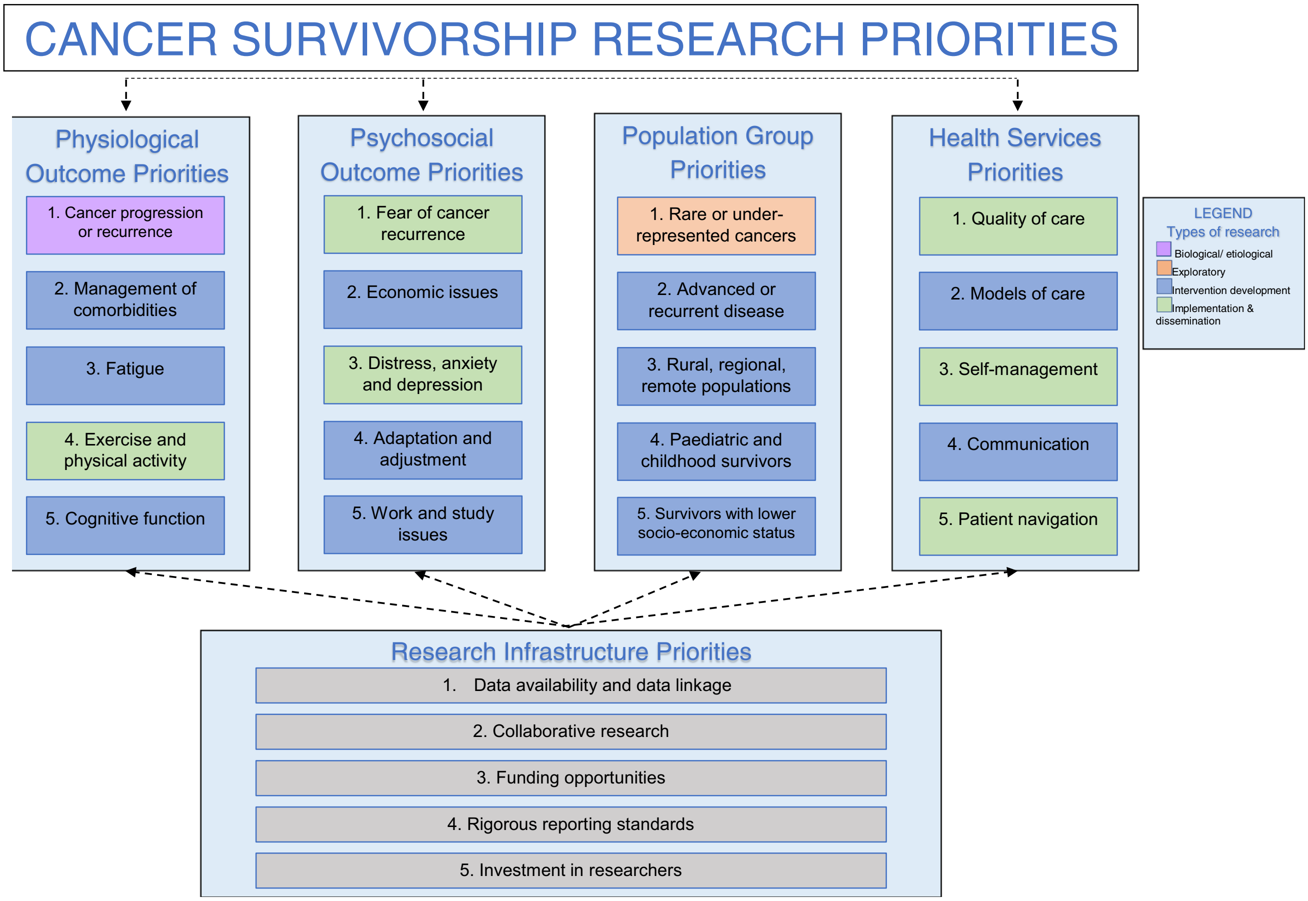

Fig. 1 Highest ranked research and infrastructure priorities

cancer patients are still high [34], and the logistical differences in health insurance coverage and government regulation between other countries can make comparisons difficult. Thus, while solutions to addressing financial toxicity and return-to-work need to be country and context dependent, many learnings may be shared internationally.

Research priorities for cancer survivorship have begun to recognize the needs of understudied population groups to make sure that improvements in cancer care do not increase health disparities, ensuring equitable care across diverse groups [35, 36]. Across many developed countries, underserved populations such as those residing in rural areas or living with lower socioeconomic position, have higher mortality rates and poorer cancer outcomes than those in metropolitan centers [37]. In addition, disparities in cancer outcomes among racial and ethnic minority groups, including Aboriginal and Torres Strait Islander populations in Australia, are well recognized [38]. There is consensus internationally, that equitable care will require cancer survivorship research that focuses on a range of population groups, encouraging a focus on geographic and ethnic minorities, as well as a broad spectrum of age cohorts including the elderly and pediatric cancer survivors, and cancer types other than breast cancer [7, 13, 14, 16, 17, 19, 28].

Primary-care provider, nurse-led, and shared care models of follow-up have been found to be equally effective at addressing cancer survivors needs and are promoted as alternatives to traditional, oncologist-led care [39, 40]. Thus, investigation into the cost-effectiveness and implementation of various models of care is required as identified in the current study. Additionally, although there is evidence supporting the effectiveness of self-management interventions in survivorship care [41], there remains a need for high-quality research investigating how best to optimize self-management support in specific population groups and how to integrate effective survivorship care models across different settings taking into account the complexity of differing health systems [42, 43]. Pragmatically, multiple items in the health services category could be explored simultaneously. For example, alternative models of care (second highest ranked) could include the provision of care through telehealth and community services, both of which achieved lower rankings (item 9 and item 13 respectively). Overall, the identified priorities should not be viewed as mutually exclusive, and future research may be able to address multiple priorities at once. Further, the implementation of health system research, including personalized self-management and tailored models of care, is also likely to have positive effects on patient outcomes such as pain, physical activity and disease progression which will address other identified research priorities [39, 44].

Limited other research prioritization activities have focused on infrastructure barriers that need addressing to conduct quality cancer survivorship research. Enhancing the availability of patient records and data linkage was a high priority identified by Australian panellists, which has been recognized internationally [7, 14, 19], and may include the standardized collection of clinical information such as Patient Reported Outcomes (PROs) [8]. One solution proposed in Europe is to create integrated Cancer Centers (combining care delivery and research) which can be used to link detailed treatment data and long-term health of cancer survivors and may serve as a structure for translational research [8], allowing for collaborative partnerships and multi-disciplinary research [8, 13, 19]. Another key factor in ensuring quality cancer survivorship research is investing in researchers, including training and development opportunities [7, 13]. However, to date, there has been limited guidance on how best to achieve this, particularly in the field of cancer survivorship [45]. Similarly, the engagement of survivors in research has been an increasing requirement for many funding agencies, yet researchers face challenges in involving consumer advisors in research and more guidance is needed for the research process to be truly inclusive and cooperative [46, 47]. Although not considered in the development of the survey, improvements in research infrastructure may also play a role in reducing healthcare disparities and conducting research that benefits underserved populations. For instance, accurate ‘big’ data can assist in understanding the mechanisms behind cancer and healthcare disparities and evaluation of population-wide interventions [48]; while stakeholder involvement and co-design can ensure solutions better meet the needs of the population groups who require them.

Strengths and limitations

This study used a modified Delphi approach to rank the importance of cancer survivorship research priorities, rather than establishing consensus through workshops or group meeting. The benefit of this method was that it identified the highest priorities, as we acknowledge that there are many priorities for cancer survivorship research and that all items reviewed are important; however, prioritization can help to focus future research directions. Additionally, the current study allowed participants to identify the types of research required for each priority, separated into biological or exploratory research, intervention development, and implementation research, a novel contribution of the study. The large number of participants and high response rate is a further strength, ensuring diversity of opinions in both rounds of the Delphi. Further, the inclusion of a wide range of professional roles and consumers enabled all key stakeholders to have a voice and ensured that the ranked priorities were not dominated by the opinions of any one group, allowing all participants to have meaningful involvement.

One limitation of the study is the individual and subjective nature of the ranking process. Items that were regarded as the highest priorities were generally issues known to impact a large number of cancer survivors, while physiological and psychosocial aspects that impact a smaller number of survivors were often ranked lower, suggesting that the panel may prioritize the impact of a research area based on population level need rather than individual needs. An additional challenge of the Delphi process is that smaller issues may be overwhelmed by larger categories of issues during the process of being ranked against each other. As discussed in the results, the modifications after the round 1 survey attempted to take this into consideration and create items of similar size within each category, although this was not always possible and thus the highest-ranked priorities may relate to overarching concepts and issues of larger magnitude than lower-ranked priority items.

Conclusion

In summary, a list of priorities for cancer survivorship research has been determined by consensus amongst Australian experts. The identified priorities are in line with existing international frameworks and areas of unmet need reported by cancer survivors, suggesting these research priorities are generalizable to a range of healthcare systems and population groups, while also identifying specific research topics relevant to the Australian context. In order to provide effective and quality survivorship care, it is crucial that the global evidence base for what does and does not work is strengthened, so while there is significant evidence about the experience of physical and psychosocial outcomes, it is now time to turn our attention to the implementation of interventions and tailoring interventions to particular sub-groups. Additionally, research training and funding opportunities are likely to lead to significant improvements in the quality of cancer survivorship research.

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Authors' contributions BK, RC, JV, KL, MI, and MJ conceived the study and acquired the organizational support of COSA. FC and JM designed the survey tools and participant information. FC collected the data and performed the analysis. GM coordinated the study. The first draft of the manuscript was written by FC and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials The datasets generated and analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval Approval was obtained from the human research ethics committee of the Peter MacCallum Cancer Centre (HREC/69659/PMCC). The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent for publication Not applicable.

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