

Original Article

Prostate cancer survivorship essentials framework: guidelines for practitioners

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Objective

To develop contemporary and inclusive prostate cancer survivorship guidelines for the Australian setting.

Participants and Methods

A four-round iterative policy Delphi was used, with a 47-member expert panel that included leaders from key Australian and New Zealand clinical and community groups and consumers from diverse backgrounds, including LGBTQIA people and those from regional, rural and urban settings. The first three rounds were undertaken using an online survey (94–96% response) followed by a fourth final face-to-face panel meeting. Descriptors for men's current prostate cancer survivorship experience were generated, along with survivorship elements that were assessed for importance and feasibility. From these, survivorship domains were generated for consideration.

Results

Six key descriptors for men's current prostate cancer survivorship experience that emerged were: dealing with side effects; challenging; medically focused; uncoordinated; unmet needs; and anxious. In all, 26 survivorship elements were identified within six domains: health promotion and advocacy; shared management; vigilance; personal agency; care coordination; and evidence-based survivorship interventions. Consensus was high for all domains as being essential. All elements were rated high on importance but consensus was mixed for feasibility. Seven priorities were derived for immediate action.

Conclusion

The policy Delphi allowed a uniquely inclusive expert clinical and community group to develop prostate cancer survivorship domains that extend beyond traditional healthcare parameters. These domains provide guidance for policymakers, clinicians, community and consumers on what is essential for step change in prostate cancer survivorship outcomes.

Keywords

prostate cancer, survivorship, quality of life, implementation, #PCSM, #ProstateCancer

Introduction

In 2018 over 1.2 million men were diagnosed with prostate cancer globally, with overall incidence expected to increase a further 42% by 2030 [1]. As incidence rises, advances in detection and treatment have led to improved survival rates in many countries, with Australia reporting 90.6% 10-year

survival [2], the USA 98% [3], and the UK 84% [4]. Hence the prevalence of prostate cancer continues to rise: in Australia, more than 200 000 men are living with a previous diagnosis [2,5]; 3 000 000 in the USA [6,7], and over 300 000 men in the UK [8]. Problematically, after diagnosis and treatment many men (up to 40%) experience poorer quality of life and satisfaction with life over the long term (10 years)

[9] and, even with localized disease, one in five men will experience persistent anxiety and depression 1 year after treatment [10], with distress greater in men with advanced disease [11]. Poorer long-term outcomes are associated with androgen deprivation therapy, multiple comorbidities, younger age at diagnosis, and socio-economic disadvantage [9]. Survivorship care that seeks to enhance health and well-being outcomes over both the short and longer term is therefore crucial for this patient group.

Limitations of existing survivorship guidelines include an over-reliance on expert opinion [12,13], invisibility of the consumer voice [14,15], a lack of translation into policy and practice [16], and, in the case of prostate cancer survivorship, gaps in knowledge [17]. Perspectives about masculinity and men's health are notably absent [18]. Recent commentary proposes that survivorship care for men with prostate cancer needs to take into account unique disease-specific factors, both clinical and biological, as well as the subjective patient experience [12]. Given the increasing burden of prostate cancer and the lack of clear progress in the development, acceptance and delivery of quality prostate cancer survivorship care, a different approach is needed that connects current evidence, expert opinion and consumer perspectives.

The Delphi technique is a widely used method that seeks to forecast and elicit informed expert opinion and consensus in a structured and iterative approach. In health, the Delphi method has been used to develop the following: health system performance, prescribing and disease indicators [19]; clinical models of care [20,21]; patient outcome measure sets [22]; and cancer survivorship classifications [23]. The policy Delphi [24] is appropriate for complex health policy issues and uses panel participants with a range of potentially different perspectives who are well informed and have a vested interest in the issue at hand, and specifically considers feasibility as well as importance [20,25]. This method is cost-effective as it does not require multiple and ongoing committee meetings, avoids constraining committee processes and, through expert involvement, sets a platform for dissemination [26]. Accordingly, we undertook a policy Delphi to describe the current state of prostate cancer survivorship in Australia and New Zealand and identify survivorship domains and domain elements for inclusion in care guidelines taking into account evidence, importance, feasibility and consensus.

Participants and Methods

Participants

Using purposive sampling through consultation with leading Australian ($n = 46$) and New Zealand ($n = 1$) clinical and community groups we identified 47 potential panel members who were leaders in the field with recognized authority in

prostate cancer and survivorship care or who were able to represent the experiences of men with prostate cancer. Australian participants spanned six jurisdictions (New South Wales, $n = 18$; Queensland, $n = 8$; Victoria, $n = 8$; South Australia, $n = 7$; Western Australia, $n = 3$; and the Australian Capital Territory, $n = 2$). All of those invited agreed to participate. The panel included 31 nationally leading clinical, allied health, nursing and academic and community leaders and 16 consumers who had experience in the provision of support in the community (Table 1) from a range of professional and academic organizations (Table 2). Representatives from indigenous health, the LGBTIQ community, rural and regional as well as urban consumers, and partners of men with prostate cancer were included. Health professional and academic leaders had between 15 and 40 years of experience with prostate cancer, and, for men, their time since diagnosis ranged from 6 to 20 years (Table 1). Sample sizes for policy Delphi range from 10 to 30, with a maximum of 50 considered appropriate [25,26].

Procedure

A four-round policy Delphi was undertaken between 9 September 2019 and 20 February 2020, with ethical approval from the University of Technology Sydney (Approval #ETH19-3855). The first three rounds were administered

Table 1 Participant characteristics.

Demographic characteristics	% (n)
Age	
18–44 years	13 (6)
45–54 years	19 (9)
55–64 years	26 (12)
65–74 years	36 (17)
75–84 years	4 (2)
85+ years	2 (1)
Gender	
Male	66 (31)
Female	34 (16)
Role*	
Health professionals	
Urologist	4 (2)
Medical oncologist	6 (3)
Radiation oncologist	4 (2)
General practitioner	4 (2)
Physiotherapist	2 (1)
Exercise physiologist	6 (3)
Registered nurse	9 (4)
Other (health professional)	19 (9)
Consumers	
Patients	30 (15)
Partners	8 (4)
Family of survivors	4 (2)
Time since diagnosis for survivors, years	Mean (range)
Patients	12 (6–20)
Partners	15 (9–23)
Health professional and academic leaders experience, years	16 (15–40)

*Some participants were health professionals who also have or had had prostate cancer, therefore, numbers do not add up to 47.

Table 2 Panel member organizational affiliations.

Australian and New Zealand Urogenital and Prostate Cancer Trials Group
Australia and New Zealand Urological Nurses Society
Australian Prostate Centre
Cancer Council Australia
Queensland Cancer Occupational Therapy Interest Group
Cancer Voices New South Wales
Centre for Research Excellence in Prostate Cancer Survivorship
Exercise and Sports Science Australia
Flinders Centre for Innovation in Cancer
Healthy Male
Macquarie Health
Medical Oncology Group of Australia
Peter MacCallum Cancer Centre
Primary Care Collaborative Cancer Clinical Trials Group
Prost! Exercise Group
Prostate Cancer Foundation of Australia
Prostate Cancer Foundation of New Zealand
Psychology Board of Australia
Royal Australian and New Zealand College of Radiologists
Urological Society of Australia and New Zealand
Regional and Major Urban Prostate Cancer Support Group Leadership

using the QualtricsXM survey platform, with the final round conducted at a face-to-face meeting. Each survey was pilot-tested in advance and revised as needed. Survey response rates were 96% ($n = 45$) for the first survey round, 96% ($n = 45$) for the second round and 94% ($n = 44$) for the third round, and 28 panel members attended the face-to-face meeting. In Round 1, 47 people replied but only 45 had complete data. After Round 1, one of the expert panel members withdrew from the project owing to a role change.

The purpose of Round 1 was generation of ideas and views about prostate cancer survivorship. Open-ended questions invited respondents to list three words describing the current survivorship experience for men diagnosed with prostate cancer and then to outline what domains they viewed as essential for prostate cancer survivorship care. To stimulate participant reflection, full-text article links to the ASCO prostate cancer survivorship guidelines [13] and recently proposed domains for a Cancer Survivorship Care Framework [16] were provided.

In Round 2 a synthesized list of descriptors for the prostate cancer survivorship experience generated in Round 1 were provided for panel members to choose up to five words that most closely represented men's current experience. Next, participants were asked to rate the survivorship care elements synthesized from Round 1 for importance and feasibility (1 – not important at all, to 7 – extremely important; 1 – not feasible at all, to 7 – extremely feasible). Importance was defined as the degree to which a survivorship element is of significance or value to improving prostate cancer survivorship care. Feasibility was the degree to which a survivorship element can be achieved, performed or implemented.

In Round 3 the survivorship elements from the previous rounds were thematically analysed to derive survivorship domains for the panel to consider the extent to which each domain should be included in prostate cancer survivorship guidelines (1 – not at all, to 7 – absolutely). For each domain, an open-ended question invited further commentary and suggestions for missing elements.

For Round 4, at a 1-day face-to-face meeting, participants reviewed the evidence for intervention for each survivorship domain through pre-reading and discussion of relevant systematic literature reviews [17], consumer perspectives [14], and a series of expert presentations. Participants were assigned to groups for each of the survivorship domains, each group was then asked to identify priority actions for change, and to consider feasibility of change in their designated domain to improve the survivorship experience in prostate cancer. Each group reported back to the other expert panel members on their identified priority actions. The expert panel members and two clinician-researchers (A.K., M.F.) were then given 10 votes each to vote on the top priority actions to target for change to inform future implementation. The top priorities for action were determined by the priority actions that received over 50% of the combined votes.

Analysis

Data from each round were considered verbatim and then underwent independent content and thematic analysis by three authors (J.D., A.G., S.K.C.), followed by discussion and consensus to provide synthesized data for the panel to consider in subsequent rounds. There are no universally accepted rules for consensus in the Delphi method. In the present study we determined the direction of consensus on seven-point rating scales using score categories of 6–7 as highly important/feasible/essential, 5 as moderately important/feasible/essential, 4 as neutral; 3 as less important/feasible/essential, and 1–2 as not important/feasible/essential [27]. The direction of consensus was defined as the proportion of agreement in either one agreement category (e.g. 'highly important'), or across two contiguous categories according to the consensus rule [27] (e.g. 'highly important' and 'moderately important'). The consensus rule was: high consensus – 70% in one agreement category or 80% in two contiguous categories; moderate consensus – 60% in one agreement category or 70% in two contiguous categories; low consensus – 50% in one agreement category or 60% in two contiguous categories; and no consensus – less than 50% in one agreement category or less than 60% in two contiguous categories [27,28].

Results

Experience of Prostate Cancer Survivorship

Round 1 elicited 135 words or phrases to describe the prostate cancer survivorship experience from which 30

unique words/phrases were identified. Of these, 18 were negative, four neutral, and eight positive. In Round 2, the top six words endorsed by at least 25% of the panel as best describing men's current prostate cancer survivorship experience were: dealing with side effects; challenging; medically focused; uncoordinated; unmet needs; and anxious (Table 3).

Prostate Cancer Survivorship Care Elements and Domains

In Round 1, participants described 310 elements of care that were synthesized through content analysis to produce 26 unique prostate cancer survivorship elements. In Round 2, most items were rated as very important with high consensus (22 items) and the remaining four items were very important to important with high consensus (Table 4). For feasibility, six items were rated as very feasible to moderately feasible with high consensus, three items as very feasible to moderately feasible with moderate consensus and the remaining 17 had either no [5] or low [12] consensus (Table 5). Through thematic analysis [29] and data consolidation [30] of these items, six domains of survivorship care were elicited: health promotion and advocacy; shared management; vigilance; personal agency; care coordination

Table 3 Endorsement of prostate cancer survivorship descriptors.

Descriptors	Endorsement % (n)
Dealing with side effects	78 (35)
Challenging	38 (17)
Medically focused	33 (15)
Uncoordinated	29 (13)
Unmet needs	29 (13)
Anxious	27 (12)
Emotional	24 (11)
Family relationships	22 (10)
Variable	20 (9)
Surveillance	18 (8)
Optimistic	18 (8)
Resilience	18 (8)
Mostly ok	18 (8)
Decision-making	16 (7)
Well-being	13 (6)
Confusing	13 (6)
Resigned	11 (5)
Distressing	11 (5)
Living	11 (5)
Relief	9 (4)
Learning	9 (4)
Positive	7 (3)
Transformative	7 (3)
Regret	7 (3)
Burdensome	4 (2)
Poor	2 (1)
Isolating	2 (1)
Helping	0 (1)
Diminished	0 (1)
Lifelong	0 (1)

and evidence-based survivorship interventions (see Appendix 1 for domain definitions).

In Round 3, participants rated all six domains as very important with high consensus (Table 6). In Round 4, participants identified 31 priority actions for change across the six domains of survivorship care (Table 7). Participants then cast a total of 293 votes to identify the top priority actions to target for change. Seven priorities for action received over half of the combined votes ($n = 163$). These top priority actions were: a patient communication kit for health professionals; a 'My Journey Kit' from diagnosis for patients; alternative delivery models to improve access; advocacy for Medicare Benefit Schedule (Commonwealth) payments for care programmes; exercise as an avenue for personal agency; better use of technology; and innovative models for specialist nurses (Table 8).

Discussion

Consistent with our previous research, this expert panel described the current experience of prostate cancer survivorship in Australia as medically focused, not well coordinated and challenging, exacerbating the difficulty of treatment side effects and leading to unmet needs and anxiety [14,21]. The burden of prostate cancer in the individual has been well described, with the chronic nature and prolonged natural history of this disease, along with accumulated toxicities from existing and emerging treatments, exacerbating the need for survivorship guidelines [12]. Problematically, a survivorship response from a policy, research and practice perspective has been slow to emerge and where it does exist is fragmented [31]. The present study applying the Delphi method as a policy practice planning tool uniquely presents a collective high consensus statement from the Australian and New Zealand clinical and consumer community about the essential domains for prostate cancer survivorship care. Six essential survivorship domains were identified, each with important elements (Fig. 1), to guide action not only in this context, but likely elsewhere. These domains in practice will articulate closely with each other, which we propose is a strength that mirrors the realities of life as a cancer survivor where different domains of quality of life intersect and influence long-term physical and mental well-being and life satisfaction [9].

Health Promotion and Advocacy

Health promotion and advocacy is central to the early detection of prostate cancer and survivorship care after diagnosis and treatment by raising community awareness and maintaining a public focus on men's health. Key to this domain is the provision of up-to-date information to increase the Australian and New Zealand community's knowledge of men's health and prostate cancer. Information should be

Table 4 Frequency (%) of response regarding the degree to which each element of survivorship is important (Round 2; *N* = 45).

	Consensus (direction)	Very important (6–7) <i>n</i> (%)	Moderately important (5) <i>n</i> (%)	Neutral (4) <i>N</i> (%)	Less important (3) <i>n</i> (%)	Not important (1–2) <i>n</i> (%)
Management of advanced symptoms	High (VI)	45 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Access to care	High (VI)	45 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Palliative care	High (VI)	44 (97.8)	1 (2.2)	0 (0.0)	0 (0.0)	0 (0.0)
Multidisciplinary teams	High (VI)	43 (95.6)	2 (4.4)	0 (0.0)	0 (0.0)	0 (0.0)
Managing physical effects	High (VI)	43 (95.6)	1 (2.2)	1 (2.2)	0 (0.0)	0 (0.0)
Psychosocial care	High (VI)	42 (93.3)	3 (6.7)	0 (0.0)	0 (0.0)	0 (0.0)
Up-to-date information	High (VI)	42 (93.3)	3 (6.7)	0 (0.0)	0 (0.0)	0 (0.0)
Surveillance of recurrence and second cancers	High (VI)	42 (93.3)	2 (4.4)	1 (2.2)	0 (0.0)	0 (0.0)
Care coordination	High (VI)	42 (93.3)	3 (6.7)	0 (0.0)	0 (0.0)	0 (0.0)
Shared and informed decision	High (VI)	41 (91.1)	3 (6.7)	1 (2.2)	0 (0.0)	0 (0.0)
Person-centred care	High (VI)	41 (91.1)	3 (6.7)	1 (2.2)	0 (0.0)	0 (0.0)
Family support for the patient	High (VI)	41 (91.1)	3 (6.7)	1 (2.2)	0 (0.0)	0 (0.0)
Prostate cancer specialist nurses	High (VI)	40 (88.9)	5 (11.1)	0 (0.0)	0 (0.0)	0 (0.0)
Monitoring physical effects	High (VI)	39 (86.7)	4 (8.9)	2 (4.4)	0 (0.0)	0 (0.0)
Exercise, physical activity and nutrition	High (VI)	39 (86.7)	5 (11.1)	1 (2.2)	0 (0.0)	0 (0.0)
Health promotion	High (VI)	39 (86.7)	3 (6.7)	1 (2.2)	1 (2.2)	1 (2.2)
Screening for psychosocial effects	High (VI)	39 (86.7)	5 (11.1)	1 (2.2)	0 (0.0)	0 (0.0)
Self-management	High (VI)	39 (86.7)	4 (8.9)	1 (2.2)	1 (2.2)	0 (0.0)
Management of comorbidities	High (VI)	38 (84.4)	5 (11.1)	1 (2.2)	0 (0.0)	1 (2.2)
Maintaining intimate relationships	High (VI)	38 (84.4)	7 (15.6)	0 (0.0)	0 (0.0)	0 (0.0)
Advocacy	High (VI)	37 (82.2)	3 (6.7)	3 (6.7)	2 (4.4)	0 (0.0)
Surveillance of comorbidities	High (VI)	37 (82.2)	7 (15.6)	0 (0.0)	1 (2.2)	0 (0.0)
Empowerment	High (VI-MI)	35 (77.8)	8 (17.8)	1 (2.2)	1 (2.2)	0 (0.0)
Psychosocial care of family members	High (VI-MI)	30 (66.7)	13 (28.9)	2 (4.4)	0 (0.0)	0 (0.0)
Financial assistance	High (VI-MI)	28 (62.2)	9 (20.0)	6 (13.3)	2 (4.4)	0 (0.0)
Peer support	High (VI-MI)	27 (60.0)	12 (26.7)	6 (13.3)	0 (0.0)	0 (0.0)

MI, moderately important; VI, very important.

evidence-based, providing consistent messaging around prostate cancer, and tailored to take into account health literacy and preferences for different mediums [32,33]. Information should be targeted specifically to primary care providers and community workers along with dedicated training in men's health promotion to work effectively with men. Advocacy is required from the non-government sector for the effective promotion of men's health to government and to health service providers and to engaging community support. Advocacy is also required to bring attention to the support needs of survivors and their families, including advocating for programmes around peer support and self-management. This involves facilitating public access to information about prostate cancer, the provision of evidence-based interventions and improving access to survivorship care for all men and their families, including those living in rural and remote areas, LGBTQIA people, indigenous people, and people from culturally and linguistically diverse backgrounds [34–36].

Shared Management

Shared management between patients and health professionals is required to improve outcomes and ensure quality survivorship care. Development of models which facilitate informed decision-making around testing and

treatment and address physical and psychosocial effects, comorbidities, advanced cancer symptoms, and palliative care is a priority [37]. Clear explanation is required that palliative care relates to the prevention and control of symptoms earlier in the survivorship journey as well as to end-of-life issues. Informed decision-making involves access to decision aids to facilitate understanding of treatment options, side effects and associated financial costs, as well as open communication and delivery of consistent information. Shared management extends to respecting a patient's wishes to engage in decision-making around care to the extent they prefer, involves acknowledging and supporting the role family members and carers play, and requires access to patient records. Once shared and informed management decisions are made, these decisions should be supported by effective care coordination, with primary care providers and prostate cancer specialist nurses playing a central role as navigators [21].

Vigilance

Vigilance in relation to the clinical surveillance of patients is critical to prostate cancer survivorship. Vigilance from health professionals across the survivorship continuum from diagnosis to end-of-life care is necessary, with attentive surveillance of physical and psychosocial effects, comorbidities, recurrence and second cancers. This extends to monitoring psychosocial effects

Table 5 Frequency (%) of response regarding the degree to which element of survivorship is feasible (Round 2; N = 45).

	Consensus (direction)	Very feasible (6–7) n (%)	Moderately feasible (5) n (%)	Neutral (4) n (%)	Less feasible (3) n (%)	Not feasible (1–2) n (%)
Surveillance of recurrence and second cancers	High (VF-MF)	32 (71.1)	8 (17.8)	3 (6.7)	2 (4.4)	0 (0.0)
Up-to-date information	High (VF-MF)	27 (60.0)	11 (24.4)	5 (11.1)	2 (4.4)	0 (0.0)
Monitoring physical effects	High (VF-MF)	26 (57.8)	15 (33.3)	3 (6.7)	1 (2.2)	0 (0.0)
Management of advanced symptoms	High (VF-MF)	25 (55.6)	15 (33.3)	3 (6.7)	1 (2.2)	1 (2.2)
Palliative care	High (VF-MF)	22 (48.9)	15 (33.3)	6 (13.3)	2 (4.4)	0 (0.0)
Advocacy	High (VF-MF)	20 (44.4)	16 (35.6)	4 (8.9)	4 (8.9)	1 (2.2)
Health promotion	Moderate (VF-MF)	19 (42.2)	14 (31.1)	8 (17.8)	2 (4.4)	2 (4.4)
Exercise, physical activity and nutrition	Low (VF-MF)	18 (40.0)	12 (26.7)	8 (17.8)	4 (8.9)	3 (6.7)
Family support for the patient	Low (VF-MF)	18 (40.0)	13 (28.9)	9 (20.0)	2 (4.4)	3 (6.7)
Shared and informed decision	Low (VF-MF)	17 (37.8)	12 (26.7)	11 (24.4)	5 (11.1)	0 (0.0)
Prostate cancer specialist nurses	Low (VF-MF)	17 (37.8)	10 (22.2)	9 (20.0)	9 (20.0)	0 (0.0)
Screening for psychosocial effects	Low (VF-MF)	17 (37.8)	10 (22.2)	12 (26.7)	4 (8.9)	2 (4.4)
Surveillance of comorbidities	Moderate (VF-MF)	16 (35.6)	17 (37.8)	8 (17.8)	4 (8.9)	0 (0.0)
Peer support	Low (MF-N)	15 (33.3)	10 (22.2)	16 (35.6)	3 (6.7)	1 (2.2)
Management of comorbidities	Low (VF-MF)	15 (33.3)	13 (28.9)	10 (22.2)	4 (8.9)	3 (6.7)
Empowerment	Low (VF-MF)	15 (33.3)	12 (26.7)	11 (24.4)	4 (8.9)	3 (6.7)
Person-centred care	Low (VF-MF)	13 (28.9)	18 (40.0)	10 (22.2)	4 (8.9)	0 (0.0)
Managing physical effects	Moderate (VF-MF)	13 (28.9)	22 (48.9)	7 (15.6)	2 (4.4)	1 (2.2)
Multidisciplinary teams	Low (MF-N)	12 (26.7)	14 (31.1)	15 (33.3)	2 (4.4)	2 (4.4)
Psychosocial care	Low (MF-N)	11 (24.4)	18 (40.0)	13 (28.9)	3 (6.7)	0 (0.0)
Self-management	Low (VF-N)	10 (22.2)	18 (40.0)	10 (22.2)	6 (13.3)	1 (2.2)
Care coordination	None (MF-N)	10 (22.2)	13 (28.9)	15 (33.3)	6 (13.3)	1 (2.2)
Maintaining intimate relationships	None (MF-N)	9 (20.0)	12 (26.7)	12 (26.7)	7 (15.6)	5 (11.1)
Access to care	None (MF-N)	8 (17.8)	17 (37.8)	14 (31.1)	5 (11.1)	1 (2.2)
Psychosocial care of family members	None (N-LF)	5 (11.1)	8 (17.8)	17 (37.8)	12 (26.7)	3 (6.7)
Financial assistance	None (N-LF)	1 (2.2)	8 (17.8)	15 (33.3)	14 (31.1)	7 (15.6)

LF, Less feasible; MF, moderately feasible; N, neutral; VF, very feasible.

on partners and family members [38]. The level of vigilance should be tailored to the changing needs of patients through screening early on and then systematically over the survivorship journey. Additional sources of information to evaluate patients, including observations from partners and other family members, are important to take into account. Health professionals should take action on the outcomes of clinical surveillance as required.

Personal Agency

Personal agency enables a patient's ability to understand risk factors and take steps to promote personal well-being;

therefore, a focus on personal agency and the ability of individual patients to be self-aware in assessing their needs, seek assistance when required, and manage their own health is central to improving outcomes. By 'personal agency' we mean the capacity of an individual to initiate, execute and manage their actions in response to the awareness and ownership of health-related needs. Recognizing patients as actors in building personal resilience, managing their own health and with mastery in navigating the healthcare system will lead to improved survivorship outcomes. Family members and wider social support networks also play a key role in supporting patients to achieve objectives. Patient

Table 6 Frequency (%) of response regarding the degree to which each survival domain is essential (Round 3; N = 44).

	Consensus (Direction)	Very essential (6–7) n (%)	Moderately essential (5) n (%)	Neutral (4) n (%)	Less essential (3) n (%)	Not Essential (1–2) n (%)
Health promotion and advocacy	High (VE)	39 (88.6)	1 (2.3)	3 (6.8)	0 (0.0)	1 (2.3)
Shared management	High (VE)	41 (93.2)	0 (0.0)	3 (6.8)	0 (0.0)	0 (0.0)
Vigilance	High (VE)	37 (84.1)	5 (11.4)	0 (0.0)	2 (4.5)	0 (0.0)
Personal agency	High (VE)	41 (93.2)	3 (6.8)	0 (0.0)	0 (0.0)	0 (0.0)
Care coordination	High (VE)	42 (95.5)	0 (0.0)	1 (2.3)	0 (0.0)	1 (2.3)
Evidence-based survivorship interventions	High (VE)	43 (97.7)	0 (0.0)	1 (2.3)	0 (0.0)	0 (0.0)

VE, very essential.

Table 7 Priority actions for change in each domain (N = 31; Round 4).

Health promotion and advocacy		Shared management		Vigilance		Personal agency		Care coordination		Evidence-based survivorship interventions	
Priority action	Votes	Priority action	Votes	Priority action	Votes	Priority action	Votes	Priority action	Votes	Priority action	Votes
Advocacy for MBS payment for care programmes	20	Better use of technology	19	Define vigilance best practice for each patient group	9	Exercise as an avenue for personal agency	20	Alternative delivery models to improve access	22	Patient communication kit for health professionals	32
Innovative models for specialist nurses	18	Use of community nurses/teams	13	Advocate for PBS support for surveillance tools	8	Health professional role	8	Define care coordination	13	'My Journey Kit' from diagnosis for patients	32
Health professional education in health promotion	11	Knowledge and information for patients, partners, family members and friends	7	Vigilance pathways for health professionals	1	Peer support	7	Patient-centred	6	Communicating information about interventions	3
Australian online resources to connect people to local services	11	Improved health communication	4			Adaptability to changing circumstances	2	Improved communication	4		
Empowering consumers to communicate	5	Resources on side effects	4			Information dissemination	2	Team-based care delivery	1		
Engage partners, family members and friends to promote healthy choices	4	Health professional education on appropriate communication	0			Addressing personal attitudes through diverse avenues for support	2				
Continuous monitoring of consumer needs	2										
High profile policy advocates	3										

MBS, the Medicare Benefits Schedule is a list of Medicare services subsidized by the Australian Government; PBS, the Pharmaceutical Benefits Scheme provides medicines to patients at a Government-subsidized price.

Table 8 Overall ranking of priority actions for change (Round 4).

Priority actions	Votes
Patient communication kit for health professionals	32
'My Journey Kit' from diagnosis for patients	32
Alternative delivery models to improve access	22
Advocacy for MBS payment for care programmes	20
Exercise as an avenue for personal agency	20
Better use of technology	19
Innovative models for specialist nurses	18
Define care coordination	13
Use of community nurses/teams	13
Health professional education in health promotion	11
Australian online resources to connect people to local services	11
Define vigilance best practice for each patient group	9
Advocate for PBS support for surveillance tools	8
Health professional role	8
Peer support	7
Knowledge and information for patients, partners, family members and friends	7
Patient-centred	6
Empowering consumers to communicate	5
Engage partners, family members and friends to promote healthy choices	4
Improved communication	4
Improved health communication	4
Resources on side effects	4
High profile policy advocates	3
Communicating information about interventions	3
Continuous monitoring of consumer needs	2
Adaptability to changing circumstances	2
Information dissemination	2
Addressing personal attitudes through diverse avenues for support	2
Team-based care delivery	1
Vigilance pathways for health professionals	1
Health professional education on appropriate communication	0

MBS, the Medicare Benefits Schedule is a list of Medicare services subsidized by the Australian Government; PBS, the Pharmaceutical Benefits Scheme provides medicines to patients at a Government-subsidized price.

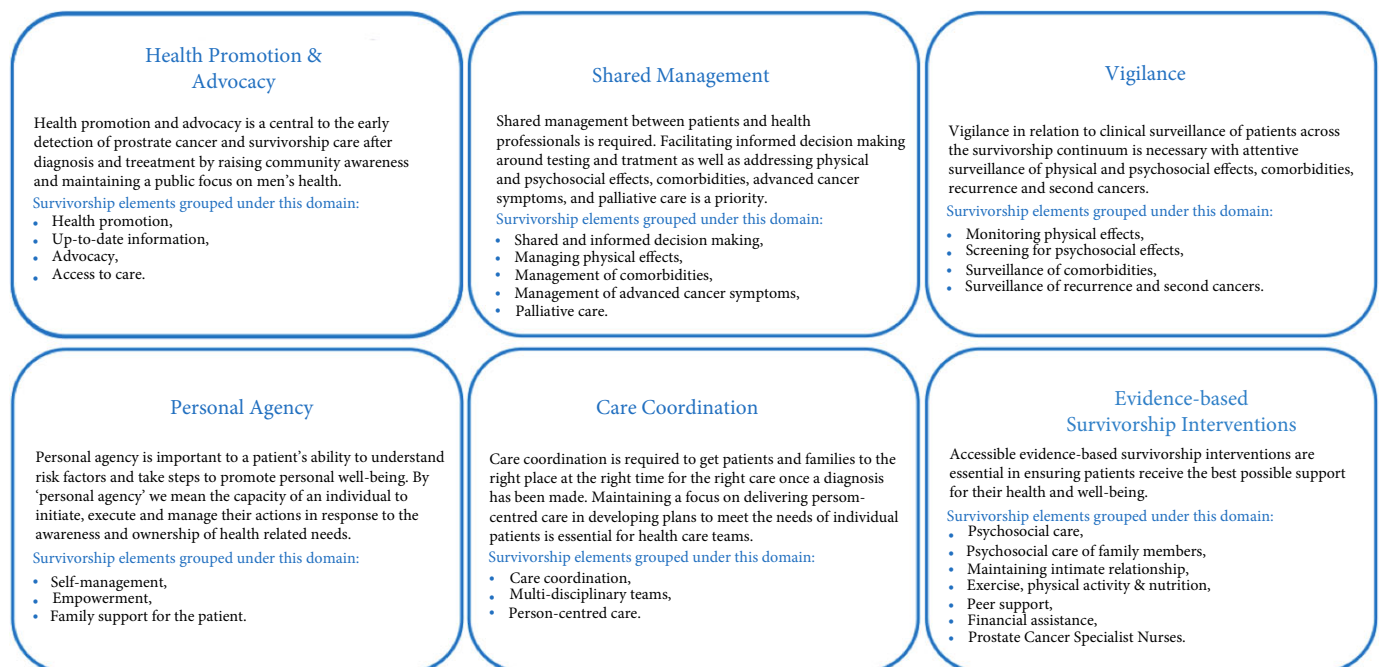
education and knowledge should be supported by the provision of information across the spectrum of survivorship care tailored to the health literacy levels of individual patients [33]. A health professional workforce skilled in supporting personal agency is required.

Care Coordination

Care coordination is required to get patients and families to the right place at the right time for the right care once a diagnosis has been made [39]. Care coordination in consultation with patients and families is critical to survivorship outcomes. Clinical teams, primary care clinicians, nurses and allied health professionals, as well as community-based health and welfare services, should all be active participants. This requires systems to support the sharing of relevant patient information between healthcare teams, and referral to community-based peer support groups where required. Underlying care coordination is the need for healthcare teams to maintain a focus on delivering person-centred care in developing plans to meet the needs of individual patients. This includes approaching care in a men-centred way, acknowledging that men-centred care is deeply contextual and dynamic, but includes a consideration of how healthcare services for men intersect with masculinity and with men's preferences for the design and delivery of prostate cancer survivorship care [14,18]. Specific consideration of access issues for indigenous men, those living in rural and

Fig. 1 Prostate cancer survivorship essentials framework.

Prostate Cancer Survivorship Essentials Framework



remote areas, and men from culturally and linguistically diverse backgrounds is required.

Evidence-based Survivorship Interventions

Accessible evidence-based survivorship interventions ensure patients receive the best possible support for their health and well-being. Key evidence-based survivorship interventions include psychosocial care, exercise and physical activity, nutrition, peer support, financial assistance, and prostate cancer specialist nurses. It is important that psychosocial care interventions to maintain intimate relationships comprise sexual health support tailored to individual men including those in different age groups and from LGBTQIA backgrounds.

Feasibility, Priorities and Limitations

It is not surprising that, while experts reached consensus about the domains and elements of prostate cancer survivorship and their importance, there was low consensus around feasibility. The extent to which a survivorship intervention element can be implemented will depend on the healthcare, social and community systems in which each individual man exists, as well as his own and his family's personal preferences. Healthcare inequities are widespread in almost all societies globally, not only in Australia, and men's healthcare outcomes have specific challenges that are seldom addressed in mainstream healthcare delivery [32]. In response, our expert panel identified seven priority actions as a practical platform for change. Action on each priority can be expected to have an impact for men across the six survivorship domains, and cumulatively could make a measurable difference in the face of prostate cancer in this country.

A limitation of this study is the Australian and New Zealand setting, such that this framework may not generalize to countries with markedly different cultural and health system characteristics. However, we would argue that a workable survivorship model requires this level of specificity and local ownership and knowledge. Additionally, a number of the participants in this Delphi study held leadership positions in support groups in their community. Although these participants had deep community understanding and awareness of survivorship issues facing men with prostate cancer, their views may not be representative of all men with prostate cancer. Most importantly, the high participation and response rates we report are evidence of rigour in our approach and of the commitment of clinicians and community to work together in novel ways to improve outcomes for men with prostate cancer.

In conclusion, the policy Delphi provided a mechanism to form a uniquely inclusive expert clinical and community

group from which a set of prostate cancer survivorship domains were developed that extend beyond traditional healthcare parameters. Guidance that spans personal agency, health promotion and advocacy, shared management, care coordination, evidence-based interventions, across to a shared vigilance between the patient and the clinician, is a new way of thinking about care. Each of these domains intersects or articulates with each other and this mirrors both the patient experience and how services operate at their best. New ways of thinking will be needed as the healthcare burden of our aging population grows, and as technological innovations in personalized medicine emerge, with their attendant costs and benefits [40–42]. New partnerships across disciplines that include consumers are needed in order to respond to these challenges, as well as to facilitate implementation [43]. This study establishes these partnerships for prostate cancer survivorship and provides a model for consideration in cancer more broadly.

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Conflicts of Interest

The authors have no conflicts of interest to declare.

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Appendix 1

Prostate cancer survivorship essential domain names, elements and definitions

Domain name	Domain elements	Domain definition
Health promotion and advocacy	<ol style="list-style-type: none"> 1. Health promotion 2. Up-to-date information 3. Advocacy 4. Access to care 	<p>Health promotion and advocacy is central to the early detection of prostate cancer and survivorship care after diagnosis and treatment by raising community awareness and maintaining a public focus on men's health. Key to this domain is the provision of up-to-date information to increase the Australian community's knowledge of men's health and prostate cancer. It is important that up-to-date information is evidence-based, provides consistent messaging around prostate cancer, and is tailored, taking into account varying levels of health literacy and preferences for different mediums. Information should also be targeted specifically to primary care providers and community workers along with dedicated training in men's health promotion to work effectively with men. Advocacy is required from the non-government sector for the effective promotion of men's health to government and to health service providers and to engaging community support. Advocacy is also required to bring attention to the support needs of survivors and their families, including advocating for programmes around peer support and self-management.</p> <p>'Making men's health a priority'</p> <p>This involves facilitating public access to up-to-date information, the provision of evidence-based interventions and improving access to survivorship care for all men and their families. Including those living in rural and remote areas, from LGBTQIA and culturally and linguistically diverse backgrounds</p>
Shared management	<ol style="list-style-type: none"> 1. Shared and informed decision-making 2. Management of comorbidities 3. Managing physical effects 4. Management of advanced cancer symptoms 5. Palliative care 	<p>Once a diagnosis of prostate cancer has been made, shared management between patients and health professionals is required to improve outcomes and ensure quality survivorship care. Developing models of shared management to facilitate informed decision-making around testing and treatment, as well as addressing physical and psychosocial effects, comorbidities, advanced cancer symptoms, and palliative care, is a priority. Clear explanation that palliative care not only relates to end-of-life issues but also that the prevention and control of symptoms earlier in the survivorship journey is required. Informed decision-making that includes health professional and patient access to decision aids to facilitate understanding of treatment options and side effects, associated financial costs, as well as open communication and delivery of consistent information, is important. Shared management extends to respecting a patient's wishes to engage in decision-making around care to the extent they prefer. It is important for health professionals to acknowledge the role family members and carers play in shared management for some patients and support their involvement.</p> <p>'Fully informed decision-making'</p> <p>Health professional access to patient records is important to informing shared management. Once shared and informed management decisions are made by patients and health professionals, these decisions should be supported by effective care coordination, with primary care providers and prostate cancer specialist nurses playing a central role as navigators</p>
Vigilance	<ol style="list-style-type: none"> 1. Monitoring physical effects 2. Screening for psychosocial effects 3. Surveillance of comorbidities 4. Surveillance of recurrence and second cancers 	<p>Vigilance in relation to clinical surveillance of patients is critical to prostate cancer survivorship. Vigilance from health professionals across the survivorship continuum from diagnosis to end-of-life care is necessary with attentive surveillance of physical and psychosocial effects, comorbidities, recurrence and second cancers. Health professionals' vigilance is important in monitoring psychosocial effects on the partners and family members of patients. The level of vigilance should be tailored to the changing needs of patients through screening early on and then systematically over the survivorship journey. Additional sources of information to evaluate patients, including observations from partners and other family members, are important to take into account.</p> <p>'Surveillance of recurrence is very important and gives you hope as you survive your journey'</p> <p>Vigilance includes health professionals taking action on the outcomes of clinical surveillance as required</p>
Personal agency	<ol style="list-style-type: none"> 1. Self-management 2. Empowerment 3. Family support for the patient 	<p>Personal agency is important to a patient's ability to understand risk factors and take steps to promote personal well-being. Therefore, a focus on personal agency and the ability of individual patients to be self-aware in assessing their needs, seek assistance when required, and manage their own health is central to improving outcomes. Family members and wider social support networks play a role in building personal agency and supporting patients to achieve objectives</p> <p>By 'personal agency' we mean the capacity of an individual to initiate, execute and manage their actions in response to the awareness and ownership of health-related needs. Recognizing 'patients as actors' in building personal resilience, in managing their own health and with mastery in navigating the healthcare system will lead to improved survivorship outcomes. Patient education and knowledge enables personal agency and should be supported by the provision of information across the spectrum of survivorship care tailored to the health literacy levels of individual patients. A health professional workforce skilled in supporting the personal agency of patients is important</p> <p>'Survivors should be encouraged to assess their own needs, learn how and where to seek assistance. . .and what questions they should be asking of health professionals'</p>

Table (continued)

Domain name	Domain elements	Domain definition
Care coordination	<ol style="list-style-type: none"> 1. Care coordination 2. Multidisciplinary teams 3. Person-centred care 	<p>Care coordination is required to get patients and families to the right place at the right time for the right care once a diagnosis has been made.</p> <p>'Guidance navigating the health system'</p> <p>Care coordination in consultation with patients and families is critical to survivorship outcomes. Clinical teams, primary care clinicians, nurses and allied health professionals as well as community-based health and welfare services should all be active participants in Care coordination. This requires systems to support the sharing of relevant patient information between healthcare teams, and referral to community-based peer support groups where required.</p> <p>'A central healthcare professional connecting all the services, appointments and treatments'</p> <p>Underlying care coordination is the need for healthcare teams to maintain a focus on delivering person-centred care in developing plans to meet the needs of individual patients. This includes approaching care in a men-centred way, acknowledging that men-centred care is deeply contextual and dynamic but includes a consideration of how healthcare services for men intersect with masculinity and in the context of this study with men's preferences for the design and delivery of prostate cancer survivorship care. Specific consideration of access issues to care coordination for men living in rural and remote areas and men from culturally and linguistically diverse backgrounds is required.</p> <p>'Whole of person care. . .creation of personal packages'</p>
Evidence-based survivorship interventions	<ol style="list-style-type: none"> 1. Psychosocial care 2. Psychosocial care of family members 3. Maintaining intimate relationships 4. Exercise, physical activity and nutrition 5. Peer support 6. Financial assistance 7. Prostate cancer specialist nurses 	<p>Accessible evidence-based survivorship interventions are essential in ensuring patients receive the best possible support for their health and well-being. Key evidence-based survivorship interventions include psychosocial care, exercise and physical activity, nutrition, peer support, financial assistance, and prostate cancer specialist nurses.</p> <p>'Management of a well-planned exercise programme to meet your needs is a great help, and makes you feel good about yourself'</p> <p>Psychosocial care interventions to maintain intimate relationships that include sexual health support tailored to individual men including those in different age groups and from LGBTQIA backgrounds are important</p>

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