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Translating the prostate cancer survivorship essentials framework into clinical practice: a participatory research process analysis

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ABSTRACT

Purpose: Accessible cancer survivorship care is a key tenet of quality cancer care. However, prostate cancer survivorship care is often fragmented with best practice models of care largely undefined. The Prostate Cancer Survivorship Essentials Framework (“*Essentials Framework*”) was developed to guide the provision of integrated quality prostate cancer survivorship care. This process analysis reports the application of the *Essentials Framework* for mapping a current clinical model of prostate cancer survivorship care and identifying actions to facilitate translation of the framework into clinical practice.

Methods: A five-phase mixed-methods participatory research study undertaken in an Australian multi-disciplinary prostate cancer clinic. All occasions of prostate cancer care over a two-year period were extracted from the patient database. Data from online surveys (patients) and semi-structured interviews (service stakeholders) were integrated and mapped to each domain of the *Essentials Framework* to identify areas of alignment and translational priorities.

Results: Data from 326 patients representing 4232 occasions of care, online patient surveys ($n=61$) and stakeholder interviews ($n=14$) informed the mapping process. There was strong alignment between the service model and *Essentials Framework* largely due to the co-location of 13 multidisciplinary survivorship care services, and a dedicated focus on continuity of care and clinical surveillance across the prostate cancer survivorship care trajectory. Priority actions for translation included development of integrated survivorship care pathways across all treatment streams, integration of a survivorship care plan into the patient management system and embedding routine distress screening into survivorship care across disciplines. The five study phases

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formed the basis of a mapping template. This process analysis provides a starting point for services who wish to incorporate the principles of the Essentials Framework into their settings, through explicit description of research methods, tools and processes. An exemplar of mapping outcomes and translational priorities aligned with the Essentials Framework is detailed. This analysis shows the *Essentials* Framework articulates clearly to current clinical practice and serves as a model to guide the development and evaluation of prostate cancer survivorship care.

Conclusions: By adopting a participatory research approach, and prioritizing clinical stakeholder experience, this study demonstrates evidence of the ecological validity of the *Essentials* Framework. Cross-disciplinary partnerships emerged as critical in identifying service-relevant translational priorities and supporting quality care.

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KEYWORDS prostate cancer survivorship; participatory research; models of care; multi-disciplinary teams; translational research

Background

Prostate cancer is the second most commonly diagnosed cancer in men globally, and the most frequently diagnosed cancer in men in over 60% of countries worldwide [1]. Accessible cancer survivorship care is a key tenet of quality cancer care, however, prostate cancer survivorship care remains fragmented with best practice models of care, until recently, largely undefined [2]. Men with prostate cancer describe the prostate cancer survivorship experience as challenging, uncoordinated and medically focused, all of which lead to increased supportive care needs and heightened anxiety for these patients [3]. Similarly, health professionals caring for men with prostate cancer characterize the prostate cancer survivorship experience as disjointed, under-resourced and distressing [4].

To address these survivorship care gaps, the Prostate Cancer Survivorship Essentials Framework (“*Essentials* Framework”) was developed in 2020 by a panel of 47 prostate cancer experts and consumers across Australia and New Zealand comprising leading clinical, nursing and allied health groups/agencies, and consumer groups from diverse backgrounds, including LGBTQIA people and those from regional, rural and urban settings, to guide the provision of integrated quality prostate cancer survivorship care [2]. Importantly, almost one-third of the 47-member panel were prostate cancer survivors, ensuring a strong and contemporary consumer voice that reflects the lived experience and preferences of survivors.

The *Essentials* Framework [2] comprises six domains that directly influence long-term physical and mental well-being, and are focussed on patient, versus process, outcomes (Figure 1). These six domains reached

high consensus as being essential, by the 47-member panel. Importantly, the central domain relates to personal agency of a survivor as a key element that links all others, and all domains are framed around outcomes that matter for the patient.

Since its development, the *Essentials* Framework has been widely endorsed by leading prostate cancer and urological groups in Australia and New Zealand [5], and provides a road map for improving the delivery of prostate cancer survivorship care in a variety settings. Accompanying the *Essentials* Framework are practitioner guidelines (“*Essentials* Guidelines”) which: (i) comprehensively define each survivorship domain and provide exemplar strategies to facilitate best practice in each domain and (ii) outline seven priority actions which intersect with each framework domain to serve as a practical platform for change [2]. Since the inception of the framework targeted translational and implementation activities, including the development of supporting resources, have been underway to support the uptake of the *Essentials* Framework into clinical practice [6–9].

This paper reports the process of the survivorship model of care mapping exercise to the *Essentials* Framework as an exemplar approach to the translation of the *Essentials* Framework into clinical practice. The objectives of this study were to: (i) map the current APC model of prostate cancer survivorship care to the *Essentials* Framework to determine alignment of the APC model with the domains of the *Essentials* Framework; (ii) identify actions to facilitate the translation of the six *Essentials* Framework domains into clinical practice and (iii) develop a mapping “template” for piloting and to guide future translation/implementation activities of the *Essentials* Framework into practice.

While participatory research has a well-established history, often the systematic description of how these studies are undertaken is minimal [10]. Hence, the focus of this paper is on the mapping process versus the specific outcomes of the study, in alignment with a participatory approach to research and dissemination [10,11]. An overview of findings is presented, however, to illustrate key consideration for *Essentials* Framework translation and implementation.

Methods

This participatory research study was undertaken between the Australian Prostate Centre (APC) in partnership with the National Health and Medical Research Council (NHMRC) Centre for Research Excellence in Prostate Cancer Survivorship (CRE-PCS). The APC is unique in Australia and one of the few medical facilities in the world focused on the complete treatment and care of men with prostate cancer [12]. All medical and support services are integrated and co-located in one center to minimize



	<p>Personal Agency where patients are self-aware in assessing their needs, seeking assistance when required, and building resilience to manage their own health where possible.</p>		<p>Shared Management between patients and health professionals to improve outcomes and ensure quality survivorship care with shared and informed decision making about all aspects of care.</p>
	<p>Evidence-based Survivorship Interventions for accessible psychosocial and psychosexual care, exercise and physical activity, nutrition, peer support, financial assistance, and specialist nursing interventions.</p>		<p>Care Coordination where patients and families arrive at the right place at the right time for the right care once a diagnosis has been made. Men-centred care is central.</p>
	<p>Health Promotion and Advocacy through the provision of up-to-date information to increase the community's knowledge of men's health and prostate cancer and support awareness and advocacy.</p>		<p>Vigilance across the survivorship continuum from diagnosis to end-of-life care with attentive surveillance of physical and psychosocial effects, comorbidities, recurrence and second cancers. This includes psychosocial effects on partners and family members.</p>

Figure 1. The Prostate Cancer Survivorship Essentials Framework [2].

travel and waiting times, and stream-line care co-ordination. The service utilizes a distinctive fee and billing model for men with prostate cancer with the cost of survivorship care subsidized through bulk billing. This substantially addresses financial barriers to accessing evidence-based survivorship care interventions and facilitates timely access to treatment through the public sector for men without private health insurance.

A participatory research approach was applied to address the research objectives. Central to participatory research is the emphasis on direct engagement of researchers with stakeholders who represent local priorities, interests and perspectives, and are the end-users in the research process [13,14]. In adopting a participatory research approach, these partnerships facilitate research that is relevant to real-world contexts and can be more effectively translated into the target setting [10]. Additionally, the complement of researchers' methodological expertise and stakeholders lived expertise and experience strengthens research quality and rigor to produce research outcomes that go beyond knowledge generation, and ensure research is relevant and translational [10]. A distinguishing feature of participatory research is a collaborative inquiry process, underpinned by shared decision making, between researchers and stakeholders, where stakeholders have active roles in all stages of the research process [15]. Through this partnership, researchers and stakeholders work collaboratively to make choices that best meet the needs of the research itself, and those involved in the research. This includes the degree of participation by stakeholders at each step of the research process and consensus on more researcher-driven strategies at others [15].

Accordingly, a participatory research partnership was formed between the clinical/organizational stakeholders of the APC and the CRE-PCS research team, which prioritized shared decision making and co-leadership. APC stakeholders had active roles in all stages of the research process including: study scoping and planning; selection of study design, research tools and methodology; data analysis; study reporting and dissemination strategies.

All elements of this research were performed in line with the principles of the Declaration of Helsinki [16]. The study received ethical approval from the University of Technology Sydney (UTS) Human Research Ethics Committee (HREC): ETH20-4941 and ETH21-6216. Informed consent was obtained from all individual participants included in the study.

Research design

The research was conducted in five key phases: (i) establishment of a co-led working group; (ii) data collection; (iii) data analysis and framework mapping; (iv) consensus on findings/priorities for change and (v) dissemination of findings. Details of each phase are described below.

Establishment of a co-led working group

A Working Group comprising APC stakeholders: clinical (nursing [$n = 1$], medical [$n = 2$], allied health [$n = 1$]); organizational (executive [$n = 2$]) and consumer [$n = 1$]; and members of the CRE-PCS research team ($n = 4$) was established to determine study scope, objectives and logistics, select/develop research tools, and guide all elements of implementation. The working group met on a bi-monthly basis with ad-hoc meetings scheduled when required (e.g. time-sensitive study activities such as ethical approval).

Data collection

Data collection comprised three key elements related to prostate cancer survivorship care at the APC: patterns of patient care, patient experience and stakeholder perspectives of care provision.

Patterns of patient care. A tailored set of variables was developed to identify all patients attending the APC for prostate cancer related care between October 1, 2018 and September 30, 2020 (inclusive) through the APC patient management system. This timeframe was pragmatically selected to reflect routine care prior to the impact of the COVID-19 pandemic. Variables included basic patient demographics (age, postcode of residence), referral characteristics (into service) and service use each visit.

Patient experience. A co-designed patient survey captured in-depth patient demographics, patient service experience, patient health status and perceptions of survivorship care (refer Supplementary Material 1 for survey). The survey incorporated a number of validated tools exploring: health literacy and self-efficacy in the understanding, access and use of health information and health services [17]; prostate cancer specific quality of life and symptom burden [18]; prostate cancer related distress [19]; depression and anxiety [20,21] and leisure-time physical activity levels [22]. All patients identified attending the APC for prostate cancer related care between October 1, 2018 and September 30, 2020 were then invited to take part in anonymous online survey via email. The survey was administered by the CRE-PCS between September 8 and Oct 7, 2021 (inclusive).

Stakeholder perspectives of care provision. All APC stakeholders (clinical and non-clinical) were invited to take part in a semi-structured interview undertaken by a member of the CRE-PCS research team. Interviews explored experiences of providing/facilitating prostate cancer survivorship care at the APC (refer Supplementary Material 2 for interview question route).

Data analysis and framework mapping

All preliminary data analysis was undertaken by the CRE-PCS as mutually agreed during the planning phase. Quantitative data (patient management system; patient survey) were analyzed using descriptive statistics. Qualitative data were analyzed using thematic content analysis (patient survey) and hybrid inductive and deductive thematic analysis (semi-structured interviews) [23]. Inductive coding was guided by the semi-structured interview questions and collated data were then examined for potential themes both within the research questions and as a whole. To ensure rigor, the preliminary constructs and themes were identified independently by the CRE-PCS team and refined through collaborative analysis between the APC and CRE-PCS.

Data integration was then undertaken to connect the data from all three sources above. Inferences generated during data integration were deductively coded to align with the six domains of the *Essentials* Framework, guided by the domain definitions and elements, and priority actions described in the *Essentials* Guidelines [2]. Within each domain, themes and sub-themes were then broadly categorized into APC strengths and areas for improvement. Initial data integration was undertaken by the CRE-PCS team and results/findings was presented to the Working Group at each step for review and consensus.

Consensus on findings/priorities for change

Following data integration, a draft report comprising study background, methods, findings and recommendations was circulated to the APC Working Group for review. Draft recommendations were aligned with each domain of the *Essentials* Framework and categorized by theme. A final meeting, open to all APC clinical/organizational stakeholders, was held to reach consensus on findings, finalize the research report and identify priorities for change.

Dissemination of findings

A three-year dissemination plan was co-developed to identify avenues to disseminate findings and included: internal reports, consumer feedback, peer-reviewed publications and presentations (peer-reviewed conference presentations and others).

Results

Participants

Patterns of care data from 326 patients representing 4232 occasions of prostate cancer related service were extracted from the patient management

system. These data captured all patients attending the APC for prostate cancer related care between October 1, 2018 and September 30, 2020. Of these patients, 61 then took part in the online patient survey (18.7% response rate). Survey respondents had a mean age of 71.8 years (± 8.0), with the majority being Australian born (67%, $n = 40$), partnered (77%, $n = 47$) and retired from the workforce (69%, $n = 42$). Just over half (51%, $n = 31$) had been diagnosed within the last five years, and 36% ($n = 22$) were currently receiving treatment, predominantly androgen deprivation therapy (39%, $n = 24$).

APC stakeholders ($n = 14$) comprised allied health (36%, $n = 5$ [psychology $n = 2$, exercise physiology $n = 2$, physiotherapy $n = 1$]), medical (21%, $n = 3$) and nursing (14%, $n = 2$) clinical staff, and non-clinical management/executive staff (29%, $n = 4$). Clinical stakeholders had spent an average of 11.5 years (± 12.2) in their current discipline and had worked at the service for an average of 4.5 years (± 5.0).

Framework mapping

The mapping exercise identified a strong alignment with the existing APC model of survivorship care and the *Essentials* Framework (Table 1). Alignment with the *Essentials* Framework was facilitated by: the co-location of 13 survivorship care services encompassing medical, nursing and allied health services within one center; a holistic, multidisciplinary approach to patient-centered prostate cancer survivorship care which was highly valued by patients; a subsidized fee and billing model to facilitate access to evidence-based interventions and survivorship care for all men and their families; and a dedicated focus on continuity of care and clinical surveillance across the prostate cancer survivorship trajectory of care.

The strongest alignment of the APC model of survivorship care with the *Essentials* Framework was seen in the domains of Evidence-based Survivorship Interventions and Shared Management. This was largely facilitated by the co-located multidisciplinary approach to service provision, and a robust and responsive internal referral system which seeks to connect patients to relevant clinicians/interventions at the time the patient first enters the service.

Actions to facilitate the translation of the *Essentials* Framework into clinical practice

Translational priorities (Table 1) included: the development of a tailored survivorship care plan integrated into the patient management system to support men in identifying their care needs and accessing relevant services (Personal Agency, Care Co-ordination, Vigilance); embedding routine

Table 1. Exemplar of mapping outcomes and translational priorities: APC model of survivorship care and the essentials framework [2].

Essentials Framework Domain and Elements (numbered) [2]	APC Model of Survivorship Care: Alignment with Essentials Framework
<p>Personal Agency: Where patients are self-aware in assessing their needs, seeking assistance when required, and building resilience to manage their own health where possible.</p> <ol style="list-style-type: none"> 1. Self-management 2. Empowerment 3. Family support for the patient 	<p>The APC model of survivorship care is structured and resourced to support men in fostering personal agency through the provision of co-located holistic, multi-disciplinary supportive care. Clinicians undertake routine needs assessment, and cultivate an environment that encourages men to engage with the services they need when they are ready. For men, regular engagement with APC services was a conduit to building personal agency.</p> <p>Translation priorities:</p> <ul style="list-style-type: none"> • A tailored survivorship care plan to support men in identifying their care needs and accessing relevant services was supported by men and clinicians. • Exploration of personal agency support needs for the culturally and linguistically diverse (CALD) prostate cancer patient cohort.
<p>Evidence-based Survivorship Interventions: For accessible psychosocial and psychosexual care, exercise and physical activity, nutrition, peer support, financial assistance, and specialist nursing interventions.</p> <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><i>Accessibility</i> Accessibility to evidence-based survivorship interventions is facilitated by the co-location of 13 multi-disciplinary services offered to patients in one center, including: prostate cancer specialist nursing and nurse-led clinics (sexual function, prehabilitation, hormone therapy), prostate cancer specialist medical services (general practitioner, endocrinology, urology), cancer services (medical and radiation oncology), and allied health (exercise physiology, pelvic floor physiotherapy, psychology). Patients routinely access more than one service per visit and engage with more than three services on average over their period of attendance at the APC. The APC fee and billing model addresses financial barriers to accessing evidence-based survivorship care interventions and also facilitates timely access to treatment through the public sector for men without private health insurance. <i>Prostate focussed care</i> Patients value the prostate cancer focussed care they receive at the APC which is often not provided by other members of their health care team.</p>
<p>Health Promotion and Advocacy: Through the provision of up-to-date information to increase the community's knowledge of men's health and prostate cancer and support awareness and advocacy.</p> <ol style="list-style-type: none"> 1. Health promotion 2. Up-to-date information 3. Advocacy 4. Access to care 	<p><i>Quality of information</i></p> <p>A recurring strength of the APC noted by patients was the quality of information provided to them both in terms of written resources and advice given.</p> <p><i>Normalizing psychological care</i></p> <p>APC stakeholders noted the importance of promoting and normalizing psychological support within the center, and the psychology service available.</p> <p><i>Peer support</i></p> <p>Patients repeatedly noted they valued the opportunity to have contact with other men who have prostate cancer at the APC.</p> <p><i>Prostate cancer survivorship research</i></p> <p>Embedding research into clinical practice facilitates Health Promotion and Advocacy in prostate cancer survivorship by establishing an evidence base for prostate cancer survivorship interventions and directing attention to the support needs of survivors and their families.</p> <p>Translation priorities:</p> <ul style="list-style-type: none"> • CALD patient reach and engagement was identified as a priority area, given the diversity of prostate cancer patients attending the APC. This extended to service engagement and experience, patient information needs, and exploration of resource support needs for the CALD diverse prostate cancer patient cohort. • Ongoing investment in research infrastructure including integration of patient reported outcome and experience measures into patient management system, and growing research partnerships.
<p>Shared Management: Between patients and health professionals to improve outcomes and ensure quality survivorship care with shared and informed decision making about all aspects of care.</p>	<p>The APC is ideally placed to foster Shared Management through the current model of survivorship care. A multi-disciplinary prostate cancer survivorship care team, in one location, ensures patients have ready access to a variety of services to inform their decision making. Having a large number of survivorship services co-located at the APC enables a very responsive internal referral system, which supports patients to engage in informed decision making around care. APC stakeholders consistently spoke of actively engaging their patients in decision making across the survivorship continuum. For patients, all the above factors translate to a supportive environment that facilitates informed decision making for patients and their families and improves outcomes. APC stakeholders also confirmed the messaging around prostate cancer is consistent across the center, irrespective of discipline, which is central to the domain of Shared Management.</p>

(Continued)

Table 1. Continued.

Essentials Framework Domain and Elements (numbered) [2]	APC Model of Survivorship Care: Alignment with Essentials Framework
<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>For many patients the APC bridges the gaps in care men face when their healthcare team is dispersed or survivorship care services are erratic. Prioritizing continuity of care both ensures men are receiving the survivorship care they need and facilitates clinical surveillance across the survivorship continuum.</p> <p>Translation priorities:</p> <ul style="list-style-type: none"> • Consideration of centralized tools to support clinical surveillance, such as a follow-up reminder system. • A long-term care summary for each patient, which can be read at-a-glance, to streamline consultations and provide a ready summary of the patient’s survivorship journey in the short and long-term for the clinician. Given survivorship care at the APC is routinely shared with other centers and hospitals, the summary would also reduce clinician time spent following-up results and repetition of seeking/confirming results with the patient. • The addition of a centralized “vulnerable patient” or “distress” flag in the patient management system which both alerts clinicians to vulnerable patients and provides some context. • Embedding routine distress screening and documentation into survivorship care across disciplines.
<p>Vigilance: Across the survivorship continuum from diagnosis to end-of-life care with attentive surveillance of physical and psychosocial effects, comorbidities, recurrence and second cancers. This includes psychosocial effects on partners and family members.</p> <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>For many patients the APC bridges the gaps in care men face when their healthcare team is dispersed or survivorship care services are erratic. Prioritizing continuity of care both ensures men are receiving the survivorship care they need and facilitates clinical surveillance across the survivorship continuum.</p> <p>Translation priorities:</p> <ul style="list-style-type: none"> • Consideration of centralized tools to support clinical surveillance, such as a follow-up reminder system. • A long-term care summary for each patient, which can be read at-a-glance, to streamline consultations and provide a ready summary of the patient’s survivorship journey in the short and long-term for the clinician. Given survivorship care at the APC is routinely shared with other centers and hospitals, the summary would also reduce clinician time spent following-up results and repetition of seeking/confirming results with the patient. • The addition of a centralized “vulnerable patient” or “distress” flag in the patient management system which both alerts clinicians to vulnerable patients and provides some context. • Embedding routine distress screening and documentation into survivorship care across disciplines.
<p>Care Coordination: Where patients and families arrive at the right place at the right time for the right care once a diagnosis has been made. Men-centered care is central.</p> <ol style="list-style-type: none"> 1. Care coordination 2. Multidisciplinary teams 3. Person-centered care 	<p>The current APC model of care provides holistic, multi-disciplinary prostate cancer care in one location, with a focus on continuity of care and surveillance. Patients and families are supported from the point of diagnosis and can readily access multiple survivorship support services which are co-located. All of the factors are critical for the delivery of coordinated survivorship care. A distinct advantage of having a range of disciplines co-located in the provision of survivorship care is the ease of internal referrals. When a clinician identifies a survivorship care need outside of their discipline, the patient can be easily, and often immediately, referred. This benefits the patient who can readily access a number of clinicians from different disciplines to inform their decision making. Wherever possible, patient appointments are clustered to reduce the number of individual trips needed to access care, and reduce overall waiting time between appointments. The APC supports further patients in care co-ordination by advising them of their treatment options, referral status and rebate eligibility.</p> <p>Translation priorities:</p> <ul style="list-style-type: none"> • While the access to coordinated care at the APC is a key strength, APC stakeholders noted that establishing a smooth flow of care can be challenging given the range of services available to, and accessed by, patients. An additional factor impacting care coordination at the APC is that patients’ survivorship may be managed at multiple centers, which can feel fragmented and cause confusion for the patient. Given the complexity of prostate cancer survivorship care, APC stakeholders suggested strengthening care coordination processes would benefit patients and improve the flow of care. • Under the current model of care, doctors at the APC refer patients into survivorship services but there is no formal survivorship pathway connecting services. APC stakeholders felt a dedicated prostate cancer survivorship pathway would streamline referral to required services while still giving the patient the option to opt in or out of accessing the services. • A survivorship pathway was also seen as a way to “orientate” patients to the services available to them, particularly in the future when their survivorship care needs start to change. • Both APC stakeholders and patients noted that access to services for rural and remote patients is limited and can place a substantial travel and cost burden on the patient. Using a survivorship pathway to guide and schedule care was identified as one strategy to support accessibility and coordinated care for rural and remote patients. APC stakeholders acknowledged that considerations for expanding the reach of the APC to meet the needs of rural and remote patients are complex and require strategic planning.

distress screening into survivorship care across disciplines (Vigilance); development of dedicated prostate cancer survivorship pathways for each treatment type to streamline referral to required services and help “orientate” patients to the services available to them, particularly in the future when their survivorship care needs start to change (Care Co-ordination); further expanding reach and engagement with culturally and linguistically diverse populations particularly in relation to personal agency support and resource needs (Health Promotion and Advocacy); and ongoing investment in research infrastructure including integration of patient reported outcome and experience measures into the patient management system (Health Promotion and Advocacy).

A consensus on report findings and priorities to support the translation of the *Essentials* Framework into clinical practice was reached in the final study meeting by APC stakeholders. As a next step, the APC elected to commence a process mapping and implementation study to develop structured survivorship care pathways for each treatment stream across all disciplines. This included the integration of a tailored survivorship care plan and routine distress screening for all patients. This study was nearing completion in early 2023 and findings will be reported separately.

Development of mapping “template”

The five study phases (Figure 2) formed the basis of a mapping template which is currently being piloted in other services and will guide future service re-evaluation against the *Essentials* Framework within the APC.

Discussion

For many men with prostate cancer the survivorship experience is suboptimal. The prolonged prostate cancer disease course and treatment characteristics see many men experiencing both short and long-term decrements in their quality of life [24,25]. Men with prostate cancer report substantial physical and psychosocial burdens, decisional uncertainty, loss of masculinity, poor access to supportive services and uncoordinated care [3]. Hence the need for responsive and coordinated care models to support short and long-term survivorship care for men with prostate cancer is crucial.

The *Essentials* Framework was designed to provide a strongly consumer-informed model of coordinated prostate cancer survivorship care underpinned by an evidence base of interventions where gains in quality of life and survivorship outcomes might be made [2,26]. The framework represents a set of prostate cancer survivorship domains of quality of life that articulate and intersect with each other, extending beyond traditional healthcare parameters, and reflecting both the patient experience and the multi-

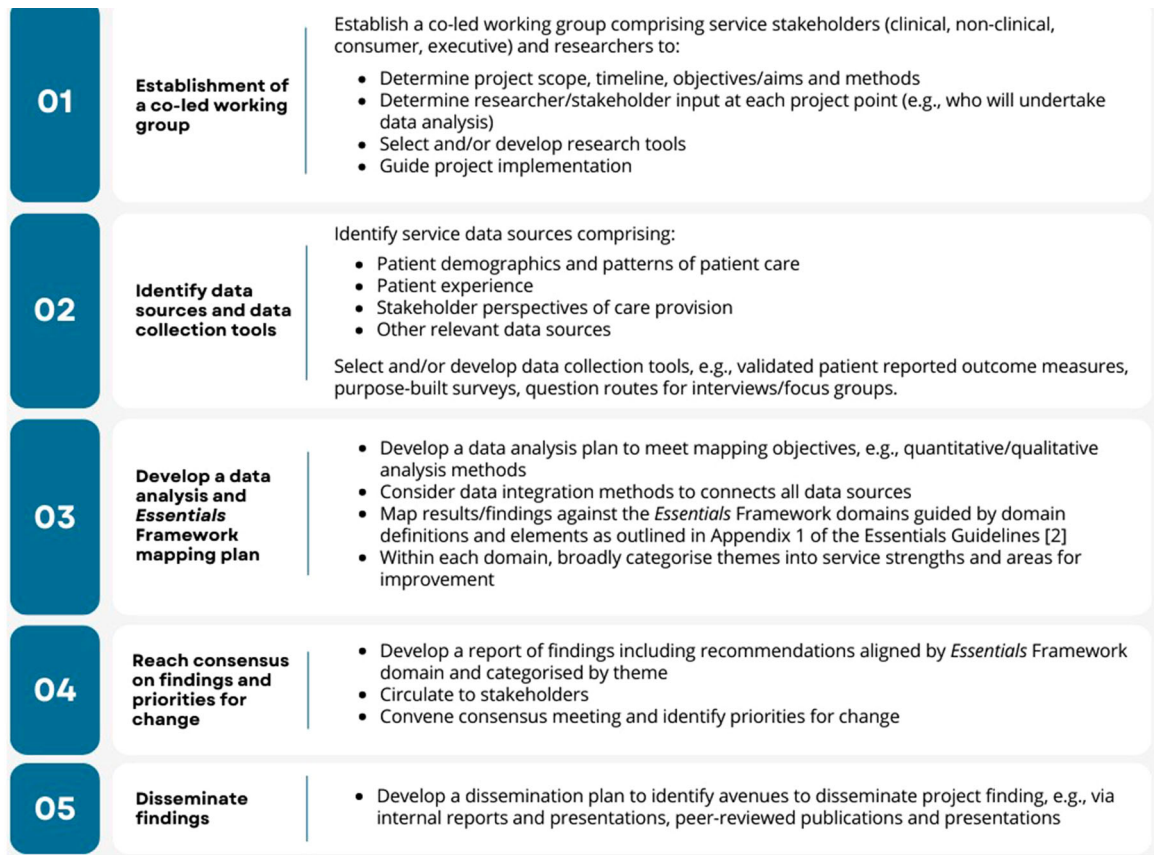


Figure 2. Participatory research phases and mapping template.

disciplinary partnerships needed to provide responsive, well-coordinated prostate cancer survivorship care [26]. In this framework, the prostate cancer survivor is at the center of their survivorship care mirroring the lived experience of a cancer diagnosis and the dynamic survivorship care trajectory that follows, irrespective of cancer stage or phase of survivorship [27]. The framework provides guidance and a road map for improving prostate cancer survivorship care in a multitude of program initiatives to suit differing patient scenarios and service settings. Given the diversity of health-care systems and prostate cancer survivorship support services, a flexible approach to the application of the framework is essential [26].

This participatory research process delivered multiple outputs including: co-designed research tools (tailored patient management system data extraction plan, patient survey, stakeholder interview question route); service data sets; patient survey data; APC stakeholder qualitative data set; a research report [24] and three-year study findings dissemination plan. At October 2023, findings have been disseminated via internal presentations to APC stakeholders and at local [APCC, ANZUP, ANZUNS] and international conferences [25,26]. This research has established that the *Essentials* Framework clearly lends itself to application and translation into clinical practice. Underpinned by the domain definitions, elements and priority actions outlined in the *Essentials* Guidelines [2] this systematic “mapping” process against the framework has proven an effective strategy to identify both the alignment of service delivery with the six essential domains of prostate cancer survivorship care, and determine key translational priorities for change.

Despite the globally growing prevalence of prostate cancer there remain substantial gaps in survivorship care, including a lack of uptake and implementation of best practice survivorship interventions and models of care [24,28]. For services seeking to deliver quality prostate cancer survivorship care that connects current evidence, expert opinion and consumer perspectives, the *Essentials* Guidelines [2] offer a practical starting point. Coupled with the mapping template and exemplars of mapping outcomes and translational priorities from this study, we encourage services to assess their prostate cancer survivorship care models, and identify and implement priorities for change.

In order to foster change in prostate cancer survivorship care and outcomes, partnerships across disciplines which progress the development and delivery of quality prostate cancer survivorship care, are needed [2]. A participatory research approach is just one example of such a partnership whereby the collaborative integration of real-world clinical stakeholder experience and researchers’ methodological expertise yields meaningful knowledge production and translation of findings to action. Only through the application of multiple coordinated strategies undertaken in partnership

can the survivorship care needs of prostate cancer populations be adequately addressed [26].

Study limitations

This study was undertaken at a single service with an already established multi-disciplinary model of prostate cancer survivorship care, which may differ from other settings and limit generalizability. However, reporting of the process and method may help support services involved in the provision of prostate cancer survivorship care and integrate the principles of the *Essentials* Framework into service delivery to advance well-coordinated and responsive prostate cancer survivorship care, irrespective of care model.

Conclusions

This participatory research study provides a structured example of the processes needed to assess and map an existing model of multidisciplinary survivorship care against the *Essentials* Framework. By adopting a participatory research approach, and prioritizing clinical stakeholder experience, this study also demonstrates evidence of the ecological validity of the *Essentials* Framework, namely, generalizability to real-world settings and the potential for more timely and effective translation of the framework into clinical practice [29,30]. With this process analysis we hope to provide a starting point for services and community groups who wish to incorporate the principles of the *Essentials* Framework into their settings through explicit description of the participatory research methods, tools, and processes used in this study, and practical examples of how the framework can be operationalized to guide the provision of integrated quality prostate cancer survivorship care.

Disclosure statement

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