

Research Article

Reporting Real-World Data on Prostate Cancer Treatment Outcomes to Consumers: The Prostate Cancer Report Card

Tenaw Tiruye ^{1,2} Kerry Ettridge ^{3,4} Michael O'Callaghan ^{5,6,7,8} Kim Moretti,^{1,5,9}
Alex Jay,¹⁰ Braden Higgs,^{1,11} Kerry Santoro,⁸ Ganessan Kichenadasse,^{6,10} David Roder ¹
and Kerri Beckmann ¹

¹Cancer Epidemiology and Population Health Research Group, Allied Health and Human Performance, University of South Australia, Adelaide, Australia

²Public Health Department, Debre Markos University, Debre Markos, Ethiopia

³Health Policy Centre, South Australian Health and Medical Research Institute, Adelaide, Australia

⁴School of Public Health, University of Adelaide, Adelaide, Australia

⁵South Australian Prostate Cancer Clinical Outcomes Collaborative, Adelaide, Australia

⁶Flinders Health and Medical Research Institute, Flinders University, Adelaide, Australia

⁷Discipline of Medicine, University of Adelaide, Adelaide, Australia

⁸Urology Unit, Southern Adelaide Local Health Network, Adelaide, Australia

⁹Discipline of Surgery, University of Adelaide, Adelaide, Australia

¹⁰Flinders Medical Centre, Bedford Park, Australia

¹¹Department of Radiation Oncology, Royal Adelaide Hospital, Adelaide, Australia

Correspondence should be addressed to Tenaw Tiruye; tenaw.tiruye@unisa.edu.au

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Aim. To describe the process of developing a resource, the “Prostate Cancer Outcomes Report Card,” that provides information for men with prostate cancer and their family members about the outcomes of different treatment approaches. **Methods.** The project consisted of two phases. The first phase involved analysis of real-world data and translating outcomes into a format that consumers found easy to understand and interpret. The Report Card was developed in consultation with a consumer advisory group ($n = 8$). The second phase involved refinements of the resource through exploratory qualitative interviews with consumers ($n = 14$), an online survey among the general public ($n = 134$), and clinician feedback ($n = 8$). **Results.** Consumer engagement to explore preferences about the content and visual presentation from the end-users’ perspective was crucial in designing this report. Consumers required trustworthy, comprehensive, simple, and up-to-date information collated in one place to help them understand the risks and benefits of their treatments. Presenting survival, cancer recurrence, and functional outcomes by treatment type and risk category was highly commended while data on high survival rates were considered reassuring. We identified high levels of unmet psychosocial and supportive care need, with differences in individual preferences around extent of information required. **Conclusions.** Communicating registry data about real-world outcomes in a consumer-friendly way may help fill a gap in information needs among prostate cancer survivors. Providing relatively simple and easily understandable evidence in a single consumer-oriented report may help prostate cancer survivors become better informed and facilitate patient-provider communication and shared decision making.

1. Introduction

Men newly diagnosed with nonmetastatic prostate cancer have a number of treatment options available to them with patient preference being a strong determinant of the final treatment decision. To aid in decision making, patients require information on the risks and benefits of each modality, including the potential impact of treatments on quality of life outcomes including sexual, urinary, and bowel function [1]. There is evidence that men diagnosed with prostate cancer have unmet information needs [2, 3]. A prospective clinical registry that captures data from a local population can provide tangible information about locally available treatments and real-world outcomes to men and their families who reside in the same catchment.

Traditional academic reporting and data presentation often comprise subject-specific terminologies and jargon which are difficult to understand by “lay audience” and are exclusionary to end-users [4]. This has led to increasing interest in engagement of consumer-friendly reporting in the health and medical research domains [5]. An important consideration in developing resources for consumers is the inclusion of consumer perspectives in the process to help identify the needs and concerns of the target group [6]. The traditional approach where consumers have only passive roles (e.g., may be asked to review a resource/tool at its final stage of implementation) causes imbalance between the resource that is developed and the resource that consumers wanted to be [7]. Consumers need to be involved in defining what outputs they would like to see and to make sure the information resources reflect this and are meaningful to them [6].

Consumers have varying levels of health literacy, and hence alternative methods of presenting outcomes are required taking this into account [4]. Concepts should be communicated in concise, factual, and easy to understand formats like infographics or pictorial representations of data [5].

The aim of this paper is to describe the methodological approaches and processes in the development of a consumer-friendly resource—entitled “Prostate Cancer Outcomes Report Card”—which summarises clinical and functional outcomes following various prostate cancer treatments so that consumers can have insight into real-life data and have realistic expectations about treatment outcomes. Our resource based on a registry data was designed to complement existing consumer-focused resources from the broader evidence-based literature, which are compiled and provided by various organisations such as the Prostate Cancer Foundation of Australia and Cancer Council Australia. A consumer engagement framework [7] was adopted to guide the development of the Report Card following the principals outlined in the Australian guidelines for integrating consumer engagement in health and medical research. Accordingly, consumers were engaged from conceptualization to final product; views from the researchers, consumers, the general public, and clinicians were incorporated to improve the document; the views of all stakeholders were equally valued; two-way communication

mediums were implemented; consumer advisors were informed about how their views were incorporated in the Report Card; and summary reports of each meeting were sent to the consumer advisors within three working days.

2. Methods

A multimethod approach was employed to design the Report Card resource for consumers, which included a development phase and a piloting (evaluation) phase, as summarised in Figure 1. The overall project took 19 months from start to completion (August 2021 to February 2023). Ethical approval for the development and piloting of the Report Card was provided by University of South Australia (UniSA) Human Research Ethics Committee (HREC) (protocol: 204570) and Southern Adelaide Clinical HREC (LNR/22/SAC/102).

2.1. Phase I: Resource Development. A multidisciplinary team of researchers including epidemiologists, clinicians (urologists, radiation oncologist, medical oncologist, and prostate cancer specialist nurse), data scientists, a behavioural scientist, and a consumer advisor (previously been treated for prostate cancer) was established.

Outcomes for inclusion in the Report Card were derived from analysis of data collected by the South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC) which manages a long standing prospective clinical prostate cancer registry covering the state of South Australia, Australia. Over 8500 men diagnosed with prostate cancer between 2008 and 2018 who were enrolled in the registry were included (approximately 60% of total prostate cancer population in the state during this period). The main outcomes investigated were survival and death probabilities, cancer recurrence after curative treatments, and the impact of treatments on physical function including urinary, sexual, bowel, and hormonal function. Analyses were undertaken by treatment type and National Comprehensive Cancer Network (NCCN) risk level (low, intermediate, and high risk) [8]. High dose rate brachytherapy and chemotherapy were not included in this Report Card due to the small number of men in SA-PCCOC registry having these treatments. Details of the statistical analyses are described in a separate paper [9].

To guide the overall design process for the Report Card, a consumer advisory group was established through a call for expressions of interest from men who had prostate cancer and any interested family members, circulated via local health, prostate cancer research, and registry networks via e-mail invitations. The advisory group ($n = 8$) comprised of six men who had undergone surgery for prostate cancer and two partners. The meetings were held via video conference, with consumer advisors being reimbursed for their time. Initial meetings covered the general concept of the Report Card, relevance of content, and methods of data presentation which were best understood. Feedback on concept designs for the Report Card was sought in subsequent meetings. After each meeting, a summary report of key points raised

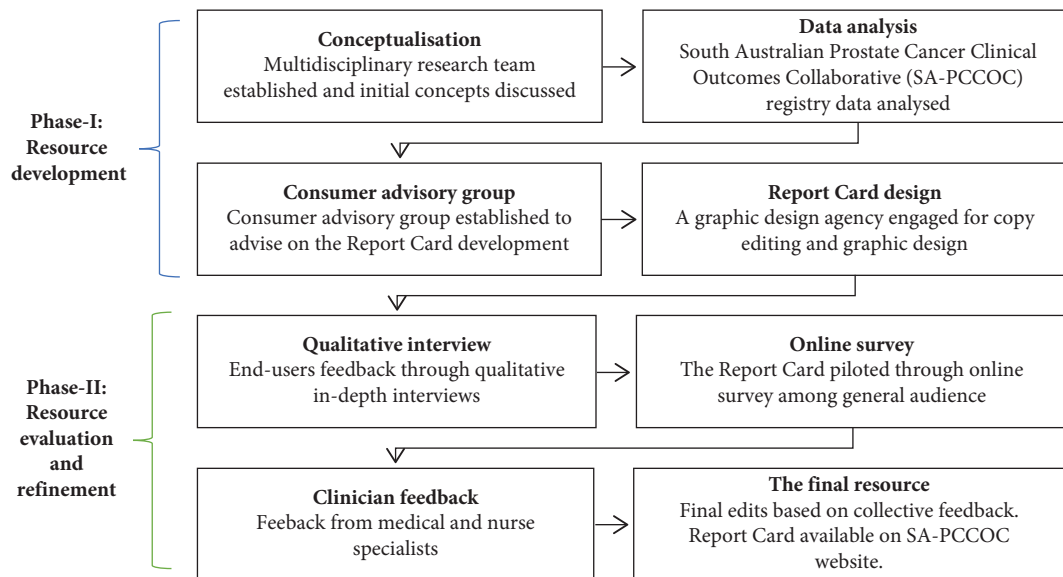


FIGURE 1: Project flow diagram.

and main conclusions was provided to consumer advisory group members to validate our interpretation of the discussions.

The presentation of the data in the Report Card was developed in collaboration with a graphic design company (Fuller Brand Communications) and involved an iterative process of feedback to determine the basic design and content and ensure clear and simple language was used, along with appropriate presentation of information (graphs, figures, etc.). Further feedback was obtained from the consumer advisors on this initial design. The draft Report Card, along with guiding questions, was e-mailed to advisory group members seeking feedback on their overall impression; what to improve (to add/remove/change); the overall presentation (graphs/colours/texts); understandability (simplicity/clarity/technicality); and any areas of concern. Four consumer advisors provided written feedback, with further follow-up by group discussion. A summary of this feedback informed an initial round of modifications undertaken by the graphic design company.

2.2. Phase II: Resource Evaluation and Refinement. Extensive evaluation and refinement of the draft resource were undertaken through qualitative interviews with consumers, an online survey, and gathering clinician feedback.

2.2.1. Qualitative Interviews. In-depth semi-structured qualitative interviews were undertaken to evaluate the first draft of the Report Card with respect to its content, visual appeal, comprehensibility, and relevance of the information provided. Postal invitations were sent to recruit men affected by prostate cancer. A total of 50 invitations were sent in two batches from local health network and the SA-PCCOC registry with a target to recruit 8–12 men. Men who participated in other research in the last 12 months were excluded to reduce research burden. Of the 20 men

who consented to be interviewed, 14 who were contactable and available within the time period allocated were interviewed.

The draft Report Card was e-mailed to participants for review prior to being interviewed. Interviews were conducted over the telephone (11 men) or by video conference (three men) and were audio-recorded with participant's consent to enable transcription for analysis. The interviewer used a semi-structured interview guide (Supplementary File 1) to prompt discussion about aspects of the draft Report Card with prompts regarding understanding of content (readability), perceptions of visual presentation, and relevance of content. The average length of interviews was 42 minutes (range: 26–65 minutes).

Our analyses involved a descriptive summary of the participant's transcripts. While qualitative descriptive research is a less theoretical, less interpretive approach compared to other qualitative designs that do not require a conceptual application of the data, it is appropriate in the context of gaining feedback on consumer resources [10, 11]. This involved one researcher reading and coding texts using both deductive and inductive coding such that the interview guide prompts provided a simple coding framework; however, the data also guided formation of codes. Two researchers then identified commonalities across the codes and developed themes. A set of recommendations were formed to refine the tool based on the qualitative feedback and provided to the graphic design company to produce a modified Report Card.

2.2.2. Online Survey. Piloting of the Report Card (modified with feedback from the qualitative interviews) was conducted with a broader cross section of the general public via an anonymous voluntary online survey. Any adult (≥ 18 years of age) living in South Australia who had an interest in prostate cancer was eligible to participate; however, the

invitation was targeted toward men who had been diagnosed with prostate cancer, partners, families and friends, and men at risk of developing the disease, based on age target of over 50 years. The purpose of this pilot was to assess whether the draft Report Card was appropriate for consumers and to identify content gaps, misunderstandings, or unanticipated issues.

The online survey questions (Supplementary File 2) were developed by the investigators to fit the project aim and programmed using Qualtrics software (Qualtrics, Provo, UT, USA). The survey contained a link to the draft Report Card so that respondents could download and review it before or while completing the survey. By completing the survey, participants were considered to have consented. The survey contained questions about the characteristics of participants; questions asking participants to rate their level of agreement with statements about the Report Card relating to appropriateness of *content* (six questions), *readability* (six questions), *visual presentation* (five questions), and *relevance* (four questions) (with five responses from strongly disagree to strongly agree); and open-ended questions to provide further qualitative feedback about specific aspects of the design and content.

Recruitment strategies included e-mailed invitations, notification on the UniSA research volunteer website, and Facebook advertisements targeting the broader public aged over 50 years. E-mail invitations were sent by SA-PCCOC data managers to 400 men who were alive and not previously sent a survey in another study with a proportionate number of men across each treatment group randomly selected. The Facebook advertisement was scheduled over two rounds: the first round from 12–21 December 2022, with a target to reach 21000 individuals, and the second round from 3–17 January 2023, with a target to reach 18572 individuals. The average time taken to complete the online survey was 27 minutes (range: 4–53 minutes).

Descriptive statistics (numbers with percentages) were used to describe participant characteristics and to quantify the ratings of the Report Card. The 5-point scale questions were grouped into three categories for reporting: “disagree” (“strongly disagree” and “disagree”), “neutral,” and “agree” (“strongly agree” and “agree”). The process of identifying the common themes from open-ended questions was conducted using Text iQ™ tool built in Qualtrics. Text iQ is a tool which helps to code personal opinions using natural language processing technologies. It provides a sentiment analysis where feedback received in a survey is assigned with very negative, negative, neutral, positive, very positive, or mixed sentiments based on the language in the response and the question text [12]. The very negative and very positive sentiment labels were implemented to indicate the strongest sentiment that helps to focus on the most critical feedback. Text iQ has been used to analyse qualitative health data in previous studies [13–17]. Special focus was given to qualitative comments relating to questions that received lower mean Likert scale scores, with the overall aim of these analyses being to identify any challenges consumers faced when reading through the Report Card. Participants’ feedback was used to inform further modifications to the Report Card.

2.2.3. Clinician Feedback. Feedback was sought from South Australian-based clinicians involved in prostate cancer care simultaneously to the online survey. Physicians active on SA-PCCOC committees (some of whom were aware of the project) were asked to share their views about the Report Card. Prostate cancer nurses were invited through e-mail sent by the nurse who was part of the research team. Healthcare professionals received the draft Report Card by e-mail and were asked to send back their written feedback via e-mail giving consideration to the content, readability, visual presentation, and relevance of the Report Card, as well as any areas that may raise concern or be difficult for consumers to understand. Feedback was received from eight of the 14 invited healthcare professionals, with responses from one urologist, one radiation oncologist, one medical oncologist, and five prostate cancer nurse specialists.

3. Results

3.1. Phase I: Resource Development

3.1.1. Consumer Responses. During initial meetings, members of the consumer advisory group raised several important points that reinforced the need for a resource such as the Report Card: the need for accessible and credible information to help guide treatment decisions; the need for information and support as part of posttreatment care; confusion about evidence around prostate cancer screening, diagnosis, and recommended treatments as demonstrated by inconsistencies in information provided by different health practitioners; and inadequate access to information for carers, family members, and men living in rural areas. Consumer advisory group members also commended prostate cancer specialist nurses for sharing timely and relevant information, providing professional one-on-one support, and having good interpersonal skills. Nurse practitioners were viewed as an important channel to access information on prostate cancer outcomes.

Following a presentation of outcomes from analyses of SA-PCCOC data to consumer advisors, the consensus was that data about survival, functional outcomes, and risk of cancer recurrence should be presented in the Report Card. Advisory group members commented that the risk of “cancer recurrence” as new information and in some cases was a little alarming, nonetheless important to include in the Report Card. Consumer advisors also agreed that presenting outcomes by risk category was important to provide information that was more tailored to each man’s circumstances. In response to being inadequately informed of the impact of treatment on their own quality of life, some consumer advisors felt that being informed of the “*worst case scenario*” may help men prepare for what was to come so the experience would be “*less of a shock*.” In some instances, consumer advisors’ experiences did not match the outcome data being presented in the Report Card. For example, quantitative findings indicated very low levels of post-treatment depression. In response, consumer advisors argued that “depression” was not the right term to use, with one member commenting that, “*I haven’t been depressed but*

it has affected my mental health.” Often members used the term “*feeling down*” rather than “*being depressed*,” e.g., “*I get very frustrated with it. I feel down all the time since I have the cancer.*” To remedy this mismatch, consumer advisors suggested adding personal quotes to highlight the impact that prostate cancer can have on men’s mental wellbeing. They also recommended including real-life stories and to highlight the variation among men in their survivorship experiences.

The main amendments made after consumer advisory group meetings were as follows:

- (i) Colours, texts, and graphics modified to improve the overall presentation.
- (ii) Contents added, reordered, removed, and/or changed to ensure understandability.
- (iii) Outcomes presented by treatment type and “risk level.”
- (iv) “Risk level” definition table provided at the end of the Report Card.
- (v) Personal quotes and real-life stories included.
- (vi) Other information resources provided.

3.2. Phase II: Resource Evaluation and Refinement. The results from the qualitative interviews, online survey, and clinician feedback are presented below.

3.2.1. Qualitative Interviews. Qualitative feedback regarding the first iteration of the Report Card was obtained from 14 participants who had previously been treated for prostate cancer (mean age: 73 years; mean time since diagnosis: three years). The characteristics of qualitative interview participants are presented in Table 1.

Four themes emerged from these interviews including: *the value of the resource, appropriateness of the data, communicating in lay terms, and additional information needs.* Quotes are presented to demonstrate participants’ discussion relating these themes.

(1) Value of the Resource. The overall feedback on the Report Card was that it was considered useful, informative, up-to-date, and reassuring. Generally, participants indicated that the Report Card was well-structured and easy to navigate. Participants particularly liked the presentation of outcomes according to treatment type and risk level and that each treatment approach was laid out on a single page.

“... the way it is set up is what I like. You can find your own treatment. I went like that is not me, that is not me...and I went to hormone treatment because that is where I fit.” (Participant 13, aged 72, 2 years since diagnosis)

Participants reported that the information provided would encourage men to discuss other potential treatment outcomes further with their healthcare providers.

“Men tend to not take enough time to educate themselves about this condition, simple straightforward info that minimises the embarrassment factor can only help.” (Participant 3, aged 74, 3 years since diagnosis)

“This document is probably the easiest one to read and the easiest one to understand...” (Participant 12, aged 67, 18 months since diagnosis)

However, a few respondents felt that the Report Card did not offer a great deal over what was already available to them.

“I find some of the information a repetition of what is already in the documents the hospital given us. But yes, I found it is quite informative. It gave me an insight to some facts which I wasn’t aware of.” (Participant 10, aged 77, 3 years since diagnosis)

While all participants believed the information in the Report Card would be useful for newly diagnosed men, some men reported it was not as useful to themselves given they were further through their prostate cancer journey.

“It may be very useful for men who just got diagnosed but I couldn’t really connect with it. It is not talking about where I’m now. I have already long way through it.” (Participant 11, aged 68, 4.5 years since diagnosis)

(2) Appropriateness of the Data. In relation to content, most participants indicated that the Report Card was comprehensive, accurate, and factual. Some commented that such a resource would prevent misleading information that arose from “*online searching*.”

“The impacts show exactly how my case was. It probably confirmed my position. I think it is pretty much spot on. I found it quite informative and accurate.” (Participant 1, aged 74, 3 years since diagnosis)

“...it’s a Report Card, not a detailed look at treatment options and what they mean. There’s plenty of other information regarding what radiotherapy actually is, and does, for instance. So I think this is a good springboard for patients, family and friends to find more information if required.” (Participant 6, aged 70, 3.5 years since diagnosis)

While the data presented in relation to cancer recurrence were sometimes considered to be “*concerning*,” the overall reaction to the type of outcome data reported was positive. In particular, the high proportion of men surviving prostate cancer was considered “*reassuring*.”

TABLE 1: Characteristics of qualitative interview participants.

Age (years)	Years since diagnosis	Risk level*	Treatment/s received [‡]
74	Three	High	External beam radiotherapy and hormone
73	Two	Low	Low-dose brachytherapy
74	Three	High	External beam radiotherapy and hormone
68	Four	Advanced	Hormone/degarelix
85	Three	High	External beam radiotherapy and hormone/Eligard
68	Four and half	Low	Low-dose brachytherapy
69	Two	Advanced	Chemotherapy/docetaxel and hormone
71	One and half	Low	Active surveillance and then surgery
78	Two and half	Low	Active surveillance/watchful waiting—not sure
77	Three	High	External beam radiotherapy and hormone
70	Three and half	Low	External beam radiotherapy alone
67	One and half	Low	Low-dose brachytherapy
72	Two	High	Hormone alone
73	Five	Low	Active surveillance

*Self-reported risk levels could be different from clinical reports due to difficulty in understanding risk definition. [‡]Members of the consumer advisory group were predominantly men who had undergone radical prostatectomy, and hence we purposively selected other treatment types for this phase of feedback.

“The information from the Report Card gave me some hope. . . Information about most men died from other causes than prostate cancer is comforting.” (Participant 5, aged 85, 3 years since diagnosis)

“Maybe some more quotes. It is nice to read about other people’s experiences and how they feel and deal with it. Just adds a personal touch to all the stats.” (Participant 3, aged 74, 3 years since diagnosis)

(3) *Communicating in Lay Terms.* With respect to comprehension, most participants indicated that the terminology used was straightforward, nontechnical, and easy to understand, though a few stated that some terms such as “recurrence,” “brachytherapy,” and “watchful waiting” were too clinical. However, this latter opinion was countered by other participants.

“Most of the terms such as recurrence and wellbeing are common terms which are already in the media, they’re quite common. . . I don’t think the terminologies are hard to understand by an average person.” (Participant 8, aged 71, 18 months since diagnosis)

One of the more significant issues identified during interviews was the difficulty participants had in understanding the meaning of *risk level*. Almost all participants liked the presentation of results according to risk level but did not have a good understanding of what was meant by “risk level” in the context of prostate cancer, confusing this term with “risk factors for getting prostate cancer” or the “risk of experiencing the treatment side effects.”

(4) *Additional Information Needs.* Several respondents expressed the need for additional information, much of which was out of the scope of what we could include in a Report Card focusing on treatment outcomes. Common issues which a large number of participants felt should be incorporated into the Report Card included *“the importance of early screening,” “emotional impacts of prostate cancer diagnosis and treatment,”* and *“mental health support services.”* In addition, several suggested adding more about people’s experiences.

Based on feedback from the qualitative interviews, an explanation of “risk level” was provided at the beginning of the Report Card, more quotes and personal experiences were included, information about mental wellbeing was added, and additional support and information sources were provided.

3.2.2. *Online Survey.* Of the total 134 online survey respondents, 87% were men diagnosed with prostate cancer, 8% were partners (females), and 5% were members of the general public. Most were aged 60–79 years (84%) with only 6% being below 60 years. About half (52%) were within three years of diagnosis, while 14% were over 10 years of diagnosis. Among those who had treatment ($n = 116$), 47% reported having had surgery and 30% had radiotherapy.

Table 2 describes a summary of results for each individual quantitative item of the survey. Most items were rated very positively with 80% or more of participants in agreement (Table 2).

Responses to open-ended questions confirmed many of the views expressed in the previous qualitative interview round, with positive responses relating to providing all information in one place; presenting results by each treatment (i.e., every outcome for each treatment on one page) and by risk level (i.e., information stratification by risk); being succinct, easy to understand, and reassuring; and being short, concise, and comprehensive.

“A complicated and far-reaching subject explained with care and simpleness for the patient to understand.” (Male, age group 80+, 2 years since diagnosis)

“I thought the Report Card was very informative and extensively covered the various stages of prostate cancer in its various forms and stages, giving a clearer and simpler

TABLE 2: Summaries of quantitative Likert scale questions from the online survey.

Questions/items	Disagree		Neutral		Agree		Total*
	n	%	n	%	n	%	
<i>Content</i>							
The Report Card addresses topics that readers might want to know about	4	3.0	2	1.5	126	95.5	132
The type of information in the Report Card is appropriate	3	2.3	0	0.0	131	97.7	134
The amount of information is about right	1	0.8	13	9.9	118	89.4	132
The information in the Report Card is not too complex	8	6.0	8	6.0	117	88.0	133
I trust the information in the Report Card	0	0.0	13	9.8	120	90.2	133
There is enough information about where to get further support or information	4	3.1	14	10.5	115	86.5	133
<i>Readability</i>							
Information is presented in common everyday language	4	3.0	4	3.0	125	94.0	133
Medical terms are clearly explained	2	1.6	6	4.5	125	94.0	133
The Report Card is written in a friendly way	2	1.6	11	8.3	119	90.1	132
The Report Card is easy to read	4	3.0	9	6.8	120	90.2	133
It is easy to understand what all the numbers mean	5	3.8	17	12.9	110	83.4	132
Enough explanation of the different outcomes is provided	7	5.3	18	13.5	108	81.2	133
<i>Visual presentation</i>							
The Report Card is organised in a way that was easy to follow	1	0.8	5	3.9	124	95.4	130
The way the information is displayed makes the Report Card easy to understand	2	1.5	11	8.5	117	90.0	130
Visual graphics are easy to understand	2	1.6	12	9.2	117	89.3	131
The Report Card attracted my attention	3	2.3	29	21.8	101	75.9	133
The overall look of the Report Card is appealing	2	1.5	24	18.1	107	80.4	133
<i>Relevance</i>							
The content is relevant for men who have just been diagnosed with prostate cancer	0	0.0	4	3.0	128	97.0	132
The content is relevant for partners, family, and friends of someone with prostate cancer	1	0.8	12	9.1	119	90.2	132
The Report Card is interesting to people not affected by prostate cancer	4	3.0	46	34.9	82	62.1	132
I would send this Report Card to a family member if they needed information about prostate cancer	4	3.0	5	3.8	124	93.3	133

*Total number of respondents (out of 134) who completed the item.

understanding of the various aspects of our journey in dealing with our problem.” (Male, age group 50–59, 3 years since diagnosis)

Some participants indicated that they wished they had the Report Card before their treatment.

“Wish this had been available before my husband had a [treatment type intentional obscured] as he may have made the choice to have a different treatment option.” (Female, age group 70–79)

A common difficulty in understanding the Report Card related to the way data about the impacts on lifestyle and wellbeing is presented, with respondents indicating that it was “confusing,” “too complex to interpret,” and “too hard to understand”.

“The bar graphs weren’t that easy to interpret. . . it took me more than a moment to analyse the increase impacts and wellbeing. . . you need a better way to present the data on the changes that occur post treatment.” (Male, age group 60–69, 2 years since diagnosis)

When asked whether the Report Card outcomes made them feel anxious or concerned, most respondents reported that it had the opposite effect in that it was reassuring and confirming. A few responded that being diagnosed with cancer itself was what causes anxiety.

“Reading the Report Card put my mind at rest about what may happen in the future. . . It was good to turn the negative of having cancer into a positive outcome.” (Male, age group 70–79, 3 years since diagnosis)

“. . . in fact perhaps it has had the opposite effect and provided some reassurance about a continued longer term positive outcome.” (Male, age group 50–59, 5 years since diagnosis)

There was some variation in responses regarding the amount of information provided in the Report Card. Although most believed enough information was provided, others believed more information could be included, while some indicated that the amount and level of information presented were already too complex to fully digest.

“Would like to see more on the mental issues. How men or even women handle the sexual inability issues. How men choose to discuss their cancer with friends or family. E.g., openly, shut down, or keep it a secret.” (Male, age group 70–79, 14 months since diagnosis)

Based on this feedback, the main changes to the document included modification of the infographics on “impacts on lifestyle and wellbeing,” more information about mental wellbeing, and inclusion of links to additional information and resources.

3.2.3. Clinician Feedback. Overall, feedback from clinicians was positive, with only one clinician concerned that the information presented may be too complex.

“I found the Report Card very informative. It’s nice to have a comparative and visual presentation of the information, and South Australian specific. . . the information in the Report Card seems to provide the information they would require.”

“. . . it will resonate strongly with a lot of chaps but I will admit, some will find it overwhelming and challenging—depending on their headspace and health literacy for understanding that sort of thing.”

Most specific comments were related to providing better lay explanation of clinical words and phrases. No concerns were raised about specific content or data that might cause anxiety for patients. In general, the Report Card was considered to be a useful resource for their patients. In particular, prostate cancer nurse specialists indicated their interest in using it in their clinical practice, with one nurse suggesting it be regularly updated.

“It will be a great tool to use when counselling men about treatment options. Keen to start using it!”

Following clinicians’ feedback, better lay explanation of words and phrases was provided and some typographical errors were corrected.

3.3. Description of the Report Card. The final version of the “Prostate Cancer Outcomes Report Card” is available through the SA-PCCOC website (<https://www.prostatehealth.org.au/men-families-affected-prostate-cancer/>). The first page describes what the Report Card is about, how it was developed, and what outcomes are reported, along with their definitions and a brief description of risk level. The second page provides an overview of prostate cancer statistics and description of the data that were used to develop the Report Card (men’s age, risk level, residence, and treatment). Pages three to eight cover specific treatment types (one treatment per page): surgery, external beam radiotherapy, low dose rate brachytherapy, active surveillance, watchful waiting, and hormonal treatment. For each treatment, the Report Card presented



FIGURE 2: The Report Card.

definition of the treatment, group characteristics, survival rates, cancer recurrence (where applicable), impact on lifestyle and wellbeing, and quotes from personal experiences. Pages 9-10 include a summary emphasising “A positive prognosis” and provide links to support and information services relating to mental health, treatments’ side effects, and sexual health. The last page covers glossary of terms, people involved in the development of the Report Card, and the funding source (Figure 2).

4. Discussion

Our aim in undertaking this work was to translate clinical registry data, which are usually collected to inform clinicians and researchers about real-world outcomes, into a consumer-friendly report focusing on communicating outcomes back to patients who provided their data. This resource was designed to provide relevant and relatable data to help inform men and family members about prostate cancer outcomes concisely in one document. Research translation and reporting back research findings enable newly diagnosed nonmetastatic prostate cancer patients to become better informed about the benefits and harms of their treatments, and those who have undergone treatment can provide some reassurance about how they are progressing after treatment.

Feedback processes indicated that the Report Card was highly valued by consumers as informative, concise, comprehensive, and trustworthy. Reporting a set of treatment outcomes in one place and presenting outcomes by risk level and treatment type were favourable aspects of the design. Across all stages of development, feedback from men

affected by prostate cancer indicated that presenting information about the relatively high prostate cancer survival rates offered them “reassurance.” A study has shown that being informed about the relatively high survival rates is an important factor in decreasing worry and anxiety about “how long they would live” and any associated mental health impacts [18]. Important features of the Report Card which were influenced largely by consumer feedback included the use of both figures and text to explain the findings, personal stories to add a “personal touch to the stats,” and links to other helpful resources.

Although this Report Card was not designed to be a treatment decision aid, it does serve to increase information access and patient awareness regarding treatment approaches and likely outcomes. The more informed the patients are, the more likely they are to participate in decision making [19]. Shared decision making is relevant to prostate cancer treatment because of a complex treatment decision where patients express regret about treatment impacts on their physical functioning [18]. Patient engagement in decisions reduces decisional regret and fosters patient satisfaction with treatment outcomes [20] as well as uncertainty and decisional conflict [21]. As prostate cancer specialist nurses were highly commended by our participants for their counselling and supporting role and nurse practitioners themselves expressed their interest in using it, we expect the Report Card to be valuable additional resource in their clinical practice to enhance patient-provider information exchange. We also found that many patients had difficulty understanding “risk level” which implies patients’ need to receive lay explanation of their risk level and how it affects treatment choice.

While undertaking this project, we identified high unmet information and supportive care needs, especially around psychosocial aspects of prostate cancer. Some men with prostate cancer experience negative psychological impacts such as anxiety and depression due to decision-related distress, fear of cancer return, treatment side effects, declining physical functioning, and treatment-related costs [22]. While addressing these needs was out of the scope of the current project, mental health aspects of men with prostate cancer requires greater attention going forward. Determining what psychosocial support services are available, the extent to which consumers' needs are being met, and which services are most suitable and feasible to apply in local context should be further investigated, ideally using a consumer engagement framework.

The Report Card is freely available online on SA-PCCOC website. SA-PCCOC, which is the data source for this project, was believed to be easily accessible, trustworthy, and appropriate to place the resource. Further dissemination plans are underway to make the resource available through Prostate Cancer Foundation of Australia and Freemason Men's Health websites, where men with prostate cancer will have access to. This Report Card will be updated subject to availability of data from SA-PCCOC and/or by exploring patients' experience from clinical practice.

Overall, the key lessons from the resource development process include the following:

- (i) *Consumer engagement* was crucial to guide the resource development.
- (ii) Patients required trustworthy, comprehensive, easily to understand, and simple information collated *in one place*.
- (iii) Participants had difficulty in understanding clinical jargon. Academic literature should consider communicating *lay summaries for end-users*.
- (iv) *Multiple insights* were gained from a wide range of stakeholders including patients and clinicians.
- (v) *Multiple channels* were used to recruit participants and maximise viewpoints.
- (vi) *Media and Communication* professionals were involved to help design the resource.
- (vii) Important *channels* were identified to *communicate* information.
- (viii) *Additional information sources* were included within the resource.
- (ix) *Real-life stories* and *personal quotes* were included to provide personal touch to the data.
- (x) High levels of *unmet psychosocial and supportive care* needs remained, especially around mental wellbeing and sexual health, which require further investigation.

There were limitations and challenges encountered during the process of developing this Report Card. First, almost all our consumer advisors had been treated via surgery. To ensure a balanced representation of views

relating to different treatment groups, men who received other primary treatment were purposefully recruited for the qualitative interviews. Second, given considerations not to overload consumers, it was not possible to provide detailed information on all outcomes and aspect of care that were indicated by consumers while keeping pages to the minimum. For example, unmet information and support care needs of patients and their families, gaps in psychosocial support services, measurement issues around mental health, and decisional regret were raised by participants which were not within the scope of this Report Card but can be addressed in future research and consumer-oriented publications. Third, prostate cancer treatment patterns are complex, in that some men could have a combination of several different treatments. For simplicity, we focused on the first (most definitive) treatment. As such the findings may not be directly applicable to men who had multiple treatments. Also, the Report Card did not cover all treatment types, for example, those undergoing high dose rate brachytherapy or chemotherapy, due to inadequate sample sizes for meaningful reporting. Fourth, there was significant individual differences and contradictions around extent of information and visual presentation that could not all be incorporated. In this case, the majority's preference was considered. Fifth, data on change in functional outcomes were not available for all men enrolled in SA-PCCOC registry due to lack of baseline survey data resulting from late notification of their diagnosis and modest survey response rates (~60%). Feedback obtained through qualitative and quantitative methods is also subject to response biases. Finally, the Report Card is based on data from the state of South Australia. As there are regional variations in treatment practice and outcomes, interpretation of the data in the Report Card should take this into account.

5. Conclusion

The purpose of this project was to develop a consumer-friendly, relatively simple, and easily understandable set of prostate cancer treatment outcomes for men diagnosed with prostate cancer and their family members. The resource was designed using real-world experiences of men and employed a consumer engagement framework, involving patient input, general public participation, and clinicians' evaluation in collaboration with local researchers and clinical practitioners. This first step will drive patient-clinical communication and shared decision making which will bring improvements in prostate cancer care and support services. This project demonstrates the importance of including consumer and community engagement in consumer-focused resource development to arrive at a relevant and valued resource. The procedures described in this paper can be adapted for other projects that attempt to translate population-based data into easily understandable consumer-friendly health resources and applied to a range of conditions or disease groupings and/or other settings with a broader applicability.

Data Availability

The data that support the evidence included in the Report Card are available from SA-PCCOC registry (<https://www.prostatehealth.org.au/>) but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of SA-PCCOC data custodians. Data generated during the piloting phase are available from the corresponding author on reasonable request.

Ethical Approval

This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the University of South Australia Human Research Ethics Committee (protocol: 204570) and Southern Adelaide Clinical Human Research Ethics Committee (LNR/22/SAC/102).

Consent

Informed consent was obtained from all interview participants included in the study. Completing and returning the anonymous online survey was considered as implied consent as was clinicians' feedback provided by e-mail.

Disclosure

The funders had no role in the design or conduct of the study including the collection, management, analysis, and interpretation of data, writing of the manuscript, or decision to submit for publication.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by KB, TT, KE, MO, and KS. The first draft of the manuscript was written by TT, KB, and KE, and all authors commented on previous versions of the manuscript. All authors have read and approved the final manuscript.

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Supplementary Materials

Supplementary File 1: qualitative interview questions. Supplementary File 2: online survey questions. (*Supplementary Materials*)

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