Research Square

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Co-Design and Qualitative Development of a Patient-Reported Experience Measure (PREM) to Capture Cancer Patients' Experiences of Peer Health Navigator Support

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Abstract

Introduction:

Peer Health Navigator (PHN) programs for patients with cancer are a relatively new concept in Australia. To ensure the effectiveness and scalability of such programs it is important to understand the experiences of patients who receive this type of support. However, there are a lack of Patient-Reported Experience Measures (PREMs) to capture the experiences of patients with cancer receiving PHN support.

Aim

The aim of this study was to co-design a PREM with partners who have had a lived experience of cancer, clinicians, researchers and policy makers.

Methods

An iterative qualitative instrument development process was undertaken using a co-design approach. This involved two sequential online workshops with partners with lived experience of cancer, clinicians, researchers and policy makers to generate and refine PREM items, followed by individual think-aloud cognitive interviews with partners with lived experience of cancer to test item clarity, interpretation, and response options. Data from workshops and interviews were analysed thematically to inform iterative refinement of the PREM.

Results

The co-design process resulted in a preliminary PREM comprising nine domains and 31 items capturing key aspects of patient experience related to PHN support. Partners with lived experience of cancer contributed to item generation, refinement, and interpretation, ensuring the measure reflected patient-identified priorities and used accessible, meaningful language. Feedback from clinicians, researchers and policy makers supported alignment with service delivery and implementation considerations. Think-aloud interviews confirmed item clarity and interpretability, with minor refinements strengthening face and content relevance.

Conclusion

Engaging people with lived experience of cancer as partners in the co-design of a preliminary PREM enabled the development of a patient-centred, practical measure of PHN support. The preliminary PREM provides a foundation for evaluating patient experiences and informing service improvement. Psychometric testing is required to assess reliability and validity of the PREM prior to broader application.

Patient or Public Contribution:

The co-design process involved engaging individuals with a lived experience of cancer throughout the development of the PREM.

INTRODUCTION

Cancer is recognised as a National Health Priority in Australia due to its substantial burden of disease and impact on the healthcare system. An 88% increase in new cancer cases and 41% rise in cancer-related mortality in Australia between 2000–2023 has been primarily attributed to population growth and an ageing population (Australian Institute of Health and Welfare,

2025a). Cancer presents as one of the leading causes of death in Australia, and by the age of 85 two in five people (43%) will be diagnosed with cancer (Australian Government - Cancer Australia, 2025). Despite increases in cancer incidence and mortality, the five-year survival rate improved from 50% in 1987–1991, to 72% in 2017–2021 (Australian Institute of Health and Welfare, 2025b).

Peer Health Navigators (PHNs) are lay individuals from the community who are able to connect with patients through shared experience (Cvetanovska et al., 2025). PHN programs have been widely implemented internationally, a policy brief by the World Health Organization (WHO) highlights global programs supporting PHN roles across the cancer care journey (Budde et al., 2022). Research outcomes from such programs have identified PHN roles in supporting patients with cancer to improve rates of cancer screening, timely diagnosis (Nguyen et al., 2010; Tian et al., 2022; Tong et al., 2017) and maintaining treatment regimens and appointment attendance (Rohan et al., 2018). Improvements in overall health system engagement (Patel et al., 2020) and improved effectiveness in access to cancer care have also been observed through PHN support roles (Chan et al., 2023).

In 2023, the Australian Cancer Plan for 2023–2033 was released (Cancer Australia, 2023). The plan, informed by evidence, existing plans and extensive stakeholder consultation, is underpinned by a conceptual framework that identifies enhanced consumer experience as one of the strategic objectives to enhance cancer outcomes (Cancer Australia, 2023). The plan recognises the importance of personalised patient navigation in cancer care to overcome barriers to accessing healthcare and provide adequate support for patients through their cancer journey (Cancer Australia, 2023). This reflects a growing acknowledgement of the role of PHNs in supporting patients as they move through complex cancer care pathways (Cancer Australia, 2023). Individuals diagnosed with cancer can often face mixed emotions and may feel isolated and uncertain about the direction of their treatment (Fereidouni et al., 2024). These emotional challenges can compound difficulties in decision-making and create additional barriers to navigation in an already fragmented healthcare system (WHO, 2024).

Patient-Reported Experience Measures (PREMs) are an important instrument in cancer care, as they capture patients' perspectives on their experiences and perceptions of care processes and the quality of the care they receive. PREMs go beyond clinical indicators to provide insight into key aspects of care such as communication, coordination, respect, and whether care was delivered in ways that aligned with patients' needs and expectations (Bull et al., 2022). This information enables services to identify what is working well and where improvements are needed, ensuring that care is more responsive to patients' needs and expectations (Bull et al., 2019; Newman et al., 2026). For PREMs to be meaningful, they should be co-designed with people who have lived experience of cancer. Co-design helps ensure that the measures reflect the concerns and priorities of patients rather than solely those of clinicians or researchers (Grindell et al., 2022). When developed in partnership with patients, PREMs are more likely to capture experiences that influence satisfaction, engagement, and quality of care, and can be used to drive changes that strengthen cancer services.

The implementation of PHN programs for patients with cancer is relatively new in Australia. To ensure these programs are effective and scalable, it is important to understand the experiences of patients who receive this form of support. At present, however, no PREMs exist that specifically capture the experiences and perspectives of people with cancer working with a PHN. Developing such a measure through co-design with individuals who have lived experience will enable their voices to shape how navigator programs are implemented and improved, ensuring these models of care genuinely respond to patient needs. Therefore, the aim of this study was to co-design and qualitatively develop a preliminary PREM to capture the experiences of people with cancer working with a PHN.

METHODS

Study Design

We undertook an iterative, qualitative instrument development process using a co-design approach, comprising two sequential workshops with partners with lived experience of cancer, clinicians, researchers and policy makers, followed by think-aloud cognitive interviews to refine the instrument's content and wording. This study constitutes Phase 1 (qualitative item development) of a two-phase program of work. Phase 2 comprises psychometric evaluation of the resulting instrument and is reported separately.

Ethics and consent

Ethical approval for the conduction of this study was obtained through the [*Name of Ethics Committee] (HREC Approval number)* (Victoria, Australia).

In line with established frameworks for patient and consumer involvement in research, people with lived experience of cancer in this study were engaged as co-investigators and members of an expert panel (Canadian Institutes of Health Research (CIHS), 2014; NHMRC, 2025). This approach reflects international best practice that distinguishes between patients as research "partners" and research "participants" (Canadian Institutes of Health Research (CIHS), 2014). By positioning people with lived experience as partners, the research team ensured that they contributed to the initial study design, workshop processes, and interpretation of findings as equal members of the team, rather than being the subjects of study. This aligns with the National Statement on Ethical Conduct in Human Research (NHMRC) on Consumer and Community Involvement in Health and Medical Research, which emphasises the active involvement of consumers in all aspects of health research, including co-design and governance (NHMRC, 2025). Framing lived experience contributors as co-investigators upholds the principles of partnership and genuine co-design, ensuring that the resulting PREM is both meaningful and grounded in the priorities of those it is designed to serve.

Partnership (with people with lived experience of cancer) and expert panel compilation

The *[Hospital Name]*, located in Melbourne, Australia, is one of the world's leading cancer research, education, and treatment facilities. As a specialist cancer hospital, *[Hospital Name]* is dedicated exclusively to cancer care, offering a comprehensive range of services, from diagnosis and treatment to supportive care and research. *[Hospital Name]* provides cutting-edge cancer treatment through its multidisciplinary teams, which include oncologists, surgeons, radiologists, pathologists, and allied health professionals. The Centre is known for its expertise in various cancer types, providing access to innovative therapies, including advanced surgical techniques, chemotherapy, immunotherapy, and radiotherapy.

Partners with lived experience of cancer were invited to join our expert panel through the *[Hospital Name]* Consumer Register. The Register has over 300 registered consumers who have lived experience of cancer (or caring for someone with cancer), and who are interested in improving cancer research and patient care. These members are notified and invited to participate in a variety of activities such as focus groups, consultations, project collaborations, education activities or committees. On the 6th and 21st of August 2024, a newsletter was emailed out to all members to express their interest in being involved as research investigators in co-designing a PREM for cancer patients receiving PHN support; two consumers were approached in-person by the research team at *[Hospital Name]* and *[Hospital Name]*. Nine consumers expressed interest in being involved in the co-design of the PREM with a final seven included based on availability.

The expert panel comprised clinicians, researchers, academics and policy makers. Clinicians, researchers and academics were contacted from *[Hospital Name]*, *[Hospital Name]*, *[University Name]* and *[University Name]*. Policy makers were contacted from the *[Institution Name]*. Each individual was invited to be a part of the expert panel via email during December 2024 to February 2025. A total of eighteen individuals expressed interest in being a member in the expert panel.

Final study team reflexivity statement

The research team brought diverse professional and experiential perspectives to the design, conduct, and interpretation of this study. The primary author (*Author initial*) is an independent early career researcher with training in qualitative research methods, providing a reflexive and methodologically rigorous approach to data collection and analysis. The senior author (*Author initial*) is an experienced health services researcher with extensive expertise in co-design, patient experience research, and instrument development, who provided methodological oversight and mentorship throughout the study. The broader research team included members with expertise in health and medical services research (*Author initials*), nursing and cancer prevention and wellbeing (*Author initial*), social work and patient and carer support (*Author initial*), and patient experience and service improvement (*Author initial*). Partners (*Author initials*) brought lived experience across a range of cancer types, including lung, haematological, upper gastrointestinal, and head and neck cancers, providing diverse perspectives on cancer care experiences. All study partners were actively involved throughout the co-design process, contributing to item generation, refinement, and

interpretation. Reflexivity was supported through ongoing multidisciplinary discussion, deliberate centering of lived experience perspectives, and critical consideration of how professional roles, assumptions, and power dynamics may have influenced the development of the PREM.

Conceptual framework

The Patient Experience Conceptual Framework developed by Oben (2020) was used as a guiding structure to inform discussions in the initial co-design workshops. This framework situates patient experience within three interrelated domains: personal identity (the values, expectations, and perspectives patients bring to their care), the lived experience of illness (the physical, psychological, and social impact of disease), and the interaction with healthcare services (processes of care and the way these are experienced, including communication, coordination, and respect). By recognising both what happens to patients and how it happens, the framework provides a useful reference point for exploring the multiple dimensions of cancer care (Oben, 2020).

Phases of PREM development

The development of the PREM involved a staged, co-design approach consisting of two online workshops with partners with lived experience of cancer, clinicians, researchers and policy makers, followed by a series of think-aloud interviews (Figure 1). The workshops focused on generating and refining item content and assessing domain coverage, while the think-aloud interviews were used to examine comprehension, clarity, and response options in the penultimate PREM. These activities generated preliminary evidence of content relevance and face validity. Each of these phases is outlined below in greater detail.

Workshop One

As part of the iterative qualitative instrument development process, the first co-design phase comprised a 1.5-hour workshop (November 2024) with our seven partners with lived experience of cancer and led by an experienced researcher (*Author initial*). The purpose of the workshop was to identify the initial items for inclusion of the PREM.

The workshop commenced with a brief outline on the purpose of the workshop highlighting the importance of lived experience of cancer in the co-design process of the PREM. Each partner with lived experience of cancer was asked to introduce themselves and to provide one word that they thought described peer health navigation from their perspective. A brief overview on PREMs, their role in capturing patient experiences of care and the importance of these instruments for the care of patients was provided. Partners with lived experience of cancer were informed on how the instrument will be utilised in the study to improve care for people with cancer, and background details were briefly provided on the PHN model outlining emotional support, addressing access barriers and enhancing care coordination. The Patient Experience Conceptual Framework by Oben (2020) was introduced to partners with lived experience of cancer to guide discussions in the workshop, the five key themes from the framework include: 1) access to care; 2) communication and information; 3) emotional and practical support; 4) coordination and continuity; and 5) empowerment and involvement (Oben, 2020).

Using the five key themes, partners with lived experience of cancer were asked to brainstorm on their experiences for each theme by answering the following question – “what do you think will be the most important aspects of the interaction between patients with cancer and their PHN?”. Participants were encouraged to write down their thoughts and open discussions were undertaken to briefly explain their responses. Following the identification of the key experiences for each theme, the framework themes were presented sequentially with two questions used as a focus point: 1) what specific questions could we ask patients to measure this experience, and 2) how can we ensure these questions reflect diverse needs and circumstances. Partners with lived experience of cancer wrote down and shared one to two questions for each theme. Preferences for response options to each question were also discussed including binary responses, Likert scale responses, and open-ended question formats. The draft questions developed by the partners with lived experience of cancer were then summarised in the workshop. Questions were collaboratively reviewed for clarity and relevance on context. Prior to the conclusion of the workshop, partners with lived experience of cancer were asked to share their insights on the session with any suggestions for improvements. The workshop concluded with the next plans for researchers to develop a preliminary draft of the PREM based on the insights shared.

The workshop was conducted and recorded on Microsoft Teams, the recording was transcribed verbatim, and a thematic analysis was conducted. Thematic analysis followed the Braun and Clarke six-step process (Braun & Clarke, 2006). Two researchers (*Author initials*) familiarised themselves with the data by reading all workshop transcripts in full (Step 1). They then independently conducted inductive coding across the dataset (Step 2). The researchers met to compare codes and sort using framework themes as parent codes (Step 3). Overlapping concepts were merged, and then refined until consensus was reached on a final set of codes (Step 4). This agreed coding framework was subsequently applied independently to the full dataset by both researchers (Step 5). In the final analytic phase, coded data were synthesised to create a draft set of items for the PREM (Step 6). These items were then emailed to partners with lived experience of cancer for review and to decide whether the items reflected discussions from the workshop (member checking).

Workshop Two

The second phase consisted of a 1.5-hour workshop (February 2025) with five of the seven partners with lived experience of cancer from workshop one, nine clinicians, seven researchers and two policy makers. The purpose of workshop two was to design and further develop the second preliminary version of the PREM.

All partners with lived experience of cancer, clinicians, researchers and policy makers were provided with the preliminary version of the PREM prior to the workshop. The session commenced with brief introductions, followed by an overview of the workshop objectives: 1) to review and refine key themes identified in workshop one; 2) to identify gaps or areas requiring clarification; and 3) to assess the practicality and relevance for both users and implementers. Participants were then divided into two breakout groups: one comprising partners with lived experience of cancer, and the other comprising clinicians, researchers and policy makers. Each breakout group addressed the workshop objectives from a different perspective to assess the relevance and coverage of the draft items. The lived experience group was led by (*Author initial*) and reviewed the draft PREM items to assess their relevance, clarity, and alignment with what mattered to their cancer care experiences, while clinicians, researchers and policy makers focused on the structure of the survey, item framing, and the contribution of each question to understanding consumer experience as a whole. Each group systematically reviewed the draft PREM items, with a designated member documenting feedback and suggestions. Following the breakout discussions, participants reconvened in the main group, where key points from each breakout room were presented and discussed. The workshop facilitator (*Author initial*) collated overlapping feedback and synthesised the suggested refinements.

The workshop was recorded on Microsoft Teams, the recording was transcribed verbatim. Amendments were applied to the PREM based on thoughtful consideration of the feedback received in the workshop.

Think-aloud cognitive interviews

The third phase comprised think-aloud cognitive interviews. Think-aloud is a qualitative technique, originally developed to examine cognitive processes during task completion and commonly applied in instrument development to explore how participants interpret and respond to draft items (Willis, 2004; Willis & Artino Jr, 2013). Partners with lived experience of cancer were asked to read each item aloud and verbalise their immediate understanding, thoughts, and response reasoning. This approach enabled the research team to identify issues with clarity, wording, or relevance, and to understand whether items capture the intended construct. The interviewer used verbal probes where appropriate to explore item interpretation, response selection, and the feasibility of scoring.

Seven partners with lived experience of cancer from workshops one and two were invited to participate in the think-aloud interviews: four partners with lived experience of cancer expressed interest and took part. Interviews were conducted individually in April 2025 by a member of the research team (*Author initial*) and lasted approximately one hour. Sessions followed a structured sequence, with participants progressing through each item in turn and verbalising their cognitive responses in real time. Minimal prompts, for example, “can you tell me what you are thinking?” were used to encourage narration, with more focused probes used to clarify interpretation, explore response boundaries and assess item clarity. Partners with lived experience of cancer were also invited to comment on overall survey structure and suggest improvements.

Interviews were audio-recorded via Microsoft Teams and transcribed verbatim. Tracked amendments were made to the PREM which was then reviewed by a second researcher (*Author initial*) alongside the interview transcripts. Any conflicting views about interpretation of changes required was resolved with a third researcher (*Author initial*).

Assessment of Item Relevance, Coverage and Comprehension

The second and third phases (i.e. workshop two and subsequent think-aloud interviews) of the co-design were undertaken to refine the instrument and to assess whether items were relevant, comprehensible, and covered the domains considered important by lived-experience partners and stakeholders. The workshop allowed partners with lived experience of cancer, clinicians, researchers and policy makers to review and refine items for relevance, clarity, and comprehensiveness, ensuring the measure addressed all key domains of patient experience. The think-aloud process further explored how people with lived experience interpreted the items, whether questions were understandable, and whether they reflected the intended concepts. Together, these steps provided assurance that the PREM was both meaningful to patients and grounded in the essential elements of peer health navigation in cancer care.

RESULTS

The staged co-design process resulted in a preliminary PREM that reflects consumer-identified priorities and is acceptable and interpretable for end users. Across two workshops and subsequent think-aloud interviews, PREM items were generated, refined, and consolidated to strengthen clarity, relevance, and comprehensiveness.

Workshop one focused on initial item generation led by partners with lived experience of cancer. Thematic analysis of workshop discussions identified candidate items across five conceptual domains aligned with the Patient Experience Conceptual Framework, including access to care, communication and information, emotional and practical support, coordination and continuity, and empowerment and involvement. The initial pool of draft items generated through this process is summarised in Table 1 and formed the basis for subsequent refinement.

Table 1
Partner (with lived experience of cancer) led item generation from Workshop one

Conceptual theme	Developed questions addressing patients' challenges	Suggested Response Type
Access to Care	The peer health navigator helped me understand wait times for treatment and appointments	Likert Scale
	It was easy for me to access a peer health navigator after my first appointment	Likert Scale
	Did the peer health navigator help you overcome barriers to accessing care (e.g. transport, scheduling)?	Binary
	If yes, what barriers were addressed?	Open-ended
Communication and Information	The information provided to me by the peer health navigator was easy to understand	Likert Scale
	Did the peer health navigator assist you in preparing for appointments (e.g., creating question lists)?	Binary
	Can you provide some examples of ways in which the navigator helped you to prepare?	Open-ended
	The peer health navigator helped me understand the next steps in my treatment plan	Likert Scale
	Did the peer health navigator follow up with you after appointments to clarify or provide additional information?	Binary
Coordination and Continuity	Did the peer health navigator assist in coordinating your appointments and treatments?	Binary
	My experience of care was seamless with the peer health navigator's support?	Likert Scale
	Were you made aware by the navigator of services available to support you? (e.g. [Hospital Name] Wellbeing Centre, [Hospital Name] Wellness Lounge)	Binary
	If yes, how did the peer health navigator assist with using these tools?	Open-ended
Emotional and Practical Support	The peer health navigator helped address my emotional needs during my treatment journey	Likert Scale
	The peer health navigator connected me with practical resources (e.g., support groups, financial assistance)?	Likert Scale
	What types of emotional support did you find most helpful from the peer health navigator?	Open-ended
Empowerment and Involvement	The peer health navigator helped me feel more confident in managing my care	Likert Scale
	The peer health navigator was accessible when I needed support?	Likert Scale
	Did the peer health navigator help you feel empowered to ask questions during appointments?	Binary
	I felt involved in decision-making about my care with the support of the peer health navigator	Likert Scale

Likert Scale: Strongly Disagree/Disagree/Agree/Strongly Agree option; **Binary**: Yes/No option

Workshop two supported further development of the PREM through structured review by partners with lived experience of cancer, clinicians, researchers and policy makers. Breakout discussions enabled focused consideration of item relevance, wording, structure, and response options from complementary perspectives. Feedback across groups converged on the need to simplify language, broaden the scope of support-related items, reorder questions to foreground the role of the PHN, incorporate

open-ended items, and include neutral or ‘not applicable’ response options where appropriate. Shared and distinct priorities identified during this phase, and how they informed item refinement, are illustrated in Fig. 2.

Think-aloud interviews provided further insight into how partners with a lived experience of cancer interpreted and responded to the draft PREM items. Feedback confirmed overall clarity, interpretability, and feasibility of the instrument, with minor refinements made to item wording, headings, and response framing to support lay understanding and consistent interpretation. These refinements strengthened face validity by ensuring items reflected consumer experiences as intended.

The preliminary PREM, presented in full in Table 2, comprises nine domains and 31 items capturing experiences of PHN support across the cancer care journey.

Table 2: Candidate Patient-Reported Experience Measure following co-design and cognitive testing

As part of the Peer Health Navigator Program, we are interested in your experience of receiving navigator support in cancer care. Your experience is important to assist us with further refining the program. The survey may take up to 15 minutes to complete and covers questions on your experience with your health navigator. Thank you for providing the time to complete the survey. We look forward to hearing your experiences.

Overall Experience

On a scale from 1 to 10, how would you rate your overall experience with your Health Navigator?

WORST EXPERIENCE BEST EXPERIENCE

1	2	3	4	5	6	7	8	9	10

The next questions are about your experience of care BEFORE receiving support by a Health Navigator

BEFORE I had a Health Navigator to assist me I felt….

	Strongly Disagree	Somewhat Disagree	Neither Agree/Disagree	Somewhat Agree	Strongly Agree
Fearful or anxious about my cancer journey	O	O	O	O	O
Confused or uncertain about my diagnosis	O	O	O	O	O
Confident about my care	O	O	O	O	O
In control of choices about my care	O	O	O	O	O
Supported during my cancer journey	O	O	O	O	O

The next questions are about your experience of care AFTER receiving support by a Health Navigator

AFTER I had a Health Navigator to assist me I felt….

	Strongly Disagree	Somewhat Disagree	Neither Agree/Disagree	Somewhat Agree	Strongly Agree
Fearful or anxious about my cancer journey	O	O	O	O	O
Confused or uncertain about my diagnosis	O	O	O	O	O
Confident about my care	O	O	O	O	O
In control of choices about my care	O	O	O	O	O
Supported during my cancer journey	O	O	O	O	O

The next questions are about how the Health Navigator helped you to access care						
	Strongly Disagree	Somewhat Disagree	Neither Agree/Disagree	Somewhat Agree	Strongly Agree	Not Applicable
The Health Navigator helped me understand wait times for treatment and appointments	O	O	O	O	O	O
The Health Navigator helped me to overcome healthcare challenges or obstacles	O	O	O	O	O	O
The next questions are about how the Health Navigator helped you with finding information and communicating						
	Strongly Disagree	Somewhat Disagree	Neither Agree/Disagree	Somewhat Agree	Strongly Agree	Not Applicable
The information provided to me by the Health Navigator was easy to understand	O	O	O	O	O	O
The Health Navigator helped me to find reliable information	O	O	O	O	O	O
The Health Navigator helped me understand the steps in my treatment plan	O	O	O	O	O	O
The Health Navigator helped me to prepare for appointments	O	O	O	O	O	O
The next questions are about how the Health Navigator helped you stay connected to your care and helped different parts of your healthcare work together						
	Strongly Disagree	Somewhat Disagree	Neither Agree/Disagree	Somewhat Agree	Strongly Agree	Not Applicable
The Health Navigator helped me to organise or keep track of my appointments	O	O	O	O	O	O
The Health Navigator made me aware of available services or tools to support me	O	O	O	O	O	O
The next questions are about how the Health Navigator supported your wellbeing and helped you with practical needs related to your care						
	Strongly Disagree	Somewhat Disagree	Neither Agree/Disagree	Somewhat Agree	Strongly Agree	Not Applicable
The Health Navigator provided me with suggestions for my practical needs such as transport or accommodation	O	O	O	O	O	O
The Health Navigator connected me with resources relating to	O	O	O	O	O	O

my wellbeing and self-care						
The Health Navigator helped me to connect to a support network relating to my wellbeing and self-care	O	O	O	O	O	O

The next questions are about how the Health Navigator helped you feel more confident and involved in your care decisions

	Strongly Disagree	Somewhat Disagree	Neither Agree/Disagree	Somewhat Agree	Strongly Agree
The Health Navigator was easy to contact when I needed support	O	O	O	O	O
The Health Navigator helped me feel confident to ask questions to my doctors, nurses or other healthcare professionals	O	O	O	O	O
The support of the Health Navigator made me feel more confident in making decisions about my care	O	O	O	O	O

General Feedback

On a scale from 1 to 10, how likely would you be to recommend the Health Navigator program?

NOT AT ALL LIKELY EXTREMELY LIKELY

1	2	3	4	5	6	7	8	9	10

	Not Important at all	Slightly Important	Important	Fairly Important	Very Important
How important was the Health Navigator to your healthcare experience?	O	O	O	O	O
At what point in your cancer journey did you find the Health Navigator most helpful?	*(please write in the blank box)*				
What was the most helpful	*(please write in the blank box)*				

thing your Health Navigator did for you during your cancer journey?	
Did you find the program helpful for your needs? If so, in what way?	*(please write in the blank box)*
Based on your personal experience, do you have any suggestions for how we could improve the program?	*(please write in the blank box)*

DISCUSSION

This study describes the co-design and development of a PREM to capture the experiences of people with cancer receiving support from a PHN. Through an iterative process involving partners with lived experience of cancer, clinicians, researchers and policy makers, the study produced a preliminary PREM grounded in lived experience and aligned with key dimensions of patient experience across the cancer care journey. To our knowledge, this is the first PREM developed in Australia specifically to evaluate PHN support for people with cancer.

The resulting PREM reflects domains that are consistently identified as central to patient experience, including access to care, communication and information, coordination and continuity, support, and empowerment. These domains align with the Patient Experience Conceptual Framework by Oben (2020) and with international evidence highlighting the role of navigation programs in providing relational support, addressing system complexity, and empower patients to engage and make decisions about their health (Sleiman et al., 2024). Importantly, the co-design process ensured that these domains were operationalised using language, framing, and response options that were meaningful and acceptable to consumers, rather than being imposed solely from clinical or research perspectives.

A key strength of this study was the active involvement of partners with a lived experience of cancer as co-investigators throughout the development process. Rather than participating as research subjects, people with lived experience of cancer contributed to item generation, refinement, and interpretation, shaping both the content and structure of the PREM. This approach supports the growing emphasis on genuine lived experience partnership in health research and responds to calls for experience measures that reflect what matters to patients, not only what services seek to measure (Silvola et al., 2023). The structured engagement of clinicians, researchers and policy makers alongside partners with lived experience of cancer further supported the relevance and implementation feasibility of the items, although this stakeholder input should be understood as contributing to content relevance rather than as formal evidence of content validity.

The use of think-aloud cognitive interviews provided additional insight into how draft items were interpreted and answered, enabling refinement of wording, response options, and survey structure. This step was particularly important in supporting face validity and ensuring that items captured intended concepts without ambiguity or unnecessary complexity. Findings from the think-aloud phase indicated that the PREM was generally clear and easy to complete, with only minor refinements required, suggesting that the co-design process effectively addressed many potential issues earlier in development.

This study has limitations that should be considered when interpreting the findings. Partners with lived experience of cancer represented a limited number of cancer types and were recruited from a single health service consumer register, which may influence the perspectives reflected in the PREM. In addition, the co-design and cognitive interviewing processes provide only preliminary, qualitative evidence of face validity and content relevance. No measurement properties have been evaluated and

further research should be conducted to assess internal consistency, test–retest reliability, structural and construct validity, and responsiveness. The instrument should therefore be regarded as a preliminary measure rather than a validated one. A further methodological consideration concerns the 'before' and 'after' items. Unless administered prospectively at two time points, these items rely on retrospective comparison and are therefore best interpreted as a measure of perceived change rather than as a true pre–post assessment – these items may be susceptible to recall, response-shift and attribution biases, and this will be examined in subsequent evaluation work. A preliminary evaluation is currently underway using data from patients enrolled in a PHN program.

Despite these limitations, this study makes an important contribution by providing a rigorously developed, lived experience-informed PREM for evaluating PHN support in cancer care. In addition, it provides an overview of an authentic partnership with people with lived experience to co-design a PREM that reflects the items to be measured that are important to the people having the experience. As navigation programs continue to expand in Australia and internationally, instruments that meaningfully capture patient experience will be essential for understanding their impact and informing service improvement. The preliminary PREM developed through this study offers a practical and patient-centred measure to support the ongoing evaluation and scaling of PHN models in cancer care.

CONCLUSION

This study demonstrates the value of engaging people with lived experience of cancer as partners in the co-design of a PREM. The engagement of consumer partners provided valuable insight on the perspectives of patients with cancer, with the resulting PREM reflecting patient-identified priorities relevant to the measurement of experiences associated with PHN support. By integrating lived experience perspectives with clinical and research expertise, the instrument was developed to be both relevant to patients and practical for use in cancer services. Future research should conduct a psychometric evaluation of feasibility and item performance in a cohort of patients receiving PHN support.

Declarations

ETHICS APPROVAL

This study was conducted in accordance with the Declaration of Helsinki. This study was approved by the Peter MacCallum Cancer Centre Human Research Ethics Committee (HREC/107172/PMCC) (Victoria, Australia).

CONSENT TO PARTICIPATE

Informed consent was obtained from all participants prior to participation in the workshops and think-aloud cognitive interviews.

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Author Contribution

RLJ conceptualised the study, led the overall program of research, contributed to data collection and analysis. H.M contributed to data collection, analysis, wrote the main manuscript text and prepared figures. S.S, P.H, G.M, FM, PW contributed to editing the main manuscript. MQ, HB, SKS, JC, TN, RD, SS, KB, IM, TL provided perspectives on cancer care experiences and contributed to editing the main manuscript. All authors reviewed, edited and approved the manuscript.

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Figures

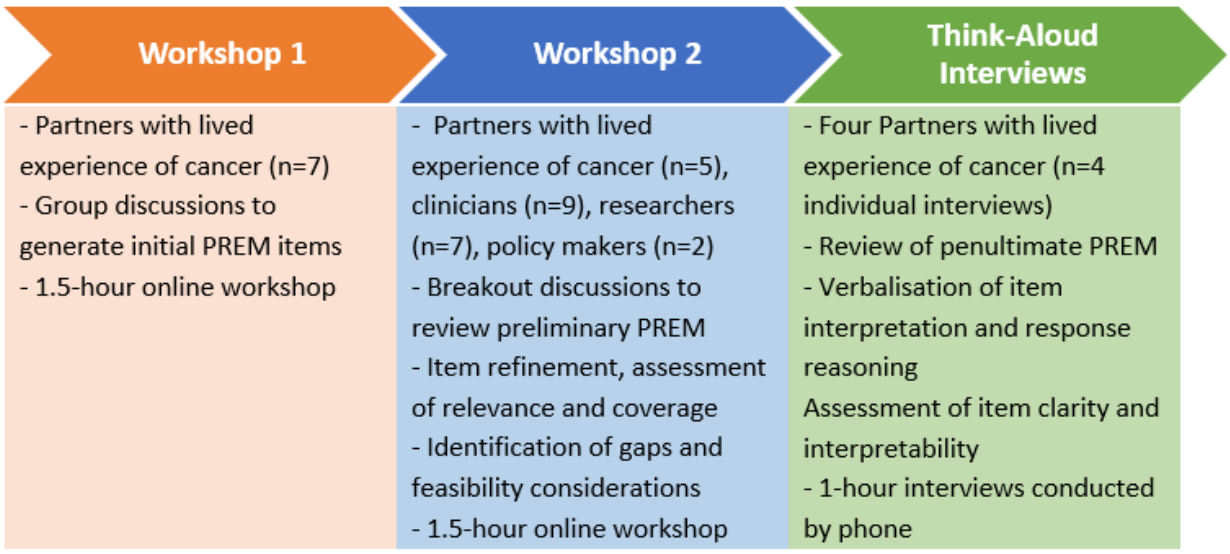


Figure 1

illustrates the overview of the three stages involved in the development of the PREM.

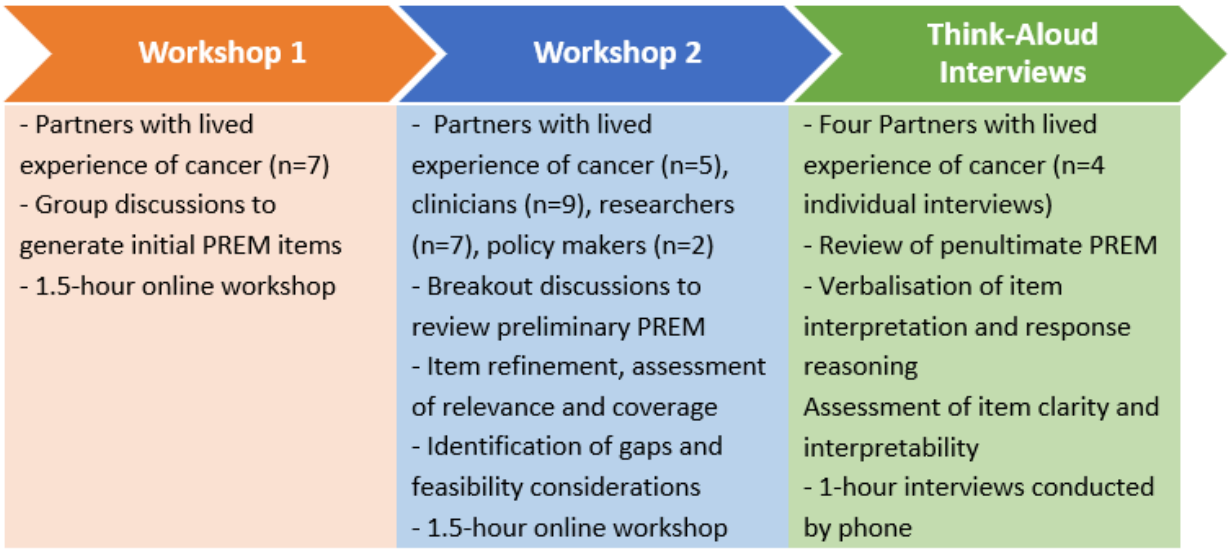


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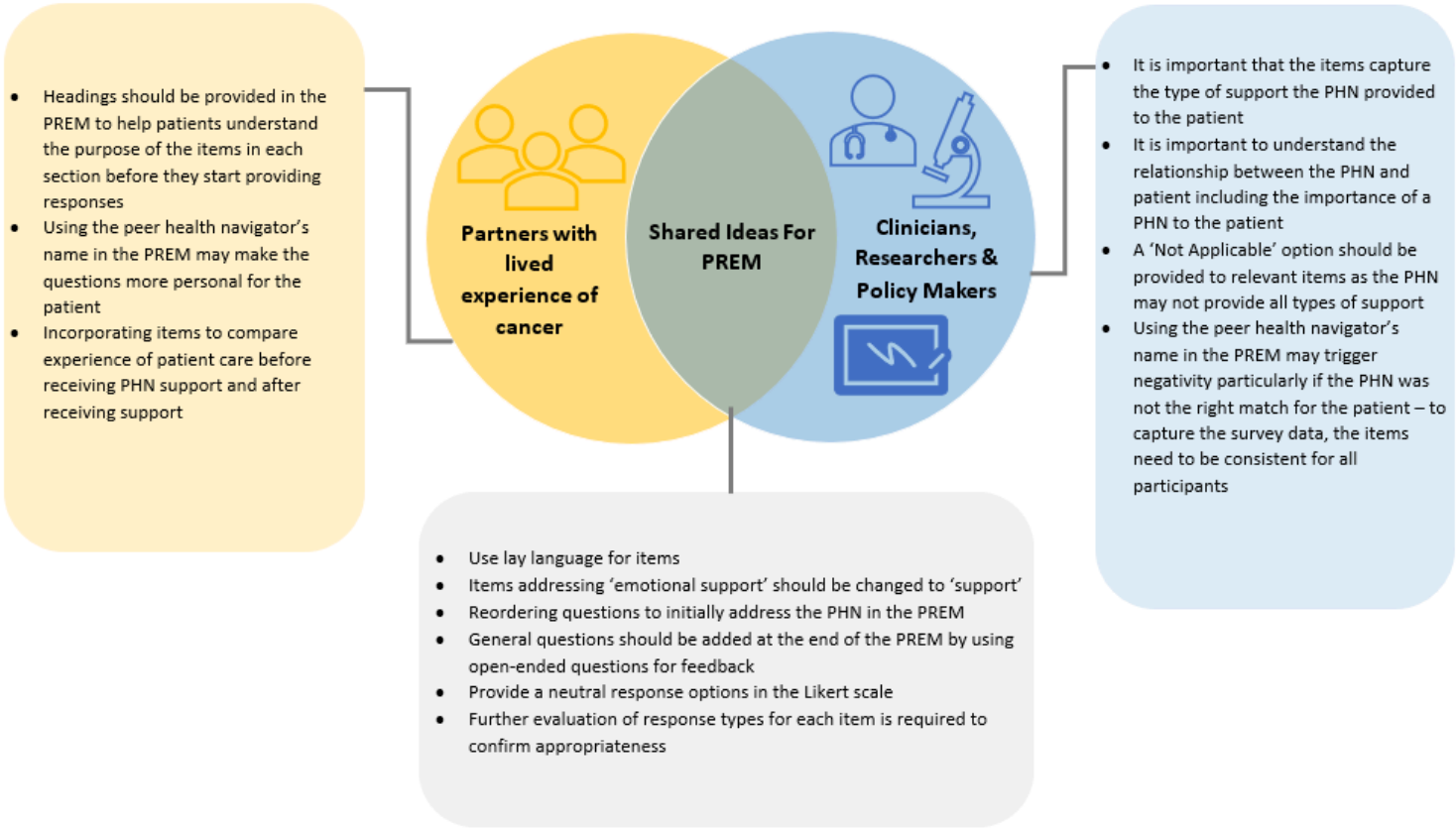


Figure 2

Idea generation from Workshop two

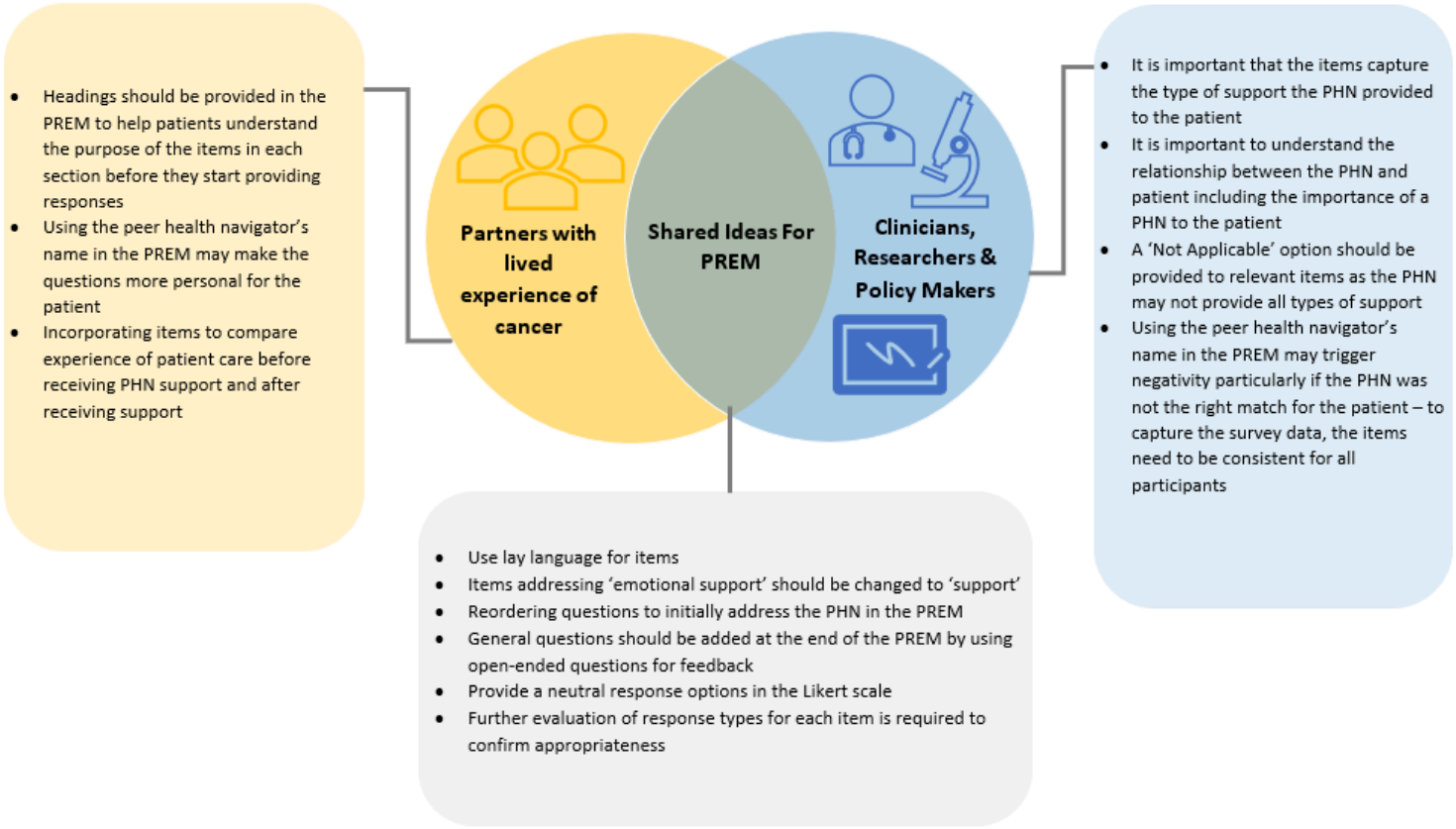


Figure 2

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