Supportive Care in Cancer (2026) 34:68
https://doi.org/10.1007/s00520-025-10300-7

COMMENT

A Co-design of a digital platform to support self-management of breast cancer–related lymphoedema

Navaz Naghavi[1] · **Monique Bareham**[2] · **Olivia Cook**[3] · **Neil Piller**[1,4] · **Raymond J. Chan**[1] · **Lisa Beatty**[1] · **Kerry A. Sherman**[5] · **Emma Kemp**[1] · **Ganessan Kichenadasse**[1,4] · **Richard L. Reed**[1] · **Matthew P. Wallen**[1] · **Richard Woodman**[1] · **Billingsley Kaambwa**[1] · **Bogda Koczwara**[1,6]

Received: 7 July 2025 / Accepted: 24 December 2025 / Published online: 6 January 2026

Introduction

Breast Cancer-Related Lymphoedema (BCRL) is a chronic condition that requires long-term management [1]. In Australia and elsewhere, BCRL services are limited and fragmented, leaving survivors unsure of where to seek support [2]. An Australian study of a web-based Lymphoedema Self-Care intervention in 97 women with breast cancer showed a significant increase in self-efficacy and a reduction in distress and BCRL symptom scores [3]. To inform a future implementation study, we undertook a co-design with consumers (breast cancer survivors with or at risk of lymphoedema) and healthcare professionals (breast care nurses, lymphoedema therapists, massage therapists, and representatives from compression garment organizations) to develop an online platform to support self-management of BCRL in Australia.

Methods

Design

This study utilised a qualitative co-design approach, within the Ideate (brainstorm and prioritise content that could be included in intervention) and Prototype (present a mock-up/template of the proposed solution to obtain feedback) stages of Standfor's Design Thinking co-design framework [4].

Participants and procedure

Participants in this study included breast cancer survivors and healthcare professionals. breast cancer survivors were either living with BCRL or at risk of developing it. Healthcare professionals comprised those involved in CRL management, including breast cancer nurses, lymphoedema therapists, massage therapists, oncologists, surgeons, and general practitioners (GPs) and representatives of the organizations that provide care or support to people with lymphoedema.

A purposive sampling approach was used to recruit participants, leveraging the second and last authors' professional networks and key partner organizations to ensure diverse representation of stakeholders. Initially, an invitation email was sent to 90 individuals from the authors' network, with recipients encouraged to share the opportunity with others who met the inclusion criteria.

Additionally, Breast Cancer Network Australia (BCNA) disseminated the invitation to its network, and the McGrath Foundation promoted participation among its breast care nurses. All sessions took place between mid-November 2024 and mid-December 2024.

Ethics approval was obtained from Flinders University's Human Research Ethics Committee (Ref: #7672), and the study was conducted in accordance with the National Statement on Ethical Conduct in Human Research (NHMRC, 2007; updated 2018).

A total of 31 participants were recruited for this study. The participants consisted of 23 survivors and 8 healthcare professionals. 71% ($n=22$) took part in focus group discussions, 29% ($n=9$) attended in-person and 42% ($n=13$)

✉ Bogda Koczwara
b.koczwara@unsw.edu.au

[1] Flinders University, Adelaide, South Australia, Australia

[2] South Australia Health Lymphoedema Compression Garment Advisory Group, Adelaide, Australia

[3] Monash University, Clayton, VIC, Australia

[4] Flinders Medical Centre, Adelaide, South Australia, Australia

[5] Macquarie University, Sydney, NSW, Australia

[6] University of New South Wales (UNSW), Sydney, NSW, Australia

participated online. The remaining 29% ($n=9$) completed individual interviews, with 3% ($n=1$) conducted in-person in Adelaide and 26% ($n=8$) conducted online.

Following informed consent, two focus group sessions (one face-to-face and one online), each including consumers and health professionals, were conducted and facilitated by the first and last authors in Nov and Dec 2024. Individual interviews were then offered for those unable to participate in the group sessions.

Participants were presented with a prototype wireframe, a visual guide of the platform's framework and content. The wireframe was developed based on previous qualitative work [5] and guidelines for lymphoedema management [6].

The wireframe included three core modules as illustrated in Fig. 1.

- Learn More– Myth-busting, Risk reduction, Self-care and Specialised care.
- Community – Forum, Private Chat, Online Booking and In-Person Visit.
- My Profile – Goal setting, My day, Read and Reflect, My Health Status

Participants were guided by semi-structured questions to explore their perspectives on content, usability, and engagement features. The semi-structured interview and focus group guide is provided in Appendix. The guide explored user preferences, informational needs, and perceptions of platform features. Interviews and focus groups continued until thematic saturation was reached, defined as the point at which no new themes or codes emerged across at least three consecutive sessions. Saturation was assessed iteratively throughout the data collection and analysis process.

To enhance data credibility, multiple forms of member checking were embedded within the co-design process. All participants were shown the prototype wireframe during focus groups and interviews and were asked to comment on, clarify, and refine its structure and content in real time. This iterative interaction enabled immediate validation of participants' intentions and ensured accurate interpretation of their views. In addition, a subset of participants ($n=5$) who indicated interest in further involvement were invited after the sessions to review a summary of the preliminary themes.

Data analysis

Two researchers independently conducted a thematic analysis following Braun & Clarke's [7] framework using NVivo software to identify key themes and sub-themes. Discrepancies in coding were resolved through discussion and consensus.

Reflexivity and credibility measures

Reflexivity was an integral part of the BCRL co-design process, especially as the two facilitators (the first and last authors) were also involved in the development of the digital platform. To minimize the influence of their preconceptions or professional roles, reflective memos were written after each focus group and interview session. These memos captured personal assumptions, power dynamics between consumers and clinicians, and any perceived influence the facilitators may have had on participants' openness. The research team discussed these reflections during regular debriefings, particularly when interpreting codes and developing themes,

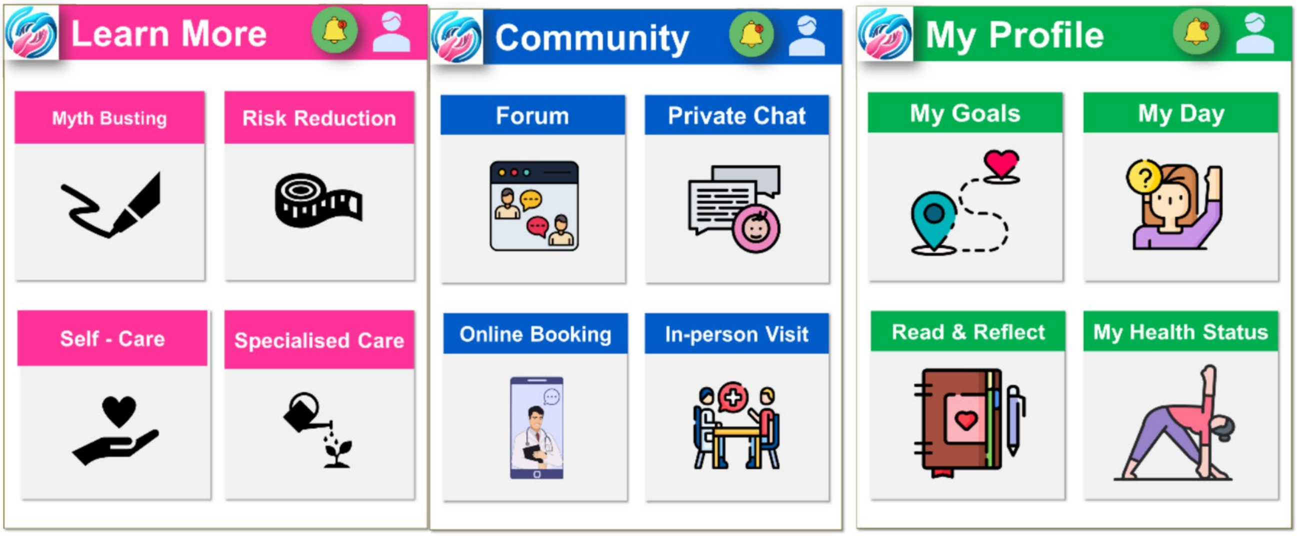

Fig. 1 Samples of wireframe presented to participants

to ensure that data interpretation was grounded in participants' views rather than facilitators' expectations.

Results

This study explored stakeholders' perspectives on the design and content of a digital platform for the self-management of BCRL. Thematic analysis identified three overarching themes: (1) Elements of the platform, expected content, and features; (2) Navigating professional and peer support; and (3) Uptake and engagement in self-management. Each theme was further categorized into sub-themes, with direct quotations illustrating key insights. The summary of the thematic analysis is presented in Table 1.

Theme 1: Elements of the platform, expected content, and features

Participants viewed the prototype platform as a potential central hub which would address the knowledge gap with simple, jargon-free, and evidence-based information on treatment and management strategies.

Sub-theme 1.1: Terminology and naming conventions

The majority of participants found the visual layout intuitive, but they emphasized that the landing page should immediately communicate the platform's purpose. The *"My Profile"* section was debated, with stakeholders suggesting that it should be renamed to better reflect its function. One participant proposed,

> *"Could this be called 'What I Can Do' to have a more empowering tone?" C1*

Further discussions centered on the classification of care categories. Participants expressed concerns that the term *"Basic Care"* may not fully capture the scope of self-management practices, suggesting that *"Self-Care"* would be more appropriate. Similarly, the term *"Advanced Care"* was perceived as potentially misleading, with some participants associating it with palliative care. Instead, *"Specialised Care"* was recommended as a more accurate representation of expert-led management strategies required for later stages of BCRL.

> *"… I don't like the term basic care because it says, you know, you do the basic stuff, whereas the real good stuff is called advanced care that somebody else does.…" HCP1*

Sub-theme 1.2: Practical and evidence-based tips

Participants suggested including a "Myth-Busting" section to address misconceptions about lymphoedema. One healthcare professional noted,

> *"People assume lymphoedema always looks a certain way, so they don't follow up on their concerns until it's too late." HCP2*

A key point raised by consumers was the need for references and citations for all educational content within the platform. Many felt that seeing academic sources would increase trust in the information provided. Participants suggested that a separate "References & Further Reading" section could be included to provide academic credibility and transparency for users.

> *"There's so much misinformation out there. If I can see proper references, I'll know this is evidence-based."*

Theme 2: Engagement and adherence in self-management

The need for sustained user engagement with an online platform was considered important by participants. Participants identified goal setting, self-tracking and motivational reinforcement as essential for sustained engagement.

Table 1 Themes, sub-themes, and supporting quotations from co-design sessions

1. ***Platform features and content***	
1.1 Terminology and naming	"The term 'basic care' suggests it's less important." (HCP1)
1.2 Practical and evidence-based tips	"If you're gardening, wear gloves to avoid tiny cuts." (HCP4)
2. ***Engagement and adherence in self-management***	
2.1 Self-directed care and goal setting	"Tracking my arm measurement would help… before it becomes a problem." (C12)
2.2 Trust and data security	"If a university or BCNA is behind this, I'd trust it more." (C4)
3. ***Specialised care and peer support***	
3.1 Directory of specialist services	We do not need to reinvent the wheel… just consolidate services." (C8)
3.2 Peer support preferences	"We already have a great network… I wouldn't switch unless it offered something unique." (C12)

Sub-theme 2.1: Self-directed care and goal setting

Participants recognized the importance of taking an active role in managing their BCRL. They highlighted the need for features that support self-directed care, such as goal setting, symptom tracking, and personalized management plans. The ability to log health measures and track changes over time was viewed as a motivating factor.

> *"It would be great if I could track my arm measurements and weight. That way, I'd know if something is changing before it becomes a problem." C12*
> *"Having a way to see my progress would encourage me to keep up with self-care routines." C2*

Sub-theme 2.2: Trust and data security

Most consumers did not express concerns about entering health-related data, such as arm measurements or weight. However, they highlighted that the platform's credibility would be strengthened if it were backed by a university or a non-profit organization.

> *"If a university or BCNA is behind this, I'd trust it more. That kind of backing makes a difference."*

Participants also emphasized the importance of account security. They did not feel comfortable providing personal identification details, such as an address or ID number, but were open to using an email to access the platform.

> *"I'd be happy to sign in with an email, but I wouldn't want to enter my full address or ID number. That's unnecessary."*

Theme 3: Specialized care and peer support

Participants highlighted difficulties in accessing up-to-date information on lymphoedema specialists and expressed that they often had to rely on their own research skills to find a relevant provider in their vicinity. As a result, they supported adding a specialist directory to the platform that links to existing BCRL specialists.

> *"I was given one out-of-date list of phone numbers. That was it. I had to navigate it on my own." C7*
> *"We do not need to reinvent the wheel. We just need to consolidate the available services." C8*

While the element of peer support was considered valuable, participants noted the challenge of switching from their existing networks, such as BCNA, and preferred to continue engaging with familiar groups rather than building a new peer support within the platform.

> *"We already have a great network through BCNA. I wouldn't switch just to join another group unless it offered something unique." C12*
> *"Rather than setting up a whole new group, just give us a list of services and organizations we can connect with.*

Discussion

This study's findings reaffirmed the need for practical information and care navigation support for BCRL self-management [8] while also highlighting the importance of long-term engagement and tailoring to users' needs [9]**.** Participants emphasized the importance of sustained engagement, aligning with evidence that self-monitoring features and goal setting can support motivation and long-term use of digital interventions [10, 11]. Consistent with prior work demonstrating the impact of language on user engagement [9], clear and empowering terminology was considered essential, as some existing terms were perceived as misleading. To address difficulties distinguishing accurate information from misinformation, stakeholders supported the inclusion of myth-busting and practical guidance, reflecting broader literature that highlights the need for digital tools to present information using simple, non-technical language [9, 12]. The findings support the importance of co-design methodology to support usability, engagement, and applicability in digital health.

The findings of this study align with established self-management and behaviour change frameworks. The emphasis on goal setting, symptom monitoring and personalised feedback reflects core elements of self-management theory, which highlights the importance of building confidence, decision-making skills, and meaningful action planning for chronic condition management [13].

Participants' desire for practical, skills-focused guidance and positive reinforcement also aligns with key behaviour change techniques, particularly those involving goal setting and self-tracking as defined by Ntoumanis [14]. These insights suggest that embedding features informed by behaviour change techniques into the platform may enhance user motivation and sustained engagement. The preference for simple language, credible information, and practical instruction further supports theories emphasising self-efficacy, health literacy, and perceived control, reinforcing the need for a platform that facilitates skill-building rather than solely information provision.

This study has several limitations. The sample was recruited primarily through two of the authors' professional networks, which may have biased participation towards individuals who were already knowledgeable, engaged, or confident in managing their BCRL. As a result, the perspectives of newly diagnosed individuals or those with limited access to specialist support may be under-represented. Also, the study examined perceptions of a prototype rather than real-world use, meaning that findings reflect anticipated rather than actual engagement behaviours.

Appendix

Participants were asked the following questions, tailored slightly depending on whether they were breast cancer survivors or healthcare professionals:

1. Do you feel that the current list of components for the main page is too extensive, just right, or lacking?
2. How do you prefer to receive educational content about lymphoedema?
3. Do you think it would be helpful to have reminders or notifications to prompt you to continue your learning journey?
4. Is there any particular information about lymphoedema that you are especially interested in or wish you had known earlier?
5. Based on your experience, what do you believe should be the main focus of the preventive measures section?
6. If you were to rank the three most important pieces of knowledge about breast cancer-related lymphoedema to emphasize, what would they be?
7. Have you ever performed self-massage? How comfortable or daunting did you find it?
8. What important information about compression garments do you think should be included on the platform?
9. Information about specialised care, such as surgical interventions, can sometimes be overwhelming. Would you suggest this information be included on the platform?
10. Do you think a forum would require moderation to be effective? If so, would that make it unsustainable, or do you feel it's an important feature that should be included even if it means involving moderators?
11. How frequently would you like to be reminded about your routines, such as exercise, skin care, massage, and diet?
12. Would you be interested in receiving stories or motivational quotes from others who have made progress or overcome challenges related to lymphoedema management?
13. Do you like the idea of having a points- or reward-based system on the platform? If so, what kind of rewards or awards would you prefer?
14. This feature guides you to add personal health data like measurements. Do you feel comfortable and trust the platform to securely store your data?
15. Is there anything else you would like to add about the platform that we haven't covered? Are there any features you feel strongly about, either positive or needing improvement?

Author contributions N.N. and B.K. conceptualized and designed the study. N.N. and M.B. facilitated the focus groups and interviews. N.N., M.B., and O.C. contributed to data collection. N.N., E.K., and L.B. led the qualitative analysis. All authors (N.N., M.B., O.C., N.P., R.J.C., L.B., K.A.S., E.K., G.K., R.L.R., M.P.W., R.W., B.K.) contributed to the interpretation of findings and critical revision of the manuscript. All authors contributed to the study design during the project phase and reviewed and approved the final manuscript.

Funding This work was supported by the Medical Research Future Fund (MRFF; Grant ID: MRF2031135), an initiative of the Australian Government Department of Health and Aged Care.

Data availability No datasets were generated or analysed during the current study.

Declarations

Competing interests The authors declare no competing interests.

References

1. Jeong SH, Chun SM, Lee H, Kim M, Choi M, Leigh JH (2025) Association between chemotherapy and the risk of developing breast cancer-related lymphedema: a nationwide retrospective cohort study. Support Care Cancer. https://doi.org/10.1007/s00520-025-09169-3
2. Pappalardo M, Starnoni M, Franceschini G, Baccarani A, De Santis G (2021) Breast cancer-related lymphedema: recent updates on diagnosis, severity and available treatments. J Pers Med. https://doi.org/10.3390/jpm11050402
3. Sullivan-Myers C. Enhancing self-care self-efficacy and symptom experience of women with breast cancer-related lymphoedema: piloting the web-based LYSCA intervention. Department of Psychology: Macquarie University; 2018.
4. Woods L, Cummings E, Duff J, Walker K. Design Thinking for mHealth Application Co-Design to Support Heart Failure Self-Management. Stud Health Technol Inform. 217;241:97–102. PMID: 28809190.
5. Koczwara B, Lee J, Naghavi N, Bareham M, Wallen MP, Piller N et al (2025) "Do I buy my children shoes, or do I get a compression garment for my lymphoedema?" Australian stakeholder perspectives on cancer-related lymphoedema care. J Cancer Surviv. https://doi.org/10.1007/s11764-025-01770-z
6. Ryans K, Perdomo M, Davies CC, Levenhagen K, Gilchrist L (2023) Rehabilitation interventions for the management of breast cancer-related lymphedema: developing a patient-centered, evidence-based plan of care throughout survivorship. J Cancer Surviv 17(1):237–245. https://doi.org/10.1007/s11764-021-00991-2

7. Braun V, Clarke V. Thematic Analysis. In: Maggino F, editor. Encyclopedia of Quality of Life and Well-Being Research. Cham: Springer International Publishing; 2020. p. 1–7. https://doi.org/10.1007/978-3-031-17299-1
8. Wong HCY, Wallen MP, Chan AW, Dick N, Bonomo P, Bareham M et al (2024) Multinational association of supportive care in cancer (MASCC) clinical practice guidance for the prevention of breast cancer-related arm lymphoedema (BCRAL): international Delphi consensus-based recommendations. eClinMed. https://doi.org/10.1016/j.eclinm.2024.102441
9. Morton K, Dennison L, May C, Murray E, Little P, McManus RJ et al (2017) Using digital interventions for self-management of chronic physical health conditions: a meta-ethnography review of published studies. Patient Educ Couns 100(4):616–635. https://doi.org/10.1016/j.pec.2016.10.019
10. Asbjørnsen RA, Børøsund E, Hjelmesæth J, Smedsrød ML, Ollivier M, Wentzel J, Clark MM, van Gemert-Pijnen JE, Solberg Nes L (2025) Digital behaviour change intervention for weight loss maintenance in adults with obesity: a feasibility pilot study of eCHANGE. Behav Inf Technol 44(11):2577–95. https://doi.org/10.1080/0144929X.2024.2399299
11. Saleem M, Kühne L, De Santis KK, Christianson L, Brand T, Busse H (2021) Understanding engagement strategies in digital interventions for mental health promotion: scoping review. JMIR Ment Health 8(12):e30000. https://doi.org/10.2196/30000
12. Kerr D, Ahn D, Waki K, Wang J, Breznen B, Klonoff DC (2024) Digital interventions for self-management of type 2 diabetes mellitus: systematic literature review and meta-analysis. J Med Internet Res 26:e55757. https://doi.org/10.2196/55757
13. Hosseinzadeh H, Downie S, Shnaigat M (2022) Effectiveness of health literacy- and patient activation-targeted interventions on chronic disease self-management outcomes in outpatient settings: systematic review. Aust J Prim Health 28:83–96. https://doi.org/10.1071/PY21176
14. Ntoumanis N, Ng JYY, Prestwich A, Quested E, Hancox JE, Thøgersen-Ntoumani C et al (2021) A meta-analysis of self-determination theory-informed intervention studies in the health domain: effects on motivation, health behavior, physical, and psychological health. Health Psychol Rev 15(2):214–244. https://doi.org/10.1080/17437199.2020.1718529