

Understanding the value of codesign: exploring participant experiences



Background

Breast Cancer Network Australia (BCNA) is Australia's leading breast cancer consumer organisation. It works to ensure that all Australians who are affected by breast cancer receive the very best care, treatment and support.

BCNA engages with consumers through various mechanisms, including training consumers through the Seat at the Table program, to ensure that lived experience is central to its work, and to be able to embed consumer representation in external projects that seek to improve outcomes for those with breast cancer. Healthcare professionals (HCPs), researchers, and other professionals are also important stakeholders that inform, support, and collaborate on BCNA's work. National surveys conducted in 2023 reported that nurses play a key role in referring individuals to BCNA information and support services (Refer to Poster #45 "Enhancing Person-Centered Breast Cancer Care: Evaluating Information and Support Needs").

There is increasing recognition of the benefits and value of including the voices and experiences of end-users into the design and development of services and products (codesign).

The Australian Cancer Plan (ACP) states that health services should provide co-designed, culturally responsive resources to enable healthcare providers to communicate respectfully with consumers.¹ The codesign method seeks to involve end-users in both the problem definition and solution generation.^{2,3} In BCNA's capacity, these end-users may be consumers as well as other external stakeholders such as healthcare professionals.

Although co-design projects are increasingly reported, few studies have explored the experiences of participants, and even fewer explore experiences of both consumer and external stakeholders.

Aim

This research study aimed to:

- assess the experiences of consumers with lived experience (LE) and external stakeholder (ES) participants in codesign projects
- assess whether BCNA's codesign practice meets best practice.

Methodology

Participants: Eligible participants had taken part in at least one of two codesign activities conducted by BCNA in 2023 as members of established project working groups, advisory panels or attendees of the activity itself. The codesign projects include the development of a national survey (project 1) and the delivery of a roundtable event to raise awareness of the need to establish methods of counting the prevalence of metastatic breast cancer in Australia's cancer statistics (project 2). To ensure participants from both projects were interviewed, interview quotas were established.

Procedure and Data Collection: participants were invited by email to take part in the research study between December 2023 and February 2024. Semi-structured interviews were conducted via the telephone or online using an interview guide. Interviews lasted approximately 30 minutes and were conducted by the same female behavioural researcher. Notes on the interview were recorded afterwards. Participants had no prior relationship with the researcher.

Results

Eleven semi-structured interviews were conducted with participants of the codesign activities and coding structures were developed based on themes and subthemes emerging from the data.

	Co-design project 1	Co-design project 2
Lived Experience (LE)	👩👩👩👩	👩👩
External Stakeholders (ES)	👩	👩👩👩

If you need a consumer for your next project, contact BCNA for more information about the Seat at the Table Program by scanning the QR Code opposite.



Emerging themes

	Lived Experience	External Stakeholders
Respected and being heard	" [I] feel that my input was valued. Exactly the same as everyone else's, and it was a fairly good consensus kind of approach too."	ES mentioned that they thought the organisation of the discussion enabled views from different groups to be heard by all and that this respected the range of experiences in an area.
Diversity of views and experiences	LE recognised that part of their role was to ensure the experiences and needs of people from the different diverse groups were considered and generally acknowledged the need for inclusiveness. <i>"It's fabulous when people have diverse experiences coming to the table, you know, diverse work experience and life experience."</i>	Whilst ES did not comment on the need for diversity of consumer voices, but all noted the positive impact of having the consumers present at the meeting, ensuring that their voices and experiences were kept in focus during discussion.
Positive Experiences	LE reported positive experiences of working with others and the connection they felt with this group during the co-design process.	ES acknowledged the positive way BCNA works with consumers and how they utilise codesign in their projects.
Supported	LE commented that they felt well supported by BCNA in preparing for the workshops/event, managing if they missed a meeting and in recognition of their contributions. Most LE felt that communications with BCNA were managed well and that they had information about the role and the task they needed.	ES felt that they were well supported by BCNA in attending the meeting and in understanding what was expected of them during the meeting. <i>"I think also because there has been that codesign, a lot of work, you know, in the lead up to the actual day, there's so much work that's put into scoping how the issue is going to be addressed"</i>
Codesign—it's the BCNA way	LE felt supportive and positive of how BCNA uses codesign with many commenting that this was the way BCNA operated anyway. They expressed views on the importance of seeking input from a range of consumers right from the beginning of a project.	ES believe there is strong benefits to BCNA of working closely with consumers through codesign with one commenting consumer involvement increases the strength of their messages and creates engagement. <i>"They are passionate, they've got a just cause, they know how to lobby and how to produce material that is engaging."</i>

Areas for improvement

	Lived Experience	External Stakeholders
Expectations and communications	LE felt there was some lack of clarity and uncertainty around participants ongoing role in the project as it went forward. <i>"... as the committee or the people that are involved, it might be nice to get a bit more in depth feedback."</i>	ES acknowledged the positive way BCNA works with consumers and how they utilise codesign in their projects. <i>"And it is a huge priority for BCNA to do this, but we all have our own priorities as well. So if it's not sort of front and centre and pushed upon us with a formal commitment and you know, perhaps a little bit more follow up..."</i>
Managing if people cannot attend meetings	For those LE that missed a meeting there was a mix of gratitude that they could still be involved in the project but also a sense that missing a meeting particularly the first one meant they had less information about the process and decisions already made.	N/A

Conclusion

Several guidelines outline that codesign projects should adhere to a set of principles that include seeing consumers as equal partners in the design process, openness and respect to ideas and opinions, capacity building and shared purpose. Findings from this research indicates that codesign projects run by BCNA adhere to these principles and that consumers and external stakeholders thought the process was respectful of their ideas and experiences, that different

experiences were sought and welcomed and that there was a shared purpose in the work that was being undertaken. There was also initial indication of some areas in which BCNA could improve the experiences of both consumers and external stakeholders in future co-design projects.

Research such as this that seeks to evaluate the experiences of codesign participants, particularly in alignment with guidelines and frameworks that are becoming more prevalent in Australia

and globally, can also help inform the codesign practices of other organisations, researchers, government, and patient groups to ensure codesign is achieving the desired outcomes and is mutually beneficial to all participants.

Note: A limitation to this study is that interview quotas were only reached for one group and participant numbers for the other projects were lower than expected, thus, caution is needed in interpreting results for these groups.

References:

1. Cancer Australia, 2023. Australian Cancer Plan (Summary), Cancer Australia, Surry Hills, NSW. https://www.cancer australia.gov.au/sites/default/files/publications/pdf/2023_ACP%20Summary%20Report%20DIGITAL_V9.pdf
2. AFCI. NSW AFCL, ed. Patient Experience and Consumer Engagement - A Guide to Build Co-design Capability. Agency for Clinical Innovation, NSW; 2019. <https://aci.health.nsw.gov.au/networks/mental-health/resources/co-design>

3. AAHA CHF. Experience Based Co-Design Toolkit. Consumer Health Forum and AAHA; 2017. <https://ahha.asn.au/experience-based-co-design-toolkit>

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