

# Experienced-based co-design for cardiovascular and chronic disease research

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The participatory co-design method has received significant attention recently. Experience-based co-design is an approach that enables patients (service users) and healthcare providers (service delivers) to co-design services and care pathways in partnership to improve health outcomes based on their experience. Traditionally, it was used as a quality improvement technique. Yet, it is a valuable participatory research design that can help improve health outcomes and be applied in nursing research. This paper will discuss its application in research among people living with cardiovascular multimorbidity and its practicalities, usability, and impact on cardiovascular and chronic disease research and models of care.

## Keywords

Cardiovascular • Chronic care • Co-design • Methods corner • Research method

## Learning objectives

- Introduce experience-based co-design (EBCD) as a participatory cardiovascular and chronic disease research method.
- Discuss practicalities in conducting data collection and analysis activities and facilitating co-design workshops.
- Provide an example of implementing EBCD in research studies among people living with complex cardiovascular multimorbidity, their family caregivers, and healthcare providers.

## Introduction

Experience-based co-design (EBCD) is a valuable participatory, human-centred design, method to help identify the needs and preferences of patients (service users) and healthcare providers and other stakeholders (service providers)<sup>1</sup> and develop evidence-based models of care. Experience-based co-design has been identified as a powerful tool to identify significant experiences and initiate and implement health service improvements by bringing service users and service providers together to partner and co-develop shared solutions for healthcare.<sup>2</sup> Experience-based co-design is an approach that actively involves all stakeholders/partners in the design process of the study or research protocol to ensure that the results will meet their needs and priorities. It has been used in a range of clinical services such as cancer, diabetes, drug and alcohol treatment, emergency services, palliative care, and mental health.<sup>3</sup> Experience-based co-design has been applied successfully to promote sustainable care improvement strategies, achieve

positive outcomes in patients' experiences, and design interventions by working together with patients and care providers.<sup>4</sup> Recently, EBCD has been recognized as an important participatory research design methodology to develop care improvement priorities and improve health outcomes, yet limited studies have implemented this in nursing and health research.<sup>5,6</sup>

Cardiovascular disease (CVD) is one of the leading causes of morbidity and mortality globally.<sup>7</sup> It is also an exemplary condition where individuals live with two or more chronic conditions, also known as multimorbidity.<sup>8</sup> A typical individual with CVD has multiple conditions and is estimated that about 55–98% of adults aged 60 years and older have at least two chronic conditions.<sup>9</sup> The proportion of individuals living with CVD and multimorbidity is projected to increase globally with an aging population, medical care advancements, and improved longevity.<sup>9</sup> Increasing multimorbidity poses a threat to the current healthcare system<sup>10</sup> which primarily applies a single disease or system-focused model of care.<sup>11</sup> Multimorbidity impacts beyond the individual;

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it affects individual quality of life and leads to higher caregiver burden, healthcare utilization, and healthcare costs.<sup>10,12</sup> Therefore, there is a need for an approach that explores significant determinants, challenges, and management strategies<sup>13</sup> for patients living with multimorbidity, considering the diverse perspectives and needs of patients, family members, and healthcare providers. An EBCD could be such research approach focusing on shared solutions to develop realistic goals and programmes as well as models of care for CVD and multimorbidity prevention and management.

Hence, this paper aims to identify EBCD as a participatory method for cardiovascular and chronic disease research, discuss its step-by-step process, and provide an example of studies informing care improvement priorities for those living with cardiovascular and chronic diseases.

## Overview of the methodology

### Introduction to experience-based co-design

Experience-based co-design is a collaborative, participatory research method that brings together multiple stakeholders, such as patients, family caregivers, and healthcare providers, to share their experiences and work collaboratively to identify care improvement priorities and activities to implement using co-design principles.<sup>3</sup> These care improvement priorities can advance patient experience, healthcare quality, and health outcomes. Experience-based co-design is a method that evaluates the experiences and emotions of multiple stakeholders involved in a healthcare event. An important highlight of this method is the ability of the method to adapt to specific circumstances based on the focus, timeline, and budget. In these adaptations, the core of the EBCD process comprises at least two portions: one that focuses on the experience gathering and the second the co-design itself.<sup>5,6</sup>

The EBCD method consists of iterative rounds of data collection and analysis as well as co-design. The flow of the EBCD method involves collecting experiences from patients and healthcare providers using qualitative interviews, observations, and group discussions. From these data, key themes and touch points are identified. Touch points are emotionally significant experiences or key moments/events that stand out from the experience. A short, edited film (trigger film) is also created from these data specifically from interviews consisting of touch points. The use of trigger film has been identified as an impactful method to convey experiences and initiate discussion on shared improvement priorities for outcomes. Then stakeholders work together in co-design sessions and working groups to identify realistic and feasible care improvement goals and activities. All these activities culminate in creating a final output called 'toolkit' which includes a summary of the process, care improvement priorities, and identified strategies.

The outputs of the EBCD, trigger film, and toolkit are used to improve the experiences of a greater patient population in healthcare settings.<sup>2</sup> These outputs can also be used to inform evidence that can be used for practice improvements and design models of care and for education, research,<sup>14</sup> and policy. Models of care, health education, research outcomes, and policies all affect patients and healthcare providers; involving these end users early in the need identification and programme design phase is crucial in achieving effective sustainable approaches.

### Step-by-step approach

The EBCD process may vary in terms of the number of total stages, but traditionally, it includes six stages (*Central Illustration*).<sup>2</sup> The six stages can take an average of 9–12 months to complete.<sup>2</sup> An online EBCD toolkit is available to ensure consistency in documentation and processes.<sup>3</sup>

The preparation or setup phase (Stage 1) includes identifying advisory members, procuring regulatory or ethical approval, and obtaining

support from the stakeholders who are relevant to the care process. Experience-based co-design data collection and validation (Stages 2 and 3) use in-depth narrative interviewing, an approach to elicit individuals' stories of their experiences,<sup>15</sup> and observation to identify multiple stakeholders' experiences and explore touch points in the care journey.<sup>16</sup> The touch points are reviewed with the participants in multiple groups using validation feedback events where participants are asked if the identified themes and touch points are reflective of their experiences and if there is anything missed. Filmed patient interviews are also edited to create trigger films that can be used for co-design sessions and co-design working groups (Stages 4 and 5) to identify and develop action items and strategies to implement improvement priorities. In some circumstances, working groups will also implement improvements. The final output can be a toolkit summarizing the findings, improvement priorities, and strategies to achieve improvement priorities, as well as a progress evaluation of the implementation. These outputs are shared via a celebratory event (Stage 6), a reflective event, where the outcomes and assessments are to be reviewed, analysed, and evaluated for implementation.

### Data analysis and reporting

Data collection and analysis are iterative processes throughout the EBCD study. The EBCD data primarily consists of qualitative interviews and observations, providing rich insights into experiences. The baseline participants' data, such as demographic and clinical characteristics, may include quantitative measures depending on the focus of the studies and study population. The summary of interview findings is generally developed as a trigger film. The shared improvement priorities and strategies/outcomes identified for implementation are summarized in a toolkit. Generally, this toolkit identifies study summary, improvement priorities, strategies to implement those priorities, and outcomes depending on the nature of the study and focus.

## Experience-based co-design and cardiovascular and chronic disease research: our experience

### Background

The research team implemented two nurse-led EBCD research studies focusing on identifying challenges, care preferences, and needs of individuals living with multimorbidity including CVD.<sup>17,18</sup> The end goal of the research was to develop an intervention that can help improve the quality of life and decrease disease/symptom burden for individuals living with multimorbidity. The author team recognized that the unique experiences of the participants living with multimorbidity are crucial to designing and implementing care improvement. Hence, EBCD was identified as an ideal method to understand participants' healthcare experiences and co-create healthcare improvement strategies for this population. The findings from the EBCD studies among those living with multimorbidity can be useful in informing evidence-based effective models of care, interventions for research, educational approaches, and policy initiatives (*Figure 1*). In this section of the paper, the authors will discuss the two research studies that adopted EBCD and the learnings and challenges in the process of designing and implementing EBCD studies.

### Sample and setting

#### Study 1

The study proposed to assess symptom trajectory and symptom burden and develop an effective and sustainable approach to meet the health needs of critically ill adults living with multimorbidity and their family members. The study included patients aged 55 years and older

Figure Six Steps for Experience-Based Co-Design Approach

**Central Illustration** Six steps for experience-based co-design approach.

living with multiple chronic conditions and with no documentation of cognitive impairment who met the criteria for being admitted to the intermediate care unit (IMCU) ( $n = 9$ ), their family caregivers ( $n = 2$ ), and health professionals ( $n = 12$ ) with experience working with patients with multimorbidity. All patients, their family caregivers, and healthcare providers were recruited from IMCU. Intermediate care unit also known as high-dependency unit is the specialized care unit where patients' care needs are more than the general floor but does not meet the requirement for intensive care needs. More than 50% of the patients in this unit reported to have multimorbidity.<sup>19</sup>

## Study 2

This study aimed to understand multimorbidity management priorities and gender differences in order to manage care from the perspective of patients, family caregivers, and healthcare providers and collectively develop a person-centred multimorbidity management toolkit. The study included patients aged 50 years and older living with heart failure and at

least one other chronic condition identified from the list of common chronic conditions and with no documentation of cognitive impairment who were admitted to the medical institution ( $n = 24$ ), their family caregivers ( $n = 7$ ), and health professionals ( $n = 15$ ) with experience working with patients with heart failure and multimorbidity. Patients and their family caregivers were recruited when hospitalized and through MyChart, an electronic health message system, after discharge from the hospital.

Both studies were implemented at an academic medical institution in an urban USA setting. Study 2 followed Study 1 in the timeline and extended the sample size, as well as including community-dwelling participants to capture the experience of a diverse patient population.

## Application of experience-based co-design

Both studies utilized a six-stage process of the EBCD. The preparation (Stage 1) started with planning for the study, applying for an ethical

Figure Use of Experience-Based Co-Design for Multimorbidity Management

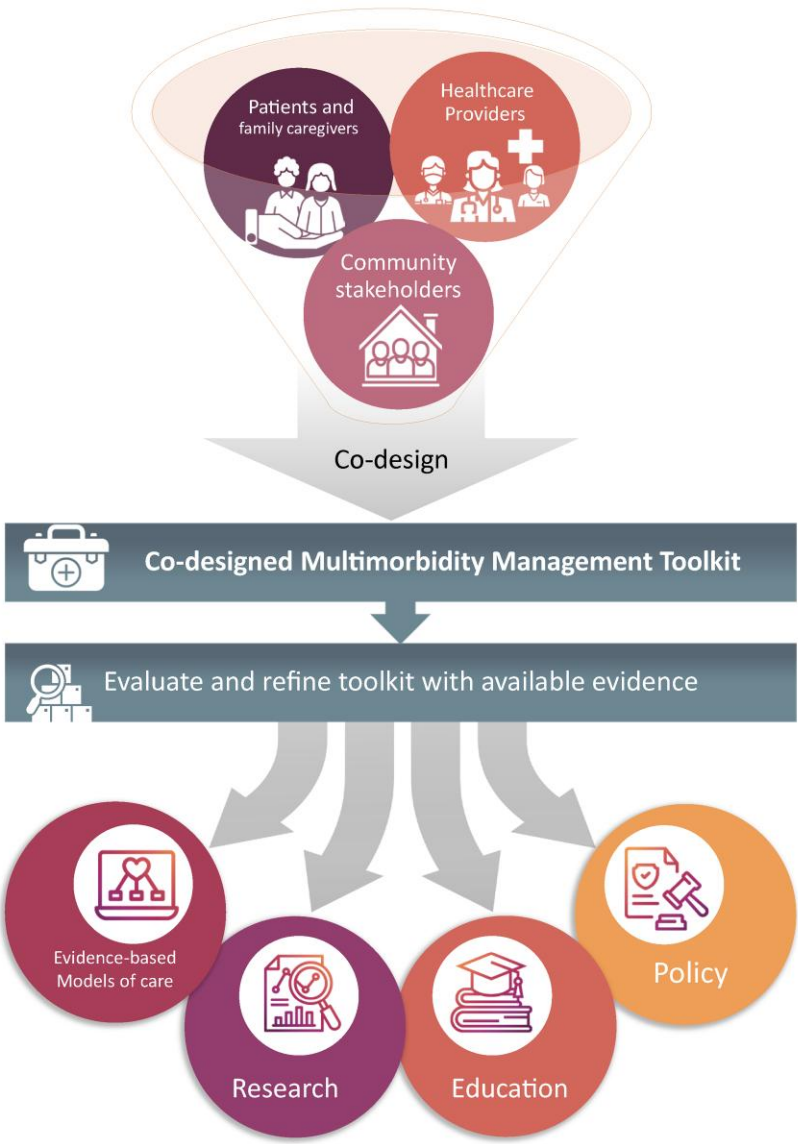


Figure 1 Use of experience-based co-design for multimorbidity management.

review board at the data collection site, training the research team, and developing rapport and relationships with clinical partners from the data collection unit, IMCU, and in the hospital. To design the EBCD processes, the study team also collaborated with human-centred design experts who were experts in social design and were dedicated to promoting the value of design in advancing diversity, justice, and equity. The integrated human-centred design approaches such as narrative interviews use storytelling, journey maps, and intervention prototypes to complement the EBCD process. Because of the unique methodology, recruitment of diverse participants (i.e. patients, family caregivers, and healthcare providers), and the recent coronavirus disease 2019 (COVID-19) pandemic, the research team had to navigate multiple committee approvals in addition to the ethical review board. These approvals included a review of project documents from the research start committee, research restart committee, departmental director of

Table 1 Question prompts were used to receive feedback on the trigger film

- What are your reactions to watching the film?
- Does it represent your experience as a patient, caregiver, or provider?
- Is there anything you would like to add to the film or the event today?

nursing, site’s nurse scientist, vice provost and chief risk officer, senior vice president of human resources, and imaging and recording project request committee. Following the ethical and regulatory approvals, the study team started recruitment activities.

**Table 2** Lessons learned when implementing experience-based co-design (EBCD)**Planning/adoption of EBCD study**

The EBCD's focus needs to be broad at the beginning, as specific improvement priorities are developed by working together with multiple stakeholders. In the first project, the study team wanted to focus on symptom burden, yet considering the experiences of participants, the improvement priorities were identified as communication, patient-provider relationship, caregiver burden, availability of resources, and care coordination and follow-up care.

The EBCD approach involves multiple parts of data collection, analysis, and teamwork, which is time-intensive and resource-intensive. Ensure teams are ready to adopt EBCD and build the skills/capabilities through working with experts and extensive trainings. Skills required include participant recruitment and retention, qualitative data collection, management and analysis, recording and editing of the narrative interview, organizing co-design session/focus group discussion, and note-taking and report-writing.

The EBCD studies have been traditionally carried out in an in-person setting; yet the COVID-19 pandemic required the research team to adjust. Although some patients were interviewed when hospitalized, most participants participated in a virtual setting utilizing HIPAA-compliant Zoom. This created challenges in coordinating study activities, including identifying appropriate times and approaches for data collection and co-design event activities. Designing a virtual EBCD study has the potential to address logistical constraints and harder-to-reach populations with certain limitations. Yet, it is critical to assess any limitations and utilize appropriate virtual conferencing technology considering participants' capacity. Technology access and literacy were some challenges for the participants to be part of the virtual co-design sessions.

**Getting approval**

As there are limited EBCD research studies and less is known about its research process, the ethical and regulatory review process might take a long time. Respect, diversity, equality, safety, accessibility, and confidentiality of the multiple stakeholders should be carefully considered in each stage of the EBCD. Hence, it comes with a thoughtful mapping of activities and a rigorous research approval process. The research team had to navigate multiple committee approval before final ethical approval. This was exacerbated by the COVID-19 pandemic. Yet, understanding it needs time and working closely with the review committee will be helpful.

The trigger film from the interview findings has been a powerful way to prompt the discussion on improvement priorities. However, some challenges were the negotiation with the ethical board and the media committee and the skills and technology requirements for recording and editing. It would be helpful to identify the needed resources and personnel at the planning of the study for recording, imaging, and editing during the planning phase.

**Recruitment and retention of participants**

It is important to consider the participants' willingness and capacity to be in the EBCD study which can be a lengthy process (9–18 months).

Identifying diverse groups of participants represented by socio-demographic characteristics as well as care experiences in each stage of EBCD is critical considering the focus of the study, as they may have different needs and outcomes. This is essential and should be considered to promote health equity. Sustaining participation process may include approaches such as being flexible on when and how participants are brought together, messaging or calling participants by identifying the right medium and time, building trust and rapport, and making participants valued for sharing their experience and inputs for the programme development.

Sustaining participation in the EBCD study could be challenging for some time depending on the focus of the participants. For example, the studies included older adults with complex cardiovascular multimorbidity, hence was challenging to have them attend each session or stage of the EBCD for a longer time. Rolling recruitment could be a valuable approach to keep the process going and receive diverse inputs and validation of previous discussions in such situations.

**Co-design sessions**

Bringing patients, family caregivers, and healthcare providers together to participate in the co-design process provides depth insight into models of care that were experienced by the participants. Yet, the facilitator's experience and skills in managing conflict and bias as well as ensuring equal voice and quality participation are some key considerations while organizing co-design session.

Multiple co-design sessions and being flexible will help get diverse perspectives and inputs. This will require flexibility in terms of how and when these people are brought together. Additionally, organizing multiple co-design sessions on multiple days and times as the second study chose to do was effective in including diverse participants' feedback and input for comprehensive data.

The goal of co-design event will help identify who attends these sessions. The need for organizing co-design sessions separately with patients and their family caregivers and healthcare providers or together in one workshop needs to be considered particularly in the view of power dynamics, relationships, and viewpoints around what is important. The need for individual or combined sessions can be identified from the participants' experiences and findings of the interviews/observations. Considering the sample size and shared themes among patients and providers, the studies invited all participants together for co-design sessions. The goal of the co-design sessions should be engaging in common goal-driven discussion which helps identify solutions or next steps.

**Other considerations**

Venue, catering, transportation, parking, and reimbursement are some of the logistical arrangements that need to be considered when designing EBCD, specifically for in-person co-design activities. As the study used a virtual platform due to the pandemic, participants received compensation (\$25 gift card) for their time and input for an individual interview, a co-design event, and a celebration event attendance.

EBCD itself is a type of human-centred design yet in the projects working with human-centred design experts added much value. Human-centred designs such as a storytelling approach during narrative interviews, journey map activities using mural platform during co-design events, and the use of Google Jamboard technology to receive inputs had facilitated EBCD activities. The authors recommend consulting with human-centred design experts to design and implement an EBCD study if resources are available.



Patients, family caregivers, and healthcare providers, including researchers, were interviewed (Stages 2 and 3) using a narrative storytelling approach to identify touch points. The transcribed interviews were shared with the participants and asked to validate to ensure verbatim transcripts correctly captured their experiences and emotions. The qualitative data were analysed using thematic analysis. Due to the COVID-19 pandemic, a virtual co-design event was held using HIPAA-compliant Zoom<sup>20</sup> technology (Stage 4). During the co-design event, participants first watched a short trigger film prepared based on the patients, family caregivers, and providers' interview themes and representative quotes. A group discussion was followed to identify participants' feedback on the film and lived experiences. Three questions (Table 1) were used to prompt responses. The discussion was followed to understand and journey map participants' disease trajectory from their lived experiences. The discussion was centred on the participants' lived experiences and directed to identify improvement priorities for multimorbidity management. A mural<sup>21</sup> platform, a cloud-based application that allows teams to work across locations, was used to facilitate the discussion. At the end of the event, participants ranked identified improvement priorities. Follow-up co-design working group sessions (Stage 5) were organized over Zoom as well, and conversations were continued via emails and Google Jamboard<sup>22</sup> platforms to identify specific strategies for improvement priorities. Additionally, the progress of the project and identified priorities were presented at clinical sites to receive additional feedback on the strategies for effectively implementing improvement priorities.

A toolkit was developed summarizing shared improvement priorities with specific strategies identified by the patients, family caregivers, and healthcare providers. As Study 2 was conducted after Study 1, the discussion and toolkit development combined improvement priorities/strategies identified from Study 1. The final toolkit developed is attached as a [Supplementary material](#) online, [Appendix S1](#). To share the study process and outcomes as well as receive additional feedback, a celebration event was organized, inviting all study participants and clinical partners (Stage 6). Additionally, findings were disseminated through conference and professional presentations as well as publications.<sup>17,18,23,24</sup>

## Summary of findings and next steps

The shared improvement findings on improvement priorities included themes such as communication, patient-provider relation, caregiver support, availability of resources during and at the time of discharge, and care coordination and follow-up care (Study 1)<sup>17</sup> and communication, health education, care coordination and follow-up care, and mental and emotional support (Study 2).<sup>23</sup> All the findings from the interview, co-design events, and toolkit were further analysed using intervention prototype methodology. Additionally, evidence-supporting findings were reviewed in the literature to help support intervention components. Through an extensive process of EBCD and human-centred designs, the findings helped to inform an intervention titled: Care COORDInatioN And sympTom managEmEnt (COORDINATE) programme for people living with multimorbidity. Currently, the research team is pilot testing COORDINATE intervention. The intervention protocol<sup>25</sup> has been published, and the pilot study results will be published elsewhere.

## Considerations in applying experience-based co-design: lessons learned

These example studies were successful in achieving aims and implementing study activities. The studies followed an online EBCD toolkit which is available online to ensure consistency in documentation

and processes.<sup>3</sup> However, there were several challenges and learnings in the process. Key learning points were identified related to planning, getting approval, recruitment and retention of participants, co-design events organization, and other considerations (Table 2).

## Conclusion

Experience-based co-design is a promising participatory research methodology where experiences of those who deliver care and who uses care are explored for a more holistic understanding of needs and care improvement priorities. The approach is ideal when the goal is to design or improve healthcare services based on the experiences and outcomes of individuals who use these services. The EBCD approach can also be a valuable tool for cardiovascular and chronic care research, bringing multiple stakeholders together to help improve outcomes. Specifically, with increasing multimorbidity and complexity of models of care, the collaborative co-design approach will help develop, implement, and evaluate a multimorbidity management toolkit with care improvement priorities that can inform models of care as well as education, research, and policy.

## Supplementary material

[Supplementary material](#) is available at *European Journal of Cardiovascular Nursing* online.

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## Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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