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Using stakeholders' experiences to redesign health services for persons living with heart failure: a case study protocol in a Swedish cardiac care setting

Anne-Marie Suutari ,[1,2] Annika Nordin,[1] Sofia Kjellström,[1] Johan Thor ,[1,3] Kristina Areskoug Josefsson[1,4]

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[1]The Jönköping Academy for Improvement of Health and Welfare, Jönköping University, Jönköping, Sweden
[2]Department of Internal Medicine and Geriatrics, the Highland Hospital (Höglandssjukhuset), Region Jönköpings län, Eksjö, Sweden
[3]Health Services Department, Stockholm County Council, Stockholm, Sweden
[4]Faculty of Health Studies, VID Specialized University, Oslo, Akershus, Norway

Correspondence to
Dr Anne-Marie Suutari;
anne-marie.suutari@ju.se

ABSTRACT

Introduction Clinical guidelines promote recognising persons with heart failure (referred to as PWHF) as coproducers of their own care. Coproduction of healthcare—involving PWHF, families and professionals in care processes—aims to promote the best possible health. Still, it is unclear how to coproduce heart failure (HF) care. This study explores whether and how Experience-Based Co-Design (EBCD) involving PWHF, family members and professionals can be undertaken online, in a Swedish cardiac care setting, to codesign improved experiences of HF care.

Methods and analysis In EBCD, stakeholders' experiences are solicited to redesign healthcare services. First, we will undertake a thematic analysis of field notes from consultations and filmed/audio-recorded interviews with PWHF (n=10–12). This analysis will identify 'touchpoints' (emotionally positive/negative events that shape overall service experiences), edited into a 'trigger film'. Next, a thematic analysis of family members' (n=10–12) and professionals' (n=10–12) interviews will identify key themes mirroring their experiences. Separate feedback events with each stakeholder group will confirm identified touchpoints and key themes and identify areas for HF care improvement. At a joint event, prompted by the 'trigger film', stakeholders will agree on one area for HF care improvement. A team including PWHF, family members and professionals, led by an improvement adviser, will then plan, design, implement and evaluate an improvement activity addressing the identified problem area. A deductive thematic analysis of field notes, project documentation and stakeholder focus group interviews, underpinned by *MUSIQ*, will identify how organisational conditions influence the process. Quantitative measurements, describing the results of the improvement activity, will be integrated with qualitative data to strengthen the case. To reduce resource intensity, we will use online tools during the process.

Ethics and dissemination The Swedish Ethical Review Authority approved the study in May 2021. The results will be disseminated through seminars, conference presentations and publications.

Strengths and limitations of this study

- This is the first Experience-Based Co-Design (EBCD) project in a cardiac care contex in Region Jönköping County, in line with the regional system-wide efforts to promote improved health for persons with chronic disease.
- Persons living with heart failure, their family members and professionals will be engaged in codesign of healthcare processes though involvement in an EBCD project.
- EBCD offers a unique opportunity to codesign healthcare services through bringing different experiences from various stakeholders together.
- The resource intensity for the EBCD process is reduced though the use of online communication tools.
- Inclusion and exclusion criteria might limit participant selection to individuals who are considered easy to coproduce health and care with.

INTRODUCTION

Heart failure (HF) is a common yet underdiagnosed chronic heart disease. Clinical HF guidelines recommend recognising persons with heart failure (from now on referred to as PWHF) as coproducers of their own care.[1 2] Coproduction of health and care—involving PWHF, their family members and professionals in the planning, design, delivery and assesment of care processes—aims to promote the best possible health through joint learning about how to meet the stakeholders' needs.[3–8] Although various approaches to coproduced HF care have been tried worldwide, it is still unclear what design to use in different healthcare settings for the best possible coproduced care.

Experience-Based Co-Design, EBCD, is a participatory quality improvement process in which patients, family members and

professionals use stakeholders' experiences to codesign improved healthcare services.[9 10] EBCD has the benefit of bringing different experiences from various stakeholders together. Thus, EBCD offers a unique opportunity to codesign healthcare services that meet the needs of all stakeholders.[9 10] EBCD might also be useful when aiming for improved health for and with PWHF. To our knowledge, this study protocol describes the first study aiming to explore and describe whether and how EBCD involving PWHF, family members and professionals can be undertaken online, in a Swedish cardiac care setting, to codesign improved experiences of HF care. The study will be set in a Swedish health district and is part of regional system-wide efforts to promote improved health for persons with chronic disease.

Living with HF

In Sweden, approximately 10% of people over 80 years of age suffer from HF.[11] However, HF is an underdiagnosed medical condition.[12] In HF, the heart's structure or function is impaired leading to failure to pump enough blood (and thus oxygen) to the body's tissues. Furthermore, fluid accumulation in the body's tissues causes symptoms such as swelling of the legs, breathlessness on exertion (due to fluid accumulation in the lungs), weight gain and fatigue.[1] HF is always caused by an underlying condition such as a myocardial infarction, hypertension, cardiac arrhythmias or valvular disease. Thus, PWHF typically are older and fragile with comorbidities leading to frequent hospitalisations, reduced quality of life and cognitive impairment.[1 13] Also, low health literacy levels among PWHF reduce their capability to engage in self-care activities.[1 14 15]

Clinical HF guidelines promote recognising PWHF as coproducers of their own care, for example, by inviting them to engage in monitoring and self-management of HF.[1 2] However, the research from Suutari *et al*[16] implies that PWHF, their family members and professionals have limited understanding of patients being codesigners or coproducers of health and care as a practice and appear to view it as an 'add-on' to traditional care and rarely as an approach for improving healthcare processes. These results are in line with research by Holland Hart *et al*,[17] indicating that clinicians and the public view coproduction as 'the patient's involvement in decisions about their own care rather than involvement in the planning, delivery and improvement of the service as a whole'. Although various approaches to HF care have been tried worldwide, it is still unclear what design to use in different healthcare settings for the best possible coproduced care.

EBCD is a step-by-step participatory healthcare quality improvement process in which patients', family members' and professionals' experiences are solicited and used to codesign healthcare services.[9 10] This approach might also be useful when aiming for coproduced and improved health and care for and with PWHF. This study aims to test this hypothesis.

EBCD: using stakeholders' experiences to redesign care services

During the EBCD process, stakeholders' care experiences are captured using observations of consultations, individual narrative-based filmed or audio-recorded interviews with patients, family members and professionals, as well as stakeholder feedback events. The patients' interviews are edited into a 20–30 min 'trigger' film highlighting the touchpoints

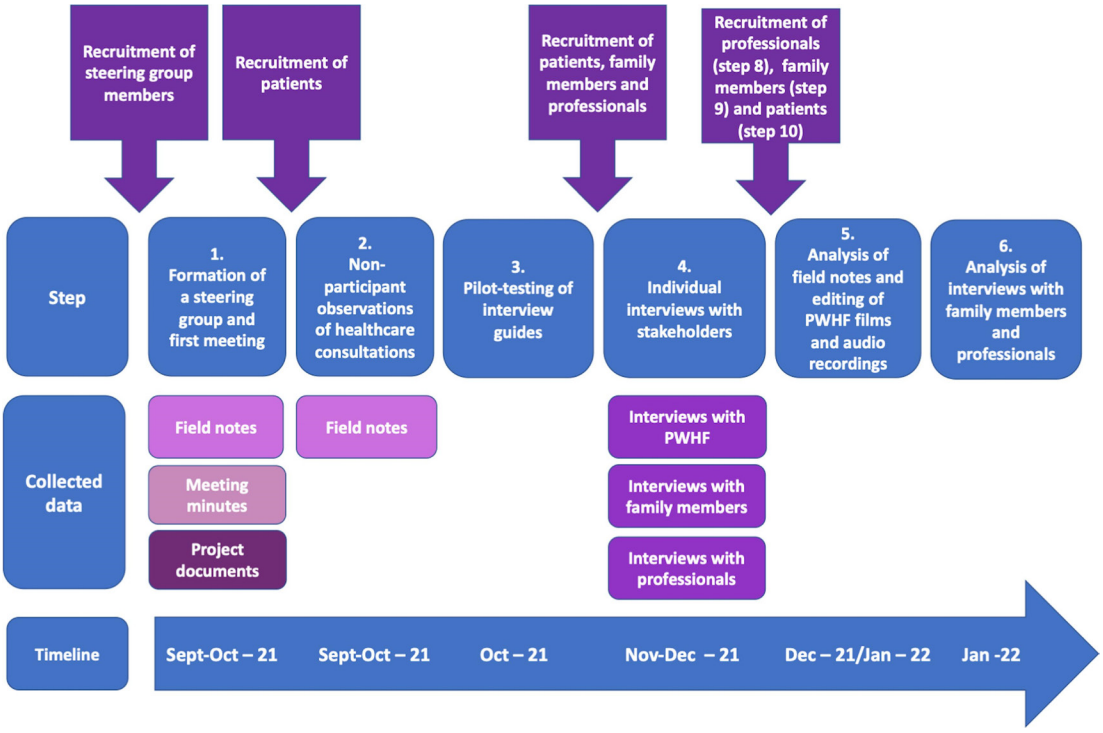

Figure 1 Data collection, data analysis and the timeline for steps 1–6 of the case study. PWHF, persons with heart failure.

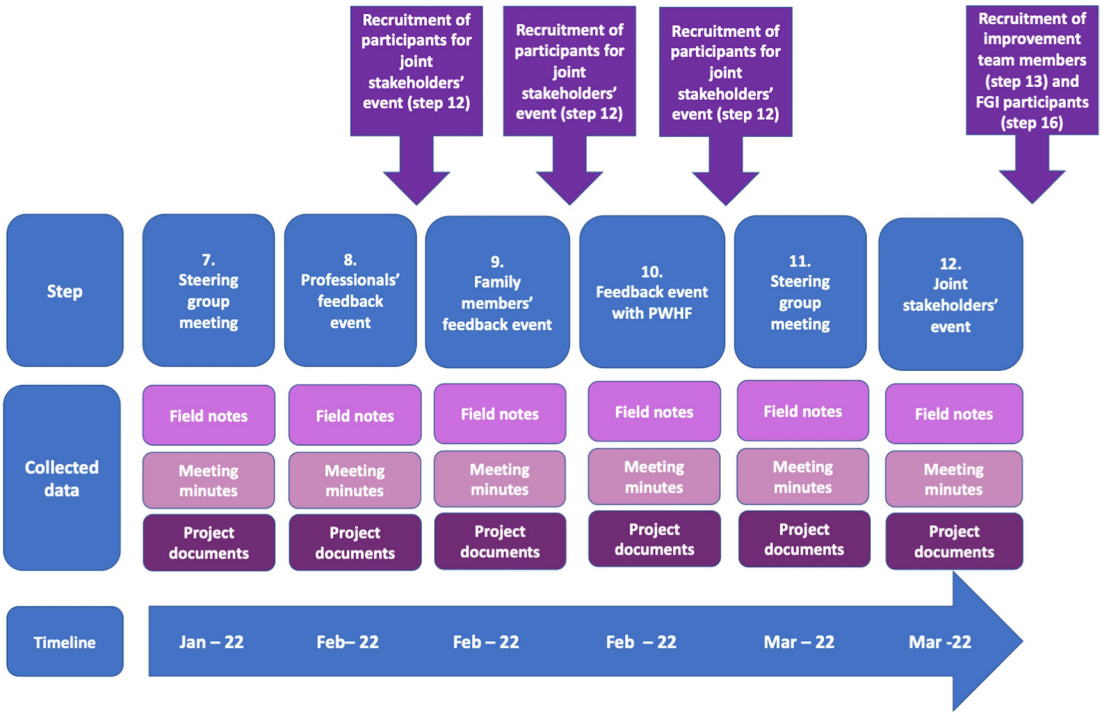

Figure 2 Data collection, data analysis and the timeline for steps 7–12 of the case study. FGIs, focus group interviews; PWHF, persons with heart failure.

identified from their interviews. Touchpoints are emotionally significant positive or negative events, situations or key resonating themes that shape patients' overall service experience and that may have arisen in several interviews.[18 19] Based on the recognised touchpoints, patients, family members and professionals jointly discuss and propose priorities for healthcare service improvements. Those proposed service changes are then designed, planned, implemented and evaluated by small improvement teams that include patients, family members and professionals.

EBCD: strengths and limitations

EBCD has the benefit of bringing different experiences from various stakeholders together. Thus, EBCD offers a unique opportunity to codesign healthcare services that meet the needs of all stakeholders.[9 10 18] Gathering experiences from various stakeholders by using step-by-step toolkits enables researchers to systematically gather stakeholders' experiences.[9 10] EBCD has been used in various healthcare contexts, for example, in emergency care,[20] maternity care,[21] paediatric care,[22] palliative care,[23] cancer care[24] and mental care.[25] Results of previous research imply that EBCD can (1) improve the individual patient experience[20]; (2) facilitate the identification of service touchpoints useful for service redesign[21 24]; (3) enable healthcare professionals to appreciate patients as equal partners in healthcare improvement efforts[22] and (4) enhance the voice of patients and families by using filmed narrative interviews.[23] Limitations of the EBCD process include resource intensity in terms of the amount of time used to complete the process and travel (for patients and carers to attend the interviews and various events).[18] Equipment and/or external expertise for filming, film editing and involvement of external designers may increase project costs and thus not always employable.[26 27]

Knowledge gaps

To our knowledge, EBCD has not been used previously within HF care. There is limited knowledge about what kind of touchpoints, influencing the health of PWHF, their quality of life and service experiences, can be identified though EBCD. Also, there is limited knowledge about what changes in HF care are suggested by PWHF, their family members and professionals based on the identified touchpoints. Furthermore, there is limited knowledge about how organisational conditions influence the stakeholders' planning, design, implementation and evaluation of an intervention aimed at improving HF care. In a traditionally technical driven healthcare sector such as cardiac care, this study addresses these gaps through bringing various stakeholders together and using different care experiences to generate new knowledge about how to redesign healthcare processes.

The EBCD process is resource intense, especially concerning (1) travel time for stakeholders to participate in interviews and EBCD events (2) needs for equipment, and (3) external expertise for filming and editing interviews.[18 28] We attempt to reduce resource intensity by increased use of online tools in the EBCD process. Relocation of participant interaction from physical meetings to the digital space can generate several challenges regarding digital meeting tools and how meetings are designed and managed.[29] To our knowledge, no previous research has explored how online EBCD would play out.

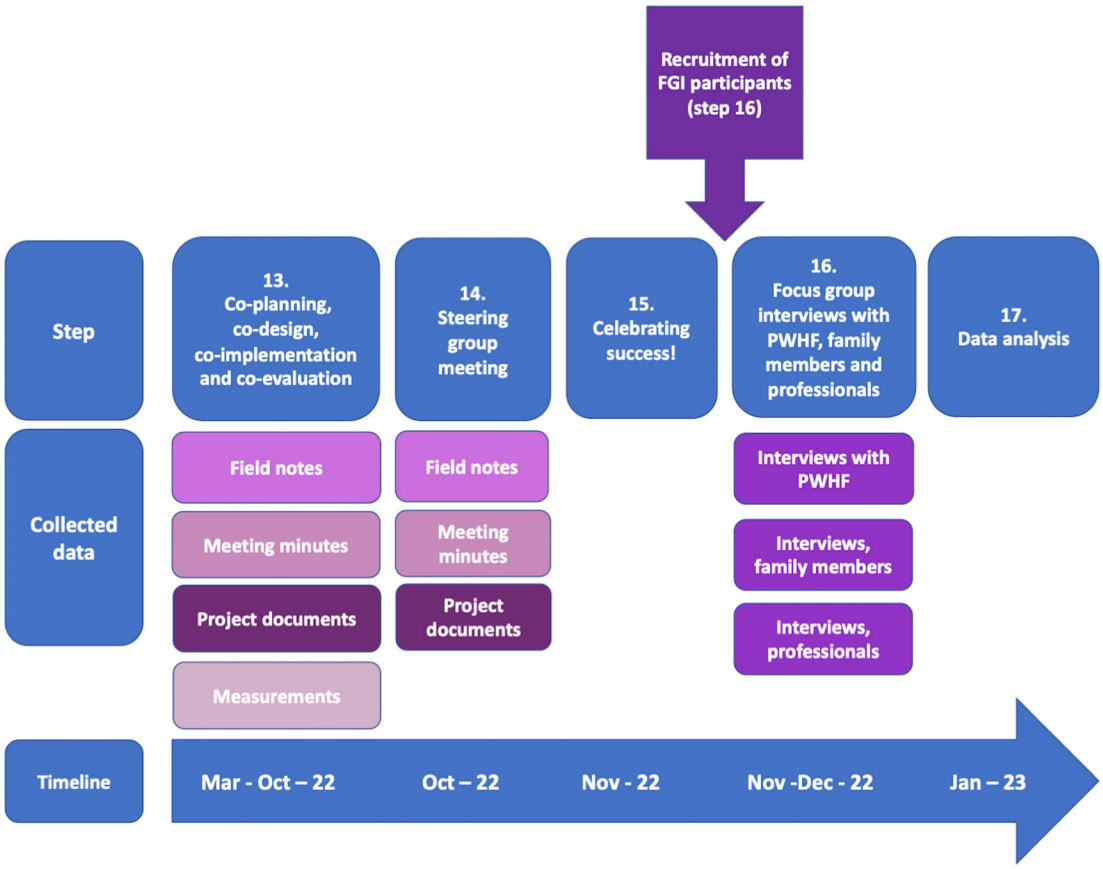

Figure 3 Data collection, data analysis and the timeline for steps 13–17 of the case study. FGIs, focus group interviews; PWHF, persons with heart failure.

Aims

This study is part of the Samskapa research programme.[30] The overall aim is to explore and describe whether and how EBCD involving PWHF, family members and professionals can be undertaken online, in a Swedish cardiac care setting, to codesign improved experiences of HF care. The research objectives are:

1. to identify emotionally significant events and situations (touchpoints), influencing the health and quality of life of PWHF, when using EBCD,
2. to identify what changes in HF care PWHF, their family members and professionals propose, based on the identified touchpoints,
3. to explore how organisational conditions influence the PWHF', family members' and professionals' design, planning, implementation and evaluation of a healthcare quality improvement intervention in a Swedish HF care context.

METHODS AND DATA ANALYSIS

Methods

Study design

This case study[31] was originally planned to start in June 2021. However, due to the COVID-19 pandemic, the start was postponed. The study started on 1 September 2021 and is planned to end on 31 January 2023. Figures 1–3 offer a detailed visual presentation of the timeline for the EBCD process and data collection.

Setting

The study will be set in a cardiac ward at the Department of Internal Medicine and Geriatrics and a primary care centre (PCC) in a health district in southern parts of Sweden. The district's hospital and PCCs serve an ageing population, with chronic heart disease being a major cause of morbidity and mortality. This context, with its long tradition of healthcare quality improvement activities,[16 32–36] has an ambition to incorporate patients' and family members' involvement in care improvement initiatives as a part of routine care.[37] Also, the health district and the region's municipalities and university have agreed to collaborate in research and education. This close relationship between frontline healthcare microsystems and academia is a further prerequisite for conducting research regarding how coproduced quality improvement initiatives work in practice. To date, the coproduction of healthcare and the involvement of patients in quality improvements have not been widespread within the context.

Study participants and recruitment

Three stakeholder groups will be recruited:

1. PWHF (n=10–12).

2. Family members to PWHF (n=10–12).
3. Professionals working in specialised cardiac care (n=5–6) or in a PCC (n=5–6).

A sample size of up to 10–12 participants for each stakeholder group has been used in other EBCD projects.[38] To describe the study sample, participant demographic profiles will be collected for PWHF (age, gender, occupation, years with HF diagnosis); family members (age, gender, occupation) and professionals (gender, profession, years in current job role). The participants' identities will be anonymised on presentation of the results. Since not all study participants are expected to participate in all steps, it may be necessary to recruit new study participants during the process. As the EBCD process unfolds, written informed consent will be obtained prior to all new steps involving stakeholder participation and data collection.

A PCC nurse working with PWHF suggests eligible persons and family members for participation. PWHF are eligible for participation if they (1) suffer from HF and (2) live and receive HF care within the health district. Family members are eligible if they are family members or informal care givers to the PWHF. Individuals are excluded if they (1) are under 18 years of age; (2) are unable to consent, for example, due to cognitive impairment or acute illness; (3) cannot speak and understand the Swedish language or (4) have received care from the lead researcher, who works as a cardiologist in the study context. The lead researcher will contact eligible persons by telephone to provide further oral information about study participation. Professionals working in a cardiac ward or in the PCC will be invited by the lead researcher to join the study during workplace meetings and through information letters sent via email. Only participants who have participated in earlier steps are invited by the lead researcher for final focus group interviews (FGIs) exploring how organisational conditions influence the stakeholders' design, planning, implementation and evaluation of a quality improvement intervention. Four to six persons represents an appropriate number of individuals to include in FGIs for data collection.[39] The next section offers a detailed description of the steps of the EBCD process including data collection for this case study.

The EBCD process, data collection and data analysis

Step 1: formation of a steering group and first meeting

The EBCD process will be led by a steering group including a project manager (the lead researcher), managers of included operations, 1–2 patient representatives, 1–2 family member representatives, 1–2 professionals and a nurse improvement adviser (IA). The lead researcher holds a cardiologist position in the study context. She has extensive knowledge about HF care as well as other cardiac care paths. Involved managers are the manager of a department of internal medicine and geriatrics and the manager of a primary care centre. The IA is employed by RJC and is trained to lead healthcare quality improvements aiming to redesign healthcare. Field notes, meeting minutes and project documentation will be collected by the lead researcher during steering group meetings to inform the case study.

Step 2: non-participant observations of healthcare consultations

After obtaining informed consent, a non-participant observer will conduct naturalistic observations during 10–12 healthcare consultations with PWHF. Non-participant observations during healthcare consultations in a PCC provides information about the relationships, behaviours and communication between PWHF and nurses or PWHF and physicians. In naturalistic observations the researcher records what he/she sees when studying the participants' spontaneous behaviour in natural surroundings and situations.[40] With non-participant observations, the researcher gets close to the research field as an outsider or as a guest.[41] By observing relationships, behaviours and communication, the researcher's understanding of the context and phenomenon being studied may improve.[42 43] Field notes, collected during these consultations, form data to inform the case study.

Step 3: pilot testing of interview guides

The lead researcher will test the semistructured interview guides exploring different stakeholders' experiences of HF care with two PWHF, two family members and two professionals prior to data collection. The semistructured interview guides, that will be used during patients' and family members' interviews, are organised to reflect a patient journey. Thus, the guides are organised to capture experiences of the following topics:

- Referral/first HF symptoms; tests and investigations; diagnosis; treatment; discharge and follow-up.
- Satisfaction; information; support; influence and coping.
- What has worked well? What can improve?

The interview guides for professionals reflect their experiences of HF care and their thoughts about patients' and family members' experiences.

Step 4: individual interviews with stakeholders

Individual interviews with PWHF (n=10–12), family members (n=10–12) and professionals (n=10–12) will be conducted by the lead researcher after informed consent. The interviews, with a duration of approximately 60–90 min, will be guided by semistructured interview guides exploring different experiences of HF care. By using Microsoft Teams, an online communication tool previously recommended for interview data collection,[44–46] the interviews can be conducted safely, enabling physical distancing during the COVID-19 pandemic. Also, using Microsoft Teams reduces the time for travel for PWHF and family members to attend the interviews and various events and simplifies the data collection of filmed and audio-recorded interviews. At the end of all interviews, the lead researcher will invite interviewees to participate in feedback events for PWHF, family members

and professionals (steps 8–10). Written informed consent will be obtained from stakeholders willing to participate in upcoming EBCD events.

Step 5: analysis of field notes and editing of PWHF films and audio recordings

The lead researcher will undertake an inductive thematic analysis[47] of field notes form observations from healthcare consultations and filmed/audio-recorded interviews. This analysis aims to identify PWHF' touchpoints to HF care. To mirror these touchpoints, the filmed/audio-recorded interviews will be edited into a 20-30 min 'trigger film' and will be structured to reflect a patient journey. This film will prompt discussions about HF care experiences and how to improve those experiences in the PWHF feedback event (step 10) and the joint stakeholder event with PWHF, family members and professionals (step 12).

Step 6: analysis of interviews with family members and professionals

To mirror the family members' and professionals' HF care experiences, the lead researcher will undertake a thematic analysis[47] of interviews with these stakeholder groups. Key themes from these analyses will prompt discussions and will be validated at feedback events with family members (step 8), professionals (step 9) and the joint stakeholders' event (step 12).

Step 7: steering group meeting

A steering group will meet to discuss work progression and to plan for future steps. Field notes, meeting minutes and project documentation will be collected by the lead researcher to inform the case study.

Step 8 and step 9: professionals' and family members' feedback events

The professionals' and family members' feedback events will be managed using Microsoft Teams. All feedback events start with participants making an agreement with each other to ensure confidentiality and to make sure that everybody is treated respectfully and is invited to share their personal stories. The IA facilitates the discussions and ensures that the discussion climate is sound. The purpose of these events, facilitated by an IA and with a duration of 3 hours each,[18] is to bring stakeholders together to discuss their HF care experiences and to identify service issues needing improvements. The necessary improvements are then further discussed, in the joint stakeholder event (step 12). The feedback events will be prompted by findings from observations and interviews. Depending on the results from the discussions, that is, depending on the chosen areas of improvement, additional stakeholders will be invited to join the joint feedback event (step 12).

Step 10: feedback event with PWHF

PWHF feedback event (duration 5 hours[18]) will be managed using Microsoft Teams and will be facilitated by the IA. After watching the 'trigger film', PWHF will be engaged in an emotional mapping exercise.[48] This exercise is a service design tool facilitating the understanding of the triggered service users' feelings, and thus making it possible to create important service improvements. Touchpoints identified from observations of consultations and interviews as well as the PWHF responses to the 'trigger film' will be written down on a timeline representing the journey through the HF care process. The exercise will generate a visual presentation of the care journey and will enable the identification of key points that PWHF feel could have been managed differently to improve their experiences of HF care. These key points represent potential areas for service improvements from the PWHF' point of view and will be discussed further in the joint stakeholder event (step 12). Depending on the results from the discussions, that is, depending on the chosen areas of improvement, additional stakeholders will be invited to join the joint feedback event (step 12).

Step 11: steering group meeting

A steering group will meet to discuss work progression and to plan for future steps. Field notes, meeting minutes and project documentation will be collected by the lead researcher to inform the case study.

Step 12: joint stakeholders' event

PWHF, family members, professionals and any additional stakeholders requested during previous steps will meet to watch the 'trigger film', followed by a joint discussion about stakeholders' experiences. The discussion will be prompted by the information gathered during previous EBCD steps. Participants will be divided into smaller groups for further discussions and exploration of the HF care experiences. The aim of this joint event is to collectively agree on one area for service improvement work. During this event, PWHF, family members and professionals will be asked by the lead researcher to form an improvement team to coplan, codesign, coimplement and coevaluate an improvement initiative addressing the priority area of choice.

This event (duration 3 hours[18]) will be managed using Microsoft Teams and facilitated by the IA. Meeting minutes, project documentation and field notes will be collected by the lead researcher during this event to inform the case study. During and after this event the lead researcher will invite patients, family members and professionals to join the final FGIs (step 16) exploring how the organisational conditions influence codesigned improvement work.

Step 13: codesign, coplanning, coimplementation and coevaluation of the improvement activity

Previous work indicates that an EBCD process typically takes 6–12 months to complete.[26] During an 8-month period, with a break for summer holidays, an IA will lead an improvement team with PWHF (n=2), family members (n=2), professionals (n=2). A team size of six people is recommended for this stage of the EBCD process.[9] The

team is going to codesign, coplan, coimplement and coevaluate an improvement initiative addressing the jointly identified priority area of choice. Quantitative measurements according to the clinical value compass[48] will be developed by the team. The clinical value compass is a tool that facilitates the evaluation of improvement activities from four different perspectives: (1) functional status; (2) satisfaction with healthcare and perceived benefits; (3) costs; and (4) clinical outcomes. Through repeated measuring, these measurements can be used to quantify the results of the improvement activity.[49] Meeting minutes, project documentation and field notes from observations will be collected by the lead researcher during team meetings to further inform the case study.

Step 14: steering group meeting

A steering group will meet to discuss work progression and to plan future steps. Field notes, meeting minutes and project documentation will be collected by the lead researcher to inform the case study.

Step 15: celebrating success!

All participants are invited to celebrate the finalised EBCD process. During this event, the outcomes of the process will be presented and discussed.

Step 16: FGIs with PWHF, family members and professionals

During the EBCD process, stakeholders are asked to participate in a final FGI. These FGIs aim to explore how organisational conditions influenced the participants' codesign and implementation process. This information will enable further codesign work in the study context. Three FGIs (duration 60–90 min) are planned—one each with PWHF, family members and professionals. FGIs, with data collection through group interaction between four to six individuals, are appropriate when differences in experiences are to be understood.[39]

The lead researcher conducts the interviews using Microsoft Teams. The interviews will be guided by a semi-structured interview guide, developed by the research team, addressing organisational conditions that influence healthcare quality improvement work according to Reed *et al*.[50] The interviews will be audio recorded and transcribed verbatim by an administrative assistant.

Step 17: data analysis

Data will consist of (1) field notes from observations of consultations, steering group meetings and EBCD events; (2) project documentation, (3) filmed and/or audio-recorded stakeholder interviews; (4) FGIs and (5) quantitative measurements guiding the improvement team's work.

To identify touchpoints and proposed service improvements to HF care, the researchers will undertake an inductive thematic analysis[47] of field notes, project documentation, meeting minutes, films and audio recorded interviews. To explore how organisational conditions influence the participants' codesign and implementation process, a deductive thematic analysis[47] will be undertaken of field notes, project documentation, meeting minutes and FGIs. The analysis will be guided by *'Model for understanding success in quality'—MUSIQ*.[50] This theoretical framework describes how context, intervention and implementation strategies interact within quality improvement initiatives in complex healthcare settings. Thus, this framework is appropriate when exploring how organisational conditions influence stakeholders' design, planning, implementation and evaluation of a healthcare quality improvement intervention in a Swedish cardiac care setting. *MUSIQ* has previously been used to understand the role of the context when implementing interventions in healthcare settings for example, in stroke care.[51] Quantitative measurements, guiding the improvement team's work, and used to quantify the results of the improvement activity, will be analysed with descriptive statistics. Employing a mixed-method approach with an exploratory design,[52] qualitative data will be used to explore the mechanisms for the quantitative results and to explore whether and how EBCD can be undertaken online, in a Swedish cardiac care setting, to improve experiences of health and care for and with PWHF.

The validity of the case study will be strengthened by data source triangulation.[31] Data analysis will be undertaken by the lead researcher in collaboration with her supervisors to ensure analytical rigour and validity, adding an outsider perspective to the data as a form of investigator triangulation.[53]

Patient and public involvement in research

Traditionally, there has been limited public and patient involvement (PPI) in Swedish healthcare quality improvements and health and social care research. To date, the Swedish Ethical Review Authority has not required a PPI statement in ethical applications concerning health and social care research. This tradition is likely to change in the future given that the interest in PPI is increasing both nationally and internationally.

Although the study context has a long tradition of healthcare improvements,[16 32–36] structured involvement of patients, family members and citizens is not yet widespread. Therefore, in this particular context, both patients, family members and healthcare professionals, need to colearn how to take each other's perspectives into consideration in healthcare quality improvement projects and research.

Given the contextual knowledge of PPI and with no formal PPI group, PWHF and family members in this study will be involved in the following activities:

- Research management: the steering group includes 1–2 patient representatives and 1–2 family member representatives. These representatives will be recruited employing the same procedure as previously described under 'Study participants and recruitment'. The steering group will meet five times during the project: before the project begins (step 1, figure 1); before the first feedback event (step 7, figure 2); before the joint stakeholders' event (step 11, figure 2); before

the celebration event (step 14, figure 2) and after the celebration event (step 15, figure 2). The patient and family member steering group representatives will coplan and co-organise EBCD events together with professionals to ensure the patient and family member perspectives are communicated throughout the process.

- Research design: PWHF and family members are involved in choosing, planning, designing, implementing and evaluating an intervention aimed at improving HF care. Outcome measures will be decided on in a small improvement team that includes two PWHF, two family members and two professionals. The improvement team will meet once a month and will be led by the IA.
- Development of interview guides: after ethical approval but prior to data collection, two PWHF and two family members will be asked to review the interview guides used for individual interviews and FGIs. This will ensure interview questions that are clear and easy to understand. These representatives will be recruited employing the same procedure as previously described under 'Study participants and recruitment'.
- Data analysis: PWHF and family member steering group representatives will be involved in sense making of study results.
- Dissemination of research findings: PWHF and their family members participating in the steering group or in the improvement team will be involved in joint presentation of study results at seminars and conferences.
- Reporting of study findings: participating PWHF and family members will be given opportunity to be involved as coauthors for relevant publications reporting the study results.

ETHICS AND DISSEMINATION

Ethics

The study was vetted and approved by the Swedish Ethical Review Authority (Dnr 2021-02076) in May 2021. Study participation will be voluntary and can be withdrawn at any point without consequences for future care or employment. No study activities will interfere with regular care visits. Informed consent will be obtained from all participants prior to data collection. Confidentiality will apply to information shared by study participants. The responsible researchers can use films and audio recordings for educational purposes in the future only after consent. To avoid digital exclusion, participants will be invited to a start-up meeting for a review of the technology. The researchers recognise that inclusion and exclusion criteria might limit the selection of participants to individuals who are considered easy to coproduce health and care with, thus limiting the generalisability of the study findings.

This study is not expected to cause any physical harm. However, in the unlikely event of participants experiencing emotional distress, for example, when participating in conversations about previous experiences of HF and its care, they will be offered individual support by a designated professional (a patient supporter or counsellor or an occupational healthcare professional). If necessary, patients will be referred to their regular healthcare team.

Participants may perceive an observer to be intrusive. A non-participant observer will therefore be employed to minimise the interference during care consultations.[41] The lead researcher will be a participating observer during steering group meetings, EBCD events and activities. Although the researcher's role and the professional's role may be difficult to separate, participant observations offer the advantage of collecting information about social practices and topics not covered in interviews.[41]

The lead researcher is a practising cardiologist in the study context. She interacts with PWHF, family members and professionals in the health district as part of her professional duties. Her roles also generate various relationships between her and the study participants. There is a risk of these relationships leading to social desirability,[54] meaning that these relationships may influence who chooses to participate in the study or what information participants are willing to share during interviews and events. PWHF and family members may feel obliged to participate for fear of not being prioritised when in need of healthcare. To minimise this risk, the PWHF treated by the lead researcher are excluded from participation. Professionals may feel obliged to participate in the study and may feel uncomfortable with sharing information about situations believed to reveal shortcomings in clinical practice. However, to express opinions regarding working practices and to suggest workplace improvements is a welcome part of the professionals' employment.

Despite the challenges related to the researcher's multiple roles, there are advantages to being an insider researcher. A major advantage is the primary access to the study context and research data.[55 56] The preunderstanding, that is, all knowledge that a researcher brings into a project, for example, hypotheses, experiences and theoretical frames of reference,[57] enables the researcher to acquire richer data by asking the right questions at the right time.[55 56] By being an insider, the researcher has a greater understanding and knowledge of the context, making it easier to adapt the research project to local conditions and the local context's goals and values.[58]

Dissemination

All data will be stored on a university computer server protected by a password. Only involved researchers will have access to data. Locally, that is, at the department and the PCC, the results will be presented and discussed in a seminar. Participating stakeholders and healthcare leaders, citizens and patient organisation representatives will be invited to this seminar. Regionally, the results will be displayed on noticeboards in healthcare environments. The results will also be presented at regional, national and international conferences. The results are planned to be published in an international scientific journal in 2023.

RESEARCH CONTRIBUTION AND FUTURE IMPACT

PWHF represent a large group of usually older individuals with complex health issues, making frequent healthcare visits and needing support for self-care. To our knowledge, this is the first case study in a cardiac care setting to explore and describe whether and how EBCD can be undertaken online, with the intention of redesigning healthcare processes and aiming for coproduced and improved experiences of health and care for and with PWHF. We look forward to learning more about and reporting on what impacts touchpoints derived from stakeholders' experiences could have on innovation in traditional technical cardiac care.

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Contributors A-MS planned and designed the study, wrote the initial draft of the paper and developed the figure. KAJ contributed to study design and to drafting the manuscript. AN, SK and JT contributed to study design and revised the manuscript for publication. All authors read and approved the final manuscript.

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ORCID iDs
Anne-Marie Suutari http://orcid.org/0000-0002-2760-4571
Johan Thor http://orcid.org/0000-0003-1814-4478

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