PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (http://bmjopen.bmj.com/site/about/resources/checklist.pdf) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

| TITLE (PROVISIONAL) | Using stakeholders’ experiences to re-design health services for persons living with heart failure - a case study protocol in a Swedish cardiac care setting |
|---------------------|----------------------------------------------------------------------------------------------------------------------------------|
| AUTHORS             | Suutari, Anne-Marie; Nordin, Annika; Kjellstrom, Sofia; Thor, Johan; Areskoug Josefsson, Kristina |

VERSION 1 – REVIEW

| REVIEWER            | Frost, Julia  
|                     | University of Exeter, Medical School |
| REVIEW RETURNED     | 04-Nov-2021 |
| GENERAL COMMENTS    | While you have gone to great lengths to explain the rationale for your research and data collection methods, crucially the data analysis is given little attention (e.g. in Figure 3 it is just a box). In the abstract you suggest that the object of the interviews is to identify key themes, but your analytical approach that you propose is merely content analysis. As you are going to such great lengths to undertake truly novel and groundbreaking research, please can you propose an analytical approach that will enable you to achieve your objectives. Thin and descriptive content analysis will not enable you to do this, whereas rich and explanatory thematic or at least framework analysis would enable you to do credit to your participants and the data that you intend to collect. Similarly, you say that the “qualitative data will be integrated with the qualitative data to describe” – surely your objective is to explain, rather than describe, and to do this requires you to detail which recognised mixed methods approach you intend to use for data integration. See for example: https://doi.org/10.1136/bmj.c4587  
|                     | It also appears as though the first researcher will conduct all of the analysis on their own, and then the draft will be revised by supervisors. Would it not be more appropriate for the supervisors to actively input into the analysis, and detail these processes, to ensure that the analysis is conducted with analytical rigour and validity? |

| REVIEWER            | Vandekerckhove, Pieter  
|                     | Erasmus University |
| REVIEW RETURNED     | 03-Dec-2021 |
| GENERAL COMMENTS    | Thank you for asking me to review this paper. The authors have written an interesting protocol to address important issues in heart failure care. Given that this is the first EBCD study in cardio, this study is probably relevant for other cardio populations, such as people living with atrial fibrillation, given that there are younger patients in this population. I |
commend the authors for introducing such an innovative approach in an often highly technical and traditional part of medicine as cardiology.

Recommendations:
Please clarify your aims. I read that the overall aim is to explore whether EBCD can be undertaken online, which you link with co-production of care. I would caution the authors with too many co-terms in the article as these are generally not clearly defined yet in this developing field, co-production, co-creation, co-design, participatory design, user-centered design all have aspects in common. I see EBCD and co-production of care as overlapping but different concepts. I follow your definition of co-production as used in the introduction as a broad concept referring to all collaborative approaches which create some aspects of care. However, I would not use the concept of co-production in your aims, as it is confusing to me.

I would emphasize that you are interested in gaining new insights which are co-designed through interaction of knowledge of different stakeholders. I would emphasize and justify the use of EBCD to generate new knowledge in the broad sense as I describe further underneath. I believe the methodological added value of EBCD lies in the generation of new knowledge through bringing various stakeholders together in a specific design research process.

Please expand on justifications and limitations of Experience based co-design: It could strengthen your paper to include or reflect on the limitations of EBCD and further incorporate it in the manuscript. Some limitations of EBCD are briefly mentioned in this paper: Langley, J., Wolstenholme, D., & Cooke, J. (2018). “Collective making” as knowledge mobilisation: The contribution of participatory design in the co-creation of knowledge in healthcare. BMC Health Services Research, 18(1), 585. https://doi.org/10.1186/s12913-018-3397-y

‘Similar to the business use of Design Thinking, the EBCD method and subsequent toolkits developed to share the methods of design and design processes without the costly support of professionally trained designers [43]. The process and use of EBCD is not always straightforward some projects have had limited tangible service improvement, others recognised the lack of ideation tools [44] and it is often de-scribed as ‘design like’ rather than designerly [45]. In EBCD activities, design methods have been distilled down into a simplified process to allow non-designers to use them but this removes a designer’s skills and experience from the process [46].’

1. EBCD has a limited methodological justification regarding the knowledge dynamics between stakeholders
Co-design has the unique advantage of bringing the knowledge (expertise, dreams, emotions) of various stakeholders together. I would highlight this argument in your introduction why you are choosing for co-design altogether.
You can specify in the knowledge aims explicitly in the aims section as well. Once you clearly know which type of knowledge precisely one needs from which types of stakeholders, you will be able to specify and justify each type of activity in your 17 steps as well in further detail and this will help you while conducting the project in practice as well. For example in step 2 you want to use non-participant observations: Why non-participant observations and where? Because you need xxx (e.g. about non-verbal communication between heart failure patients and nurses) knowledge from xxxx area (ward, home, work, garden, gym, restaurant)

2. EBCD has a limited justification to include specific stakeholders
Expand on the justification of the selection procedure for EBCD methodological aims. Consider setting selection criteria about the background knowledge and creative thinking skills and communication of stakeholders. Regarding the knowledge background: perhaps you need someone with extensive experience with a particular part of heart failure, from a patient and professional point of view. Perhaps you need a health manager to have expertise about other cardiology care paths e.g. atrial fibrillation, perhaps you need a medical device or pharma representative to think about the alignment with their products and services? Perhaps a hospital IT specialist with knowledge about the medical record?

Regarding the creative thinking, you may consider if people have any creative hobbies. Regarding the communication, you may consider how well people can express themselves in a group, shy people may be less relevant at this stage to reach the EBCD exploratory aim.

Consider involving stakeholders with an invested financial interest from the start (see experience of using co-design to improve cancer care https://www.liebertpub.com/doi/10.1089/jayao.2020.0098?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed)

3. EBCD has limited involvement of professional designers
Consider involving a professional designer at several steps where you want to emphasize the ‘production’ or ‘creation’ aspects as in the feedback event or the joint stakeholders event.

4. EBCD has a limited involvement of make tools and generative exercises
Consider involving exercises which help to bring out deeper emotions before the feedback event in the interviews. You could add small making exercise in the interviews, this does not need to be complicated and can provide great added value: e.g. a mindmap, a patient journey, see for more inspiration:

Sanders, E., & Stappers, P. J. (2012). Convivial design toolbox: generative research for the front end of design. BIS.
Luchs, M. G., Swan, K. S., & Griffin, A. (2015). Design thinking: New product development essentials from the PDMA. In Design Thinking: New Product Development Essentials from the PDMA. https://doi.org/10.1002/9781119154273
van Boeijen, A., Daalhuizen, J., & Zijlstra, J. (2020). Delft Design Guide (Vol. 53, Issue 9). BIS Publishers. https://www.bispublishers.com/delft-design-guide-revised.html

More broadly, you could reflect about the added value of using EBCD compared to the more traditional way of innovation in cardiology. From my experience cardiology on a whole is a more clinically technologically driven field of care with traditionally less involvement of patients. I would be very interested to learn about the impact of your study, please take this into account after you finish the project. Perhaps you can speculate on this question already in your protocol about the expected long term impact. I am for instance interested in the impact of touch points in care practice for health failure patients in your Swedish setting. I would be interested to see how the EBCD approach can have an impact compared to other innovation approaches on cardio practice. Often pharmaceutical and medical device companies (experts) dominate the innovation in cardiology. Perhaps EBCD can turn the tide by involving the patient, families and other care professionals more in the innovation. Perhaps this can bring new life to innovations which were previously less successful on the long term (e.g. tele-monitoring, telemedicine with cardio devices and self-management of care).
Minor suggestions:

Please consider in your online EBCD approach to make sure that it is not too time consuming even if online (see report Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions by Sara Donetto, Vicki Tsianakas and Glenn Robert) If you are interested to use a digital collaboration space, for instance in your focus groups, I would recommend Miro.com. For online group interviews I would recommend Zoom as you can make sure every participant is visible and recorded on the screen.

Please consider making use of existing film material for the trigger film to save time and money (see report Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions by Sara Donetto, Vicki Tsianakas and Glenn Robert)

It is unclear to me why the 17 steps described in the main body of the protocol are separated in three figures of three phases, I would help me

| VERSION 1 – AUTHOR RESPONSE |
|-----------------------------|
| Reviewer 1: Dr. Julia Frost, University of Exeter |

Thank you for taking the time to review our manuscript. We have found your comments useful when improving our manuscript.

While you have gone to great lengths to explain the rationale for your research and data collection methods, crucially the data analysis is given little attention (e.g. in Figure 3 it is just a box).

The data analysis is explained and elaborated under “Step 17: Data analysis”.

In the abstract you suggest that the object of the interviews is to identify key themes, but your analytical approach that you propose is merely content analysis. As you are going to such great lengths to undertake truly novel and groundbreaking research, please can you propose an analytical approach that will enable you to achieve your objectives. Thin and descriptive content analysis will not enable you to do this, whereas rich and explanatory thematic or at least framework analysis would enable you to do credit to your participants and the data that you intend to collect.

Thank you for giving us the opportunity to reflect on the chosen methods. We agree with reviewer that thematic analysis suits our objectives in a more appropriate way than content analysis. We have revised the manuscript and now state that we are going to use thematic analysis for data analysis.
Similarly, you say that the “qualitative data will be integrated with the qualitative data to describe” – surely your objective is to explain, rather than describe, and to do this requires you to detail which recognised mixed methods approach you intend to use for data integration. See for example: https://doi.org/10.1136/bmj.c4587

Thank you for giving us the opportunity to clarify. In this case we aim for a mixed methods approach. In the revised manuscript we now state: “Employing a mixed methods approach with an exploratory design\textsuperscript{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”.

It also appears as though the first researcher will conduct all of the analysis on their own, and then the draft will be revised by supervisors. Would it not be more appropriate for the supervisors to actively input into the analysis, and detail these processes, to ensure that the analysis is conducted with analytical rigour and validity?

Thank you for this comment. The analysis will be undertaken by the lead researcher and her supervisors. We have clarified this in the revised manuscript and state: “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.”

Reviewer 2: Dr. Pieter Vandekerckhove, Erasmus University

Thank you for asking me to review this paper. The authors have written an interesting protocol to address important issues in heart failure care. Given that this is the first EBCD study in cardio, this study is probably relevant for other cardio populations, such as people living with atrial fibrillation, given that there are younger patients in this population. I commend the authors for introducing such an innovative approach in an often highly technical and traditional part of medicine as cardiology.

Thank you for taking the time to review our paper. We appreciate your interest in our research. We acknowledge the need of participative improvement initiatives in cardiac care and hope that the study results will be applicable to other patient populations. We find the comments useful to further improve our study design.

Please clarify your aims. I read that the overall aim is to explore whether EBCD can be undertaken online, which you link with co-production of care.

Thank you for giving us the opportunity to clarify our aims. Please see our responses below on how we have handled this issue in the revised manuscript.

I would caution the authors with too many co-terms in the article as these are generally not clearly

Thank you for bringing this to our attention. We acknowledge co-design of healthcare
defined yet in this developing field, co-production, co-creation, co-design, participatory design, user-centered design all have aspects in common. I see EBCD and co-production of care as overlapping but different concepts. I follow your definition of co-production as used in the introduction as a broad concept referring to all collaborative approaches which create some aspects of care.

as an important component of co-production. This has been clarified in the introduction section in the revised manuscript and we now state: “Co-production of health and care - involving PWHF, their family members and professionals in the planning, design, delivery and assessment of care processes - aims to promote the best possible health through joint learning about how to meet the stakeholders’ needs.” In addition, we have removed some “co-terms” in the abstract.

However, I would not use the concept of co-production in your aims, as it is confusing to me. I would emphasize that you are interested in gaining new insights which are co-designed through interaction of knowledge of different stakeholders.

We have replaced the word “co-production” with “co-design” in our aim statement. Our revised aim in the abstract, in the introduction section and under “Aims” reads as follows: “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 co-design improved experiences of HF care.”

I would emphasize and justify the use of EBCD to generate new knowledge in the broad sense as I describe further underneath. I believe the methodological added value of EBCD lies in the generation of new knowledge through bringing various stakeholders together in a specific design research process.

We agree with the reviewer that the added value of EBCD lies in the generation of new knowledge when different stakeholders interact with each other. To highlight this important circumstance, we now state the following under “Knowledge gaps” in the revised manuscript: “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 re-design healthcare processes.”

Please expand on justifications and limitations of Experience based co-design: It could strengthen your paper to include or reflect on the limitations of EBCD and further incorporate it in the manuscript. Some limitations of EBCD are briefly mentioned in this paper: Langley, J., Wolstenholme, D., & Cooke, J. (2018). “Collective making” as knowledge.

Thank you for providing us with further readings. In the revised manuscript we have added a “strengths and limitations section” focusing on the strengths and limitations of EBCD.
mobilisation: The contribution of participatory design in the co-creation of knowledge in healthcare. BMC Health Servces Research, 18(1), 585. https://doi.org/10.1186/s12913-018-3397-y

‘Similar to the business use of Design Thinking, the EBCD method and subsequent toolkits developed to share the methods of design and design processes without the costly support of professionally trained designers [43]. The process and use of EBCD is not always straightforward some projects have had limited tangible service improvement, others recognised the lack of ideation tools [44] and it is often described as ‘design like’ rather than designerly [45]. In EBCD activities, design methods have been distilled down into a simplified process to allow non-designers to use them but this removes a designer’s skills and experience from the process [46].’

1. EBCD has a limited methodological justification regarding the knowledge dynamics between stakeholders
Co-design has the unique advantage of bringing the knowledge (expertise, dreams, emotions) of various stakeholders together. I would highlight this argument in your introduction why you are choosing for co-design altogether.

You can specify in the knowledge aims explicitly in the aims section as well.
Once you clearly know which type of knowledge precisely one needs from which types of stakeholders, you will be able to specify and justify each type of activity in your 17 steps as well in further detail and this will help you while conducting the project in practice as well. For example in step 2 you want to use non-participant observations: Why non-participant observations and where? Because you need xxx (e.g. about non-verbal communication between heart failure patients and nurses) knowledge from xxxx area (ward, home, work, garden, gym, restaurant)

Thank you for this important comment. In the revised manuscript we state the following in the introduction section and under “EBCD - strengths and limitations”:

“EBCD has the benefit of bringing different experiences from various stakeholders together. Thus, EBCD offers a unique opportunity to co-design healthcare services that meet the needs of all stakeholders." 

Thank you for highlighting the need of clarification concerning “what knowledge” and “why” in each step of the process.

We have included the following in our revised manuscript:

“Step 2: Non-participant observations of healthcare consultations”

Non-participant observations during healthcare consultations in a primary care centre provides information about the relationships, behaviours, and communication between PWHF and nurses or PWHF and physicians.”
We have clarified the structure of the semi-structured interview guides to provide the reader with information about the knowledge aims in steps 3 and 4:

“The semistructured interview guides, that will be used during patients’ and family members’ interviews, are organized to reflect a patient journey. Thus, the guides are organized 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.”

The following clarification has been added to steps 8, 9 and 10: “The need for additional stakeholders to join the joint feedback event (step 12), for example a pharmacist, a physiotherapist or a hospital IT specialist, will be requested.”

The following clarification has been made regarding step 12: 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.” We argue that the knowledge aim for step 12 is clear. We state: “The aim of this joint event is to collectively agree on one area for service improvement work.”

We have made the following clarification to step 16: “During the EBCD process, stakeholders are asked to participate in a final FGI. These FGIs aim to explore how organisational conditions influenced the participants’ co-design and implementation process. This information will enable
2. EBCD has a limited justification to include specific stakeholders
Expand on the justification of the selection procedure for EBCD methodological aims. Consider setting selection criteria about the background knowledge and creative thinking skills and communication of stakeholders. Regarding the knowledge background: perhaps you need someone with extensive experience with a particular part of heart failure, from a patient and professional point of view. Perhaps you need a health manager to have expertise about other cardiology care paths e.g. atrial fibrillation, perhaps you need a medical device or pharma representative to think about the alignment with their products and services? Perhaps a hospital IT specialist with knowledge about the medical record?

We agree that it is important to capture as many different experiences and skills as possible. To highlight this, the competencies of the participants in the steering group have been elaborated on in the revised manuscript (“under Step 1: Formation of a steering group and first meeting). To highlight the possible need of additional competencies during the project we now state under “Step 8, 9 and 10”: “Depending on the results from the discussions, i.e. depending on the chosen areas of improvement, additional stakeholders will be invited to join the joint feedback event (step 12). “

Regarding the creative thinking, you may consider if people have any creative hobbies. Regarding the communication, you may consider how well people can express themselves in a group, shy people may be less relevant at this stage to reach the EBCD exploratory aim.

All stakeholder participation is voluntary. This means that all stakeholders that meet the inclusion criteria are eligible for study participation according to the ethical application (please see under “Study participants and recruitment”). We do recognize that this may limit the variation of people that are recruited. Still, we agree that we need to encourage participants to share personal stories and to make sure that everybody is invited to participate in the discussions. 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.

We have revised the manuscript to clarify the improvement adviser’s role (please see under “Step 8 and step 9: Professionals’ and family members’ feedback events”). We have also clarified the participants responsibilities towards each other (please see under “Step 8 and step...
Consider involving stakeholders with an invested financial interest from the start (see experience of using co-design to improve cancer care [https://www.liebertpub.com/doi/10.1089/jayao.2020.0098?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20200pubmed](https://www.liebertpub.com/doi/10.1089/jayao.2020.0098?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20200pubmed)).

Region Jönköping County, the overall context for this study, is a tax-financed public Swedish healthcare provider. Involving external stakeholders with an invested financial interest is not applicable to projects run within the Swedish healthcare system.

3. EBCD has limited involvement of professional designers
Consider involving a professional designer at several steps where you want to emphasize the ‘production’ or ‘creation’ aspects as in the feedback event or the joint stakeholders event.

Thank you for this comment. Region Jönköping County, the overall research context, aims to increase patients’ and family members’ involvement in healthcare improvement initiatives. However, there is still a gap in knowledge regarding how patients, family members and professionals can and should work together in the research context. Thus, we want to explore if EBCD is a feasible model in this context.

We believe that conducting our research within existing organizational resource constraints increases the likelihood for EBCD and its outcomes to be implemented in Swedish routine cardiac care. This project is part of regional system-wide efforts to promote improved health for persons with chronic disease in Region Jönköping County and we are not planning to involve external professional designers. However, as highlighted in the manuscript, an improvement adviser will lead and facilitate feedback events, the joint stakeholder event and the improvement team’s work. An improvement adviser is a healthcare professional, usually a nurse, with employment within the Region Jönköping County. She/he has knowledge regarding how-to lead healthcare quality improvements and initiatives aiming to re-design healthcare.

In the revised manuscript, under “Setting” we now state:
“This context, with its long tradition of healthcare quality improvement activities,\textsuperscript{16} has an ambition to incorporate patients’ and family members’ involvement in care improvement initiatives as a part of routine care.”

The improvement adviser’s role and competencies are clarified under “Step 1: Formation of a steering group and first meeting”. In the revised manuscript we now state: “The IA is employed by RJC and is trained to lead healthcare quality improvements aiming to re-design healthcare.

| 4. EBCD has a limited involvement of make tools and generative exercises |
| Consider involving exercises which help to bring out deeper emotions before the feedback event in the interviews. You could add small making exercise in the interviews, this does not need to be complicated and can provide great added value: e.g. a mindmap, a patient journey, see for more inspiration: Sanders, E., & Stappers, P. J. (2012). Convivial design toolbox: generative research for the front end of design. BIS. Luchs, M. G., Swan, K. S., & Griffin, A. (2015). Design thinking: New product development essentials from the PDMA. In Design Thinking: New Product Development Essentials from the PDMA. https://doi.org/10.1002/9781119154273 van Boeijen, A., Daalhuizen, J., & Zijlstra, J. (2020). Delft Design Guide (Vol. 53, Issue 9). BIS Publishers. https://www.bispublishers.com/delft-design-guide-revised.html |

| Thank you for this comment and thank you for suggesting further readings. We do recognize patient journeys to be an important part of the co-design process. The semistructured interview guides, used during patients’ and family members’ interviews, are organized to reflect a patient journey. Thus, the guides are organized 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.

The details regarding interview guides have been added under “Step 3: Pilot-testing of interview guides” in the revised manuscript.

The trigger film, highlighting patients’ experiences, will be edited to reflect the patients’ journeys. This fact has been added in the revised manuscript under
| **More broadly, you could reflect about the added value of using EBCD compared to the more traditional way of innovation in cardiology.** From my experience cardiology on a whole is a more clinically technologically driven field of care with traditionally less involvement of patients. | **In the revised manuscript we now state under “Knowledge gaps”: “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 re-design healthcare processes.”** |
|---|---|
| | **I would be very interested to learn about the impact of your study, please take this into account after you finish the project. Perhaps you can speculate on this question already in your protocol about the expected long-term impact.**  
I am for instance interested in the impact of touch points in care practice for health failure patients in your Swedish setting. I would be interested to see how the EBCD approach can have an impact compared to other innovation approaches on cardio practice. Often pharmaceutical and medical device companies (experts) dominate the innovation in cardiology. Perhaps EBCD can turn the tide by involving the patient, families and other care professionals more in the innovation. Perhaps this can bring new life to innovations which were previously less successful on the long term (e.g. tele-monitoring, telemedicine with cardio devices and self-management of care). | **Thank you for your interest in our research and the long-term impact. To address these comments, we have revised the last section of the paper, now called “Research contribution and future impact” we now state: “We look forward to learning more about and reporting on what impacts touch points derived from stakeholders’ experiences could have on innovation in traditional technical cardiac care.”** |
| **Please consider in your online EBCD approach to make sure that it is not too time consuming even if online (see report Using Experience-based Co-design Donetto et al report on EBCD being time consuming. The following EBCD steps are resource intensive according to The Point** |  |

"Step 5: Analysis of field notes and editing of PWHF films and audio recordings".

As stated under “Step 10: Feedback event with PWHF” we plan to use an emotional mapping exercise during the feedback event with PWHF. Additional creative tools can be chosen during the process in collaboration with participating stakeholders. These tools will then be described in detail in the final report.
(EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions by Sara Donetto, Vicki Tsianakas and Glenn Robert).

of Care Foundation, the provider of the online “EBCD: Experience-based co-design toolkit” (https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/):

- Facilitator (typically 40 % for six months).
- Travel (for patients and carers to attend the interviews and various events)
- Patient and Public Involvement expenses (if paying for patient & carer involvement – see INVOLVE guidelines
- Staff time (to attend interviews and various events)
- Event catering
- Equipment and/or external expertise (video camera and/or editing expertise).

We believe that using an online tool will save time compared to “traditional” EBCD projects. The use of an online tool will reduce the time spent for travels to attend interviews and various events. However, we do acknowledge that this approach is time consuming. This is the first time that EBCD is carried out in this context. Thus, this project will be a learning experience for all participants. We anticipate a reduced project time in future projects.

| If you are interested to use a digital collaboration space, for instance in your focus groups, I would recommend Miro.com. For online group interviews I would recommend Zoom as you can make sure every participant is visible and recorded on the screen. | Thank you for suggesting Miro.com. We will take this into consideration during our research project since we are going to need a digital collaboration space. We have previously considered Zoom for this project. However, Jönköping University did not consider Zoom to be safe for research purposes at the time for ethical application (Spring 2021). The use of Microsoft Teams® was approved by the Swedish Ethical Review Authority (Dnr 2021-02076). In our study only individual interviews are recorded using Microsoft Teams®. |
| Please consider making use of existing film material for the trigger film to save time and money (see report Using Experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions by Sara Donetto, Vicki Tsianakas and Glenn Robert) | Thank you for this comment. We do acknowledge that EBCD is a resource intensive approach, especially when it comes to time and costs. We agree that the use of existing film material could save both time and money. In this study, however, we want to explore the touch points and improvement initiatives in heart failure care. To our knowledge EBCD has not been previously used in Swedish heart failure care. Thus, existing film material from other contexts, with other patient groups and with non-Swedish speaking participants are not considered to be useful in our study. |
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| It is unclear to me why the 17 steps described in the main body of the protocol are separated in three figures of three phases, I would help me as | This comment seems to end abruptly and is therefore unclear to the authors. We argue that it is necessary to divide the figure in three parts to be able to provide readable figures. However, we do agree that there is no need to divide the process in three different phases. Thus, we have revised the figures by removing “phases” The captions for the figures have been revised. We leave it to the Editor to decide if this response is sufficient or if a clarified comment from reviewer 2 is necessary for us to be able to respond correctly. |

**VERSION 2 – REVIEW**

| REVIEWER | Frost, Julia  
University of Exeter, Medical School |
| --- | --- |
| REVIEW RETURNED | 27-Dec-2021 |

| GENERAL COMMENTS | Well done on revising your research to reflect the current difficulties. You are collecting data from patients, and have 1-2 patients on your steering committee, but that is not the same as having patient involvement throughout as you suggest. I would have expected to see a clearer explanation in the PPI section of exactly where your PPI group have been recruited and convened from (presumably not your own patients), how they have been involved in planning and designing this research (e.g. were they actively involved in a stakeholder workshop, or did they review your study documents, prior to ethical review), and what your PPI group will be involved in |

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as your research progresses (e.g. how often will they meet virtually, will they be involved in sense making as your analysis progresses, and designing an impact plan). At the moment the PPI appears tokenistic, and not in keeping with the premise of EBCD.

**REVIEWER**
Vandekerckhove, Pieter
Erasmus University

**REVIEW RETURNED**
29-Dec-2021

**GENERAL COMMENTS**
Thank you for revising the manuscript. The authors have sufficiently addressed my comments. Gool luck with your research!

**VERSION 2 – AUTHOR RESPONSE**

| Comments from reviewers | Authors’ responses |
|-------------------------|--------------------|
| **Reviewer 1: Dr. Julia Frost, University of Exeter** | Thank you for taking the time to read and comment on our revised manuscript. |
| Well done on revising your research to reflect the current difficulties. | |
You are collecting data from patients, and have 1-2 patients on your steering committee, but that is not the same as having patient involvement throughout as you suggest. I would have expected to see a clearer explanation in the PPI section of exactly where your PPI group have been recruited and convened from (presumably not your own patients), how they have been involved in planning and designing this research (e.g. were they actively involved in a stakeholder workshop, or did they review your study documents, prior to ethical review), and what your PPI group will be involved in as your research progresses (e.g. how often will they meet virtually, will they be involved in sense making as your analysis progresses, and designing an impact plan). At the moment the PPI appears tokenistic, and not in keeping with the premise of EBCD.

Thank you for giving us the opportunity to reflect on this important issue. We agree that the PPI section needs clarification. We have revised under “Patient and public involvement in research” to clarify the current contextual culture related to PPI. We have also clarified the role of participating patients and family members in our study. The revised “Patient and public involvement in research” now state:

“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, 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 co-learn 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 co-plan and co-organize 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 2 PWHF, 2 family members and 2 professionals. The improvement team will meet once a month and will be led by the improvement adviser.

- Development of interview guides. After ethical approval but prior to data collection, 2 PWHF and 2 family members will be asked to review the interview guides used for individual interviews and focus group interviews. 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 co-authors for relevant publications reporting the study results.”