Author’s response to reviews

Title: Recruitment of caregivers into health services research: Lessons from a user-centred design study

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Author’s response to reviews:

Dear editor,

Thank you for the instructive comments provided on our manuscript. These have been very helpful in re-thinking our arguments and making our revisions. You will find our response to each reviewer comment in blue, below.

Editor Comments:

The first is that the Plain English Summary is too wordy and the sentence structure too complex. We would urge you to have a non-researcher sense-check it. (For example, does "partnership level engagement" mean "partnership"? Is a sub-clause beginning with the word "Extrapolating" using Plain English language and indeed is such a clause necessary at all? Where you have said "tend to" do you mean "may"?) Many of our readers are lay and they engage with full papers only if they feel the Plain English Summary is clear about what the paper contains. If it is not clear enough, they do not read the paper, and in the case of your paper we feel that the content is of direct interest to lay representatives working in research, and so we are especially keen that they should want to read your paper.

Response: Many thanks for sharing these helpful comments. We acknowledge that our summary in the original submission was wordy and the sentences were too complex for a lay public audience. We did our best to simplify and shorten the summary, targeting it appropriately. We asked a non-researcher to sense-check the final product. We hope the revised version meets the journal’s requirements and that your lay readers will find it easy to read and understand.
The second point may be related, in so far as we cannot see from the paper why you have not engaged or involved lay representatives in your work, whether as full partners or as and when needed (eg writing a lay summary). We make no judgement on whether or not lay representatives should be involved, but in a paper about recruiting caregivers to add value to research, the lack of caregiver (or other lay) input to the paper itself does need explanation. And again we would stress that it is explanation and not defence that we seek. A line or two in the methods section is usually sufficient.

Response: We have added material to the Methods section as suggested. This material describes the lay representative status of co-author, GM. GM is affiliated by personal and professional experience with family caregiving and the formal medical system, and has advised on the content and direction of the research we present in the paper since its inception. GM is involved in an Alberta based citizen-led organization, IMAGINE Citizens Collaborating for Health, who wrote a letter in support of our original grant application to AGE-WELL.

Reviewer 1:

This article is a really valuable contribution to some of the challenges of co-designing. And it is very well written. Just a couple of suggestions that I would like to see the authors give some consideration: 1. I wonder if the authors sell themselves a little short by making 'recruitment' the main focus. I would like them to consider a change in emphasis (or perhaps bring more to the fore) so that the key focus is something like 'how to develop the relationships that are a necessary part of creating the conditions that enable co-design' - (the authors do raise this in the discussion and it's the key issue for me).

Response: Thanks for your positive feedback! In light of other referees’ recommendations, we decided to keep the focus of the paper on recruitment. However, as you rightly note, a key message of this paper is how to develop the relationships that are necessary for true co-design. Our revisions highlight this message as we now emphasize the role of trust and relationship building.

2. The authors make some suggestions for tackling the issues they raise, for example seed funding to help with recruitment - could they also consider including something about research organisations reaching out and establishing ongoing relationships with the communities in which they are located? If they look at the co-production literature there are many references to the importance of developing relationships - this helps with the sharing of power and enables partnerships and co-design rather than consultation.
Response: Thanks for this helpful comment. We have included a brief description of some research organizations such as CIHR, INVOLVE, PCORI that encourage establishing ongoing relationships and partnership between researchers and members of the community for co-design research (see below).

A number of research funding agencies across the world including CIHR in Canada, and Patient-Centered Outcome Institute (PCORI) and Quality Enhancement Research Initiative (QUERI), both in the United States, and INVOLVE (a project established by the British National Institute of Health Research to increase public engagement in research) in the United Kingdom are now encouraging co-design research through partnership between researchers and other stakeholders including members of the public. The CIHR Strategy for Patient-Oriented Research (SPOR) is another funding partnership that CIHR formed to make co-design patient-oriented research a reality in Canada. In Alberta, the home jurisdiction for the case study at the center of this paper, Alberta Innovates - a provincial research funding agency - has introduced Partnership for Research and Health Innovation in the Health System and the Collaborative Research and Innovation Opportunities program to encourage partnership between researchers and community members.

We have also provided an example of organization that offers seed funding to help with relationship building at the beginning of research (see below).

An example of such funding initiative is the Coalitions Linking Action and Science for Prevention (CLASP) led by the Canadian Partnership Against Cancer that offer allowances to researchers to build relationships and coalition and partner with stakeholders as a granting prerequisite.

Reviewer 2:

Change the title of page 2 to Plain Language Summary. The whole manuscript is in English, so it is redundant to say Plain English Summary. This also follows the wording in other journals and manuscripts.

Response: This is the editorial policy of the BMC Research Involvement and Engagement journal to include a summary entitled “Plain English Summary” at the beginning of paper. As such we have to abide by the journal policy.

There should be some clear definitions around the term participant. In reading this manuscript, it reads as though you could be recruiting family caregivers as participants (subjects) in the research to validate the technology or as participants (collaborators) in the research to help develop the technology. Their role is not clearly defined although your methods are.
Response: Thanks for this comment. In revising our manuscript we have attempted to clarify the definition and how we are using the term ‘participant.’ We have avoided using the term ‘research participant’ for family caregivers as this might imply they were the subjects of research. Our intent in our co-design approach was to engage family caregivers as research partners and collaborators. We hope our revisions have made our genuine intention clear for readers.

It would be very helpful if you included examples of the criteria you were using for your recruitment ie. what skillsets you valued, previous experience working with a research team, understanding of the condition, what meaningful engagement meant to you for this study etc.

Response: Thanks for this helpful comment. We have now clarified our recruitment criteria in the method section (see below).

Our main recruitment criteria were: 1) being below the age of 65 (with the assumption this population group are more likely to adopt new technology), 2) being a caregiver to a senior citizen over the age of 65 (caregiving for the adults was the focus of the project), 3) living preferably in the Calgary or Edmonton area (driven by the time and costs associated with traveling across the province or country), 4) preferably working, either part-time or full-time (again, assuming this group is more likely to adopt new technology).

By meaningful engagement, we mean engaging family caregivers as equal partners with decision making power in our co-design research. To achieve this, we employed NGT technique, which is a well-documented democratic and participatory consensus-building process that helps create collective priorities while minimizing power imbalance between researchers and members of the public.

It would also be helpful to know what information was on the recruitment posters you put up in geriatric clinics, whether you considered recruiting in support groups as well. Was their research training offered to the family caregivers who did engage? Mentorship?

Response: Thanks for these helpful suggestions. We have included the information provided in our flyers distributed in geriatric clinics. The flyer included a very brief, lay language introduction to the project, recruitment criteria, and contact information for the research coordinator.
Regarding recruitment through support groups: This was our main source of recruitment. Most of our family caregivers were recruited through partnership with community-based caregivers support groups/organizations.

Regarding offering research training to family caregivers: We provided this training and have included the following information to the method section.

As part of our training and mentorship program and to ensure a shared understanding of the research project and to develop trust and relationships, we engaged with FCs expressing an interest in our research, through a number of email exchanges prior to convening the FGs. In those emails, FCs were given information about the research, their potential role in it, and our expectations. They were also encouraged to ask any questions. At the start of each FG, the lead researcher shared the same information with FCs while elaborating on the components of the consent form in detail.

This appears to be a 'one off' opportunity for family caregivers, did you or the organizations consider recruiting family caregivers to participate in a more meaningful way where other opportunities to engage might present themselves? The organizations may be more willing to help develop the patient and caregiver engagement piece if there was more in it for them long term.

Response: Thanks for this interesting comment. Our research looks like, on the surface, an ‘one off’ project as it was a 1-year small funded project. However, we are currently collaborating with a highly experienced and senior research team at the University of Alberta, who have been engaged with caregiver research for more than a decade. We are sharing the relationships built with our community-based caregivers organizations with our research partners. As such, we hope the relationships established will endure.

Reviewer 3:

Thank you for highlighting the challenges of recruiting for research. The topic is highly relevant and it is important that also unsuccessful attempts are described and addressed. Your case study provides good examples of both challenges and solutions to inspire other researchers.

Response: Thanks for your positive feedback!
Introduction/Discussion:

In both sections engagement and references to Carman and Arnstein are mentioned. Despite the association to the challenges of recruitment 'engagement at a partnership level' is not addressed in the following sections neither from a theoretical or from a problematizing or from a descriptive perspective. As a reader I expect the topic of engagement to be described and explored in deep when it is the first part of the Introduction. However the process of recruitment is the specific focus of the paper - not engagement. In addition engagement is the first (=most important) part of the Discussion section. But the reflections on engagement are not being backed (explored) during the Method/Results section and therefore do not serve well as a topic for discussion. The following parts of the Discussion (page 10, line 25-49) are highly relevant and well documented/backed by the experiences described. I recommend to down size the focus on engagement by removing the section in the introduction and put a specific focus on the recruitment process which is backed by your empirical data/ descriptions. The reflections on engagement and true partnerships are in line with numerous social study scholars and may be expanded further to contribute to the discussions.

Response: Thanks for this very helpful suggestion. We agree with you that our emphasis on engagement in the original submission was not backed by our results and methods. As per your helpful suggestion we have removed the ‘introduction’ section and highlighted recruitment as the key focus of our manuscript.

Comments for Table 1, page 7, line 12. (The Table is not shown in the review manuscript):

To serve as inspiration and guide to young researchers without prior experiences I recommend to include in the Table: all challenges (planning, find partners, align roles and expectations, build trust, plan suitable time slots and locations for your activities with the target group), actions, changes, time spent, money spent etc. to gather all steps of the process. It could serve also as a timeline or flowchart which would be a good way to capture your results and make them tangible for your audience.

Response: Thanks for this very helpful suggestion. Table 1 shows the number of family caregivers recruited through different recruitment strategies. We don't know why you have not been provided with this table as it was uploaded during the submission process. Following your helpful recommendation to add a table summarizing challenges, actions and costs, we have prepared a table to make our results more tangible for readers.

Conveying case study experiences to general recommendations:
Your case study serves very well as an example of challenges and implications. It is a good and easy-to-understand description because it is very close to everyday situations. However when you design/formulate recommendations for other researchers I suggest that you aim to be as general as possible. You may reach that goal by exchanging 'recruitment through caregiver agencies' (p. 10, line 58) with a more general term or description of caregiver agencies because health services may be organised differently in other countries. One suggestion is 'organisation who is a trusted partner by the target group'. The purpose is to make it relevant and manageable in all settings and not limit the thinking to a specific unit or country, but rather to describe the function of this organisation/unit that would be a good solution. In this case an organisation who has the outreach to and is trusted by the target group.

Response: Thanks for this very helpful comment. We agree with you that service delivery organizations may be organized and named differently in different countries. We have now defined what we mean by 'caregiver agencies’ as ‘an organization who has an outreach to and is trusted by family caregivers’.