

# Older people as co-researchers: a collaborative journey

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## **ABSTRACT**

In recent years there has been a distinguishable trend towards user involvement in ageing research. Researchers and policy makers both are increasingly convinced that user involvement is necessary to adapt research questions and methods to meet the needs of older people. Little is known, however, about the quality of collaborations between older people and researchers. This study systematically evaluates a collaboration undertaken between two academic researchers and three older people acting as co-researchers in an effort to identify the conditions required for equal collaboration. To evaluate the collaboration the co-researchers and academic researchers took part in individual in-depth interviews (after six months) and two reflection meetings (after six and 12 months). Throughout the collaboration, field notes were taken by both academic researchers and co-researchers. A detailed description of the collaboration is provided here, using the metaphor of a journey to illustrate the dynamics and the learning process of the participants. Interim reflection meetings – at which mutual expectations were expressed along with a frank discussion of prejudices, tasks and role divisions, and the sharing of personal and project-related needs and information – were found to be fruitful in achieving a positive working relationship and fostering an effective collaboration. We conclude that a learning perspective on participation can be a resource for learning and adaptive change.

**KEY WORDS** – co-researchers, patient participation, consumer participation, user involvement, collaboration, reflection.

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## Introduction

Ageing research finds itself in a new situation, with a top-down trend towards consumerism, increased user involvement required by funding agencies and a bottom-up surge of social movements comprised of older people who desire increased control over the decisions which affect their lives. In his response to the systematic review by Fudge, Wolfe and McKeivitt (2007), Alan Walker (2007) made a plea to involve older people in research. Two reasons were given, which can also be found in the literature pertaining to patient participation and involvement (*e.g.* Caron-Flinterman, Broerse and Bunders 2005). An epistemological reason is that older people's understanding is needed to attune ageing research agendas and methods, to better address their needs, and the findings are more likely and better able to enhance the quality of their lives (Davies and Nolan 2003). Older people have a specific perspective concerning ageing and service use, which is based on and informed by their experiential knowledge. This knowledge is gained through the daily experiences of older people with their own ageing and the care they receive. Furthermore, older people may have concerns about interventions in health care which go overlooked by policy makers and researchers. The blending of scientific knowledge with experiential knowledge in ageing research is slowly becoming more accepted as a means of increasing the practical relevance of research and validating the research process and its findings (Reed, Stanley and Clarke 2004). The involvement of users in research can be seen as an incentive for organisations to disseminate and adapt research findings (Entwistle *et al.* 1998). Successful implementation of interventions also requires commitment from the target community, with that commitment increasing if users are involved in the decision-making process governing the intervention and its implementation (Carter and Beresford 2000).

A second, ontological reason for the involvement of older people in research concerns their rights as citizens to influence decisions which could affect their lives in the long term, and the need to further social justice and human rights in the context of power differences between people (Carter and Beresford 2000; Mertens 2009). This argument is particularly strong with regard to older people because of their experiences of age discrimination, marginalisation in society and other forms of social exclusion (Walker 2007). It is not a question of whether to involve older people, but how and to what extent.

There are numerous ways in which older people can be involved in research into ageing. Based on the citizen participation model pioneered by Arnstein (1969), Abma, Nierse and Widdershoven (2009) describe different forms and levels of participation ranging from clients who inform the

research – exerting relatively little influence – to clients who act as co-researchers or even initiators of research – and thereby exert a greater amount of influence (Abma, Nierse and Widdershoven 2009). In clinical trials, for example, they can be involved as participants. The outcome measures and research questions in such scenarios are predefined by the researchers. Although older people form the core business constituency for many health-care organisations, they are often excluded from clinical trials. This is a side effect of the age and protocol restrictions that are used to create homogeneous study populations (McMurdo, Witham and Gillespie 2005). Researchers are afraid, moreover, that the enrolment of older people will cost more time and will require more expertise and work-hours due to issues such as hearing and visual impairments (Habicht, Witham and McMurdo 2008).

In qualitative research, including older people in research as respondents in interviews or as focus group participants is the most common form of participation. The older person has no direct influence on the research process when such methods are used. According to Arnstein (1969), the lower rungs on the ladder of citizen participation represent tokenistic forms of participation. In order to genuinely involve older people in the research process and to honestly collaborate with them, one needs to go further; older people can become advisors, interviewers, co-researchers or even initiators of research (Abma and Broerse 2010).

Co-researchers in ageing research are older people who collaborate on an equal basis with academic researchers in research teams. Older people can use their experiential knowledge in conversation with the researchers, thereby actively influencing the research process, for example by co-developing the research design. Both the academic researcher and the co-researcher have access to specific forms of knowledge, be it scientific or experiential; both can thus be seen as experts. The acknowledgement of the older person as an expert forms the basis for an equal relationship between co-researchers and professional researchers (Abma and Broerse 2010; Abma, Nierse and Widdershoven 2009). Examples of such research projects include a study described by Reed *et al.* (2002), in which the authors worked with older people as co-researchers in a project which aimed to improve discharge procedures in hospitals, and a second conducted by Cornes, Peardon and Manthorpe (2008), who worked with older researchers in conducting a joint review of the National Service Framework for Older People in the United Kingdom. Both studies describe how research collaboration with older people can have great benefits for researchers, older people and services. In collaborating with end users in research, however, special attention should be paid to empowerment and equal relationships. Equality should be achieved by allowing every team member

to exercise, improve and develop different skills, and thereby position themselves to maximum efficacy within the team (Cornes, Peardon and Manthorpe 2008).

Representation is a much-debated issue in the field of public participation. A distinction drawn by Warburton and Petriwskyj (2007) describes two bases upon which older people can act as legitimate representatives – they either have experiential knowledge on ageing or they are members of organisations which represent older people.

For the researcher, collaboration with older people can lead to insights into the world they inhabit. Working together with co-researchers, however, is often a new and challenging task for professional researchers and involves a mutual learning process (Nierse and Abma 2011; Nierse *et al.* 2011; Schipper *et al.* 2010). Involvement also creates possibilities for personal development on the part of the older people. It can enhance older people's self-esteem and their social contacts (Barnes and Bennett 1998). Reed, Weiner and Cook (2004) found that older people enjoyed the learning opportunities that working with experienced professionals afforded them.

The involvement of co-researchers in ageing research is not yet common practice. Biomedical researchers often believe that partnership in research results in a complex and time-consuming decision-making process which introduces subjective elements into the research. There is also a concern that more positivist-oriented journals have no interest in such research findings (Caron-Flinterman, Broerse and Bunders 2007). Even if goodwill exists among professionals, they may lack the competencies needed to foster effective research collaborations with older people (Fudge, Wolfe and McKeivitt 2007). Older people themselves can, moreover, have reservations about acting as a co-researcher in a research team. Older people expressed the concern that their participation may be tokenistic (Cornes, Peardon and Manthorpe 2008). According to Thompson and Thompson (2001), older people are less likely to become active participants because of the many stereotypes and negative conceptions that exist about ageing. Mobility difficulties and frailty can further inhibit older people from fully participating at meetings and in research activities (Thompson and Thompson 2001). Kirwan *et al.* (2005), who co-developed and managed a range of research projects within the field of rheumatology with co-researchers, found that some patients were afraid their contributions to the research would not be useful. Furthermore, patients may fear that they do not possess sufficient understanding of scientific or medical terms (Kirwan *et al.* 2005). Such fears of exclusion and disempowerment are grounded in reality. Elberse, Caron-Flinterman and Broerse (2010) found that, even when researchers deliberately used inclusionary strategies, patients or co-researchers may not feel included in the process.

These arguments against the involvement of older people as co-researchers notwithstanding, we consciously chose to work with older co-researchers because we believe there are benefits to all involved in such collaborations. Being aware of the relative novelty and possible pitfalls of this collaborative endeavour, we made this collaboration itself the subject of this paper. We involved three senior men with ages ranging from 60 to 65 years as co-researchers in a project investigating the early detection of community-dwelling, frail older people and the integrated care for those older people. The three individuals were all members of an organisation which represents and lobbies on behalf of patients, disabled persons and older people. One of these senior men is included as the fourth author of this article. The other members of the research team consisted of a PhD student (the first author) and a senior researcher (the third author). Two external evaluators, a PhD student (the second author) and a senior researcher (the fifth author) further assisted the research team in evaluating the collaboration.

The summative aim of the process evaluation described in this article is to investigate the required conditions, success factors and pitfalls in potential collaborations between professional researchers and older people acting as co-researchers. The formative aim of this study is to improve such collaborations by using insights from having observed the process evaluation in practice. We will describe the collaboration process as a journey, with field trips and stopovers along the way. We will present the lessons learned during rest breaks taken to reflect and to plan the remaining journey.

### **Setting the scene**

The collaboration between co-researchers and academic researchers took place as part of a research project which aimed to evaluate the early detection of community-dwelling, frail older people and the integrated care available for those older people. This research project was carried out from March 2010 until March 2012 in the southern regions of the Netherlands. The research project was part of the Dutch National Care for the Elderly Programme, a funding programme to improve care and support for frail older people. In-depth interviews were used to map the experiences of frail older people and their informal care-givers. The analysis of these interviews will be published in international academic journals and processed as part of a dissertation. The collaboration between co-researchers and academic researchers consisted of executing the research project together – *e.g.* preparing the research questions, interviewing frail older people in teams of two consisting of one academic researcher and one co-researcher,

adjusting the topic list for the interviews and analysing the interviews together. This article describes the findings of an evaluation focused on this collaboration between co-researchers and academic researchers.

## **Research methods**

This study evaluates a collaboration undertaken between older people as co-researchers and academic researchers in a research project which took place between March 2010 and March 2012. It was set up as a formative process evaluation, using qualitative research methods consisting of semi-structured interviews, two dialogical reflection meetings and experiences compiled as field notes kept by both the co-researchers and the main academic researcher (Polit and Beck 2008). The advantage of a formative process evaluation is that prospective insight can be obtained from the collaborative process. Timely adjustments were made possible based on the findings of the evaluation.

Four semi-structured interviews were held individually with the three co-researchers and the main researcher in order to gain insight into the experiences of the members of the research team as they participate in the collaboration. These interviews were conducted by an external evaluator, the second author of this paper. The external evaluator and her supervisor – the final author listed on this paper – both possess an academic background in participatory research involving client participation in elderly care institutions. A topic list was used to guide the interviews. This topic list was created by the external evaluator in consultation with the two academic researchers – the first and third authors. They drew upon existing academic knowledge on the participation of clients in health-care research, and from their own experiences with prior projects in which older people were involved as partners for professionals in residential care homes (Baur and Abma 2011). With the consent of the participants, the interviews were recorded and transcribed. The external evaluator and two academic researchers thematically analysed the interview content, first individually and then by cross-checking their individual analysis together. During the first reflection meeting, the academic researchers initially took the lead, as at that moment they were still unaware of the desires and capacities of the co-researchers. The reflection meeting was a joint event, however, in which the co-researchers actively participated in open dialogue and reflection on the collaboration.

The interview analysis was reported back to the three co-researchers and formed the input for the first reflection meeting, held six months into the project. This reflection meeting was meant to act as a forum for joint

learning, to foster dialogue and mutual understanding between the research team members with the aim of strengthening the collaboration. One academic researcher – the first author – developed a narrative based on the issues and experiences described by the research team members during the individual interviews. This narrative represented a story of a collaborative journey the team members were undertaking, including the challenges which confronted the travellers. Storytelling and narratives can be useful ways of approaching reflection and learning (Abma 2003). The co-researchers and the academic researchers reflected on this story and used renewed insight to plan the remaining part of the journey. In other words, the co-researchers and the academic researchers jointly decided which issues arising from the collaboration should be addressed and how, in order to improve their collaboration. During this first reflection meeting it became clear to the academic researchers that the co-researchers desired expanded responsibilities in the research project and the collaboration. The co-researchers and the academic researchers thus organised, prepared and analysed the second reflection meeting together.

Six months after the first reflection meeting, a second such meeting was organised with the aim of evaluating the changes implemented to the collaborative environment. The reflection meeting was voice recorded and thematically analysed by the co-researchers and the academic researchers, working together. The results of that second reflection meeting were used to further improve the efficacy of the collaboration.

The academic researcher and the co-researchers took field notes during their collaborative research, which consisted of various scientific tasks such as interview preparations, conducting interviews in two-person teams and analysing the interviews. The field notes of the academic researcher were based on observations made during the preparation and execution of the research and primarily concerned the collaboration between the co-researchers and academic researchers, as well as the activities performed as part of the research project which the collaboration was meant to investigate. The field notes of the co-researchers included a journal accounting for the time invested in the research project. The co-researchers were also asked to write about how they had experienced the activities they performed together with the academic researchers. After six months, it became clear that it was a burden for the co-researchers to compile these field notes and they reported seeing it as bureaucratic barrier to their involvement. They also compiled their time-logs and wrote of their experiences long after the activities had taken place. It was therefore decided that, going forward, the co-researchers would be asked to make only field notes, if they wanted to, during the execution of research activities. The focus of the field notes changed from the collaboration of the co-researchers

and academic researchers to the co-researchers' experiences in interviewing frail older people.

In order to create triangulation within the data, three different data methods were used and compared to study the dynamics of the collaboration among team members – in-depth interviews, reflection meetings and field notes (Patton 1999). Member validation of the interviews took place through the narrative written by the main academic researcher – the first author – which was reported back to the co-researchers during the first reflection meeting. The co-researchers and academic researchers reflected on that narrative and jointly made adjustments to it. Member validation of the reflection meeting took place through a report of the reflection meetings which was created by the main academic researchers and disseminated to the wider research team for validation. This member validation was used to ascertain the credibility of the qualitative data thus collected (Lincoln and Guba 1985).

In order to create a safe environment, the interviews with the co-researchers and the main academic researcher were conducted by an external researcher – the second author. This created increased opportunity for the co-researchers and main academic researcher to speak openly and honestly about the collaboration. The external evaluator further analysed the interviews together with the academic researchers, after which the academic researchers reported those analyses – in the form of a narrative – back to the co-researchers. Analysis through multiple researchers contributed to improved accuracy in the coding process, as well as less bias (Barbour 2001; Patton 1999).

Agreements on the appropriate level of engagement should be made in a dialogue between co-researchers and academic researchers. Researchers should assess the potential vulnerabilities of the co-researchers, while maintaining a balance between autonomy and paternalism (Tee and Lathlean 2004). Therefore, the co-researchers could choose those research activities in which they wanted to participate. All co-researchers participated in the data-gathering and analysing process, and all co-researchers were invited to contribute as authors of this article; only one co-researcher – the fourth author – however, agreed to take on such a role. The content of the article was discussed with all co-researchers, however, and all were given the opportunity to react to and provide feedback on the article and its prior drafts.

Although the co-researchers were appointed as volunteers in the research project, reimbursement for travel expenses was deemed appropriate. The co-researchers received a payment of the maximum amount allowed to volunteers in the Netherlands, to cover for any travel expenses they incurred as a result of participating in the collaboration.



## The journey

We employed the metaphor of a journey to describe the collaboration between co-researchers and academic researchers. In this section, we describe each phase of the journey and the experiences of the research team within those phases. Each phase of the collaboration will be discussed, in the following order: recruitment of the co-researchers, preparations associated with the research process, joint data collection and becoming a team. The description of each phase is followed by a reflection based on data from the formative process evaluation, which includes interviews, field notes and reflection meetings.

### *Recruiting the co-researchers: travellers on the journey*

The research team initially consisted of two academic researchers. The main researcher was a PhD candidate supervised by a senior academic researcher experienced in the field of qualitative research. The main researcher, age 25, had gained experience with qualitative research in the field of nursing and primary care during her Bachelor's and Master's degree studies but had little experience in using these research methods with older people. During the preparation of the research project, it became clear to the main researcher that, in spite of the literature available on ageing, immersing oneself in the lives of older adults with more life experience and a different perspective on life, ageing and care would be difficult.

In order to ensure that all relevant views and perspectives were appreciated during the journey, it would be necessary to include older travellers themselves. To give older people a genuine voice in the research, the academic researchers decided to include older people as co-researchers. Through such participation, older people would have genuine power and the opportunity to negotiate within and influence the research process.

The first issue to be encountered was the fact that inclusion of the target group in the research project seemed difficult. As the purpose of the basic project was to screen and identify community-dwelling frail older people, and they were as yet unknown to care professionals, it was not possible to approach and invite them to participate as co-researchers. The academic researchers therefore turned to the House for the Caring – in Dutch: Huis voor de Zorg – an organisation which operates in the province of Limburg, southern Netherlands, representing and lobbying on behalf of patients, the disabled and older people. The aim of the organisation is to give these people a voice in decision- and policy-making processes. The academic researchers established a profile describing potential co-researchers and distributed this to House of the Care members. The following criteria were considered when recruiting co-researchers: personal experience with

ageing, a wider knowledge of the experiences of frail, community-dwelling older people, enthusiasm for scientific research, and motivation to complete research activities and improve the care of older people. Co-researchers needed to have the ability to understand and respond to written information and to travel independently. These criteria were informed by literature on patient involvement in chronic care research (Abma, Nierse and Widdershoven 2009; Hewlett *et al.* 2006).

Issues of representation were a particular focal point during the recruitment phase. As the older population is not a homogeneous group, a statistical representation—representing a larger group through the possession of broadly similar characteristics—would be impossible. The academic researchers therefore aimed to achieve representativeness of the older adults through lived experiences of ageing.

Three senior men, aged between 60 and 65, applied for the role of co-researchers. A group interview was arranged to determine how closely they fit the specified profile. All three applicants were highly educated and had either had a professional career or personal experience in the field of elderly care, as a voluntary advisor for older people, a member of a supervisory board for a care facility and as a social researcher investigating care for disabled people, respectively. Although they did not consider themselves frail, all were familiar with frailty in their immediate environments. Only these three men applied for the role of co-researcher, and the academic researchers were not able to successfully recruit older female co-researchers to participate in the collaboration.

*Reflections.* All three co-researchers were highly motivated to participate in the project and referred to the awareness that they might easily find themselves in a situation similar to the frail older people being interviewed:

It [participating as a co-researcher, JB] makes you think about ageing. We will all become older and maybe frail. Research like this confronts you with these facts. (Interview, co-researcher JD)

One co-researcher expressed his motivation as originating primarily from negative personal experiences with the bureaucracy when seeking care and services in the welfare sector:

The biggest problem for older people is the bureaucracy and automation in our modern time. Seniors really feel hampered by that. The care sector should become more transparent and better accessible for older people. I hope I can contribute something to this by participating in this research. (Interview, co-researcher GM)

They also pointed out the value of helping others:

I support [the researcher, JB]. That is a nice thing to do. It is nice to help someone who needs it. (Interview, co-researcher JD)

It is important that I am able to contribute to society in general, and it gives me a feeling of joy and satisfaction. (Interview, co-researcher GM)

The importance of helping others and contributing to society has been identified as one of the sources of strength and resilience in later life, described as ‘the power of giving’ (Janssen, Van Regenmortel and Abma 2011). All co-researchers expressed their interest in scientific research and in an opportunity to see ‘behind the scenes’ of research.

Personally, I like to get involved in the scientific world. I always liked these things: I was involved in research projects for the local authorities when I was still working as a town clerk. (Interview, co-researcher SH)

The interviews revealed that, early in the process, some age-related prejudices played a role in the functioning of the collaboration. The junior researcher initially questioned the experiential knowledge of the co-researchers, wondering if they were not too young and too unfamiliar with the issues of frailty to accurately understand the needs and thinking of frail older people.

Obviously, these senior men are not frail older people themselves. I doubt whether they truly represent the group of frail older people. (Field notes, main academic researcher)

The co-researchers, perhaps not surprisingly, had similar doubts concerning the youthful junior researcher:

She appears to be so . . . young . . . Maybe that’s not the right word for it . . . young. But sometimes she seems to be surprised by the things we say to her. And I see that youthfulness in her reactions. (Interview, co-researcher SH)

### *Research preparations: the travel itinerary*

Shortly after the appointment of the three co-researchers, the research team began the preparations for the project. The team initially met once monthly to discuss the research questions and to develop an action plan. The main aim of the research – to evaluate integrated care for frail older people – could not be changed because funding had already been received in response to the initial research proposal. There was, however, some room within which the already-existing research questions could be adjusted. The fact that there was a finalised research proposal prior to the appointment of the co-researchers created an imbalance within the research team. The academic researchers already had the opportunity to adjust the research proposal and read relevant literature about the subject over several months prior to the co-researchers having been appointed. This resulted in differences in knowledge within the research team with regards to the research and the research topic. The implications of this became clear during the reflection meetings.

*Reflections.* One co-researcher compared the research with a ‘black box’, which became less opaque over time. This led the co-researchers to question the quality and scope of the research project, based on the limited information they had been given about the scope of the research project:

The researcher will conduct a couple of interviews, 15 in total. In the past, when I was involved in research, this would have been judged as insufficient. (Interview, co-researcher SH)

The research project consisted of 30 interviews in total; the co-researchers had only been partially informed about the project by the academic researcher at that time. The academic researcher was uncertain as to which elements of the research she could or should share with the co-researchers out of concern that the co-researchers might become overloaded with information; co-researchers were therefore given information on a bit-by-bit basis. The interviews and first reflection meeting, however, led to the insight that concerns of overloading the co-researchers with information were unfounded. The co-researchers, moreover, shared with the academic researchers their desire to be informed about all matters pertaining to the overall research project, as this would enable them to work together on a more equitable basis. This is how a joint learning process about the collaboration among the research team members began to evolve.

### *Collecting data together: travelling through different landscapes*

The research team met in person once monthly to discuss the progress of the research. During these meetings, themes potentially important to frail older people were discussed in order to develop a topic list for the interviews. Working together on concrete tasks – such as developing a topic list – helped team members come to appreciate one another’s input. The co-researchers, for example, emphasised the importance of hobbies, employment and family history for frail older people, as well as the importance of their housing conditions and living situation. In order to more fully understand the current situation and the lives of older people, they explained that gathering contextual information about those older people would be crucial. Former and current day-to-day routines and social ties thus became topics to be covered in interviews. The co-researchers furthermore suggested making notes about the housing conditions and atmosphere during interviews as such items could not be captured on audio tape. During the monthly team meetings, the interviews with older people were evaluated and, on some occasions, the topic list was adjusted to take into account the input and experiences of the research team.

In total, the research team conducted 30 in-depth interviews with older people. The interviews were conducted in two-member teams comprised of

the main academic researcher – the first author – and one co-researcher. This interview technique was adopted from a prior collaborative research project which included chronic care patients as co-researchers (Nierse *et al.* 2011).

All co-researchers are originally from and still reside in the province of Limburg, also the home province of the interviewees. Most of the frail older people interviewed spoke in the dialect common to the southern Netherlands; all academic researchers and co-researchers could understand and speak that same dialect. If older people spoke in dialect, the academic researcher and co-researcher did so, as well.

The co-researchers were also involved in analyses of the interviews. Along with the academic researchers, they constructed analytical schemes and discussed their interpretations.

*Reflections.* The influence and added value of the co-researchers was readily apparent during interviews, which increased the level of trust the academic researcher had in her partners. In some interviews, respondents addressed their answers and story to the co-researcher. The co-researchers could relate more easily to the answers the older people gave during interviews than could the academic researcher, especially if the respondents talked about contextual information such as old traditions and what it was like having grown up 60 or 70 years prior.

In some interviews, the co-researcher and interviewee found points of departure for the rest of the interview by talking about the neighbourhood and recent changes. This small talk at the beginning of the interview made the academic researcher as well as the interviewees feel at ease and helped in establishing a rapport. One example of this can be found in an interview with an older female:

Co-researcher: The neighbourhood is nice here, isn't it? I remember that I used to visit Mr. Bussen [pseudonym], in this street.

Older woman: Oh really?

Co-researcher: Yes, that is family of mine.

Older woman: Oh, you are family of Jan Bussen? Or who do you mean?

Co-researcher: Yes, and he was married to Loes Bussen.

Older woman: I know her very well; I have such good contact with her!  
(Co-researcher JD and older women during interview, using pseudonyms)

One concern for the academic researchers was that, with the ability of the co-researchers to relate to and better understand the motivations and concerns of the older interviewees, there was an increased tendency to want to help them. The co-researchers tended to find solutions to the problems some of the older people presented. One co-researcher with extensive

knowledge of the social services system, for example, used that specialised knowledge to advise the daughter of an older woman during an interview.

Co-researcher: Would it be possible to receive an electronic alarm bell for your mother?

Daughter: I already contacted the health insurance company but they rejected it.

Co-researcher: And you couldn't receive it via the Social Support Act?

Daughter: I don't know the Social Support Act...

Co-researcher: I don't know if there's a possibility to get the alarm bell that way, but I think you should phone them and ask.

(Co-researcher GM and the daughter of an older woman during an interview)

The interviews further revealed that the co-researchers wanted more responsibility during the data collection process since they felt that the academic researchers were still in charge of the project. This sentiment was largely attributable to a lack of information and communication at the beginning of the project. As noted, the co-researchers were not brought into the project until several months after the academic researchers, and therefore had less time to adjust to and familiarise themselves with the research topic.

I have only conducted one out of three interviews; the other interviews are performed by the other co-researchers. I therefore get the feeling that I am not really involved in the project. I do not know what is going on in the project. I do not have a clear view of the progress. We only discuss that during our monthly meetings and that does not give me the feeling I am part of the project... I think we should be part of the project. (Interview, co-researcher GM)

### *Becoming a team: taking a break and enjoying the view*

The reflection meetings and the interviews conducted by an external researcher with the academic researcher and the three co-researchers made it possible to reflect on the journey undertaken in a timely manner. By taking a break during the reflection meeting, the research team had the opportunity to 'enjoy the view' and reflect on the journey thus far.

The reflection meetings and interviews revealed that prejudices within the research team were present and that the team partners initially felt like strangers to one another. As is often the case with travellers on a journey in a distant country, they categorised other, unknown people into generalised groups (*i.e.* too young; not old enough). Prejudices concerning age played a role for both academic researchers and the co-researchers. Instead of leaving these prejudices unspoken, the reflection meetings helped draw them out into the open. Later in the process the team members came to realise that

some of their age-related prejudices did not appear to be valid. The adjustment of these prejudices can be seen as an important learning outcome in a research project investigating ageing and frailty.

The co-researchers and academic researchers got to know each other better over the course of the journey. They learnt each other's strengths and weaknesses and were able to adapt to them. One co-researcher – the fourth author of this paper – possesses a great interest in science and speaks fluent English, while a second has the innate ability to put older people as well as the academic researcher at ease during an interview by establishing a friendly rapport with the interviewee. The co-researchers learnt that it was difficult for the academic researcher to address all those topics on the topic lists during the interviews, as some interviewees were attracted to other, sometimes unexpected subjects. By getting to know each other's strengths and weaknesses, the team members were better able to assist one another.

The academic researchers were afraid that advising the older people during the interview would introduce bias into the research. During the reflection meeting those concerns were expressed by the academic researchers. The main academic researcher recognised and understood the tendency of co-researchers to advise interviewees on possible solutions to their problems and reflected on this during her interview with the external evaluator:

It is difficult sometimes [not to provide solutions, JB], when you see someone who is really troubled by something about which you think 'I would do this and that about it'. ... You feel sorry for someone ... , but it is not our job, because then we would interfere in the intervention. And that really should not happen. (Interview, main academic researcher)

It became clear to the academic researcher that it was very difficult for the co-researchers to identify problems in the older persons' situation without being able to advise or to help them. The reflection meeting made it possible to talk about this tendency on the part of the co-researchers to attempt to help the interviewees. Furthermore, during the reflection meeting the research team discussed the role of the researcher, and the limitations of that role, namely not being able to help the interviewees on short notice. By talking about the effects of their offering of advice to the interviewees, it became clear to the academic researchers that not all interference during the interviews would introduce bias into the research and the research team therefore agreed that advice for the older people could be given at the end of the interview, but not during. This was not only a learning process for the co-researchers but also for the academic researchers.

During the reflection meeting, the academic researcher shared with the co-researchers what other activities her job consisted of – *e.g.* attending conferences, participating in meetings with other project members,

teaching students, reading current literature and conducting other research projects. She also shared with them her motivations for pursuing this job and what aspects of it she found satisfying. This helped the co-researchers gain a better understanding of what it means to be a scientific researcher, in addition to contributing to more personalised contact between parties since the academic researcher opened up and shared more of her personal history and what it is she does.

The reflection meetings further revealed that, in order to create a more equal relationship between co-researchers and academic researchers, it was necessary to share information. A set of tools meant to assist all parties in staying informed was thus agreed upon – included in these measures, the frequency of meetings was increased and it was agreed that the academic researcher would author a blog entry every other week in which the activities were described and the actions to be undertaken in the weeks to come would be announced. Email became the preferred instrument for sharing information and communicating with the co-researchers.

This resulted in a role shift – the main academic researcher was no longer the travel guide on this journey. The fellow travellers felt empowered to assume responsibilities and, instead of following their guide, the co-researchers decided the route of their journey together with the academic researchers. An example of the manner in which co-researchers began to take up more responsibilities relates to the location of the team meetings. At first, team meetings took place at the university building. This building was chosen by the academic researchers, because they believed that it would be easily accessible to the co-researchers. During the first reflection meeting, however, it became clear that the co-researchers were not satisfied with the location – there was too much traffic and the journey to and from the university building took too long. One of the co-researchers offered to facilitate the team meetings; he searched for and arranged a new location for these meetings. Another example of shifting roles can be seen with a second co-researcher having volunteered to take over the task of keeping the minutes of the monthly team meetings. By receiving positive feedback from the research team as a whole, the co-researchers were made to feel more empowered, more involved and more responsible for the end result.

*Reflections.* The co-researchers began to develop a feeling of ownership over the research:

At the start of the project, I felt more like an observer. Now I have the feeling that we are doing something together. The idea that all of us are responsible for the research has increased since last year. (Reflection meeting, co-researcher SH)

By creating an equal relationship between co-researchers and academic researchers, the co-researchers felt more empowered. For the academic



researchers, sharing responsibilities with the co-researchers was not always easy. In the end, the academic researchers would be held responsible for the research by external stakeholders such as the funding agency and the university. Against this background, the academic researchers were very cautious about giving too much control or responsibility to the co-researchers during the first stage of the collaboration. During the first interviews conducted in two-person teams, the main academic researcher took the lead:

I was afraid they would take the interview in a completely different direction than I would have. (Interview, main academic researcher)

The academic researcher and the co-researchers came to better understand and define their mutual goals and ideas for the conducting of interviews and the role each of them could play throughout the interview process and the reflection meetings. The academic researchers learned to trust the co-researchers and to gradually grant them increased responsibility during this same period. This resulted in an empowered role for the co-researchers during the actual interviews.

During interviews with the external evaluator, the co-researchers valued their own input to the research as being rather marginal, while the academic researchers rated its import far more highly. According to the academic researchers, the co-researchers appeared to be bridging the gap between the young researcher and the older interviewees. The co-researchers were able to let the older people speak about their daily life and routines. The presence and active role of the co-researchers during the interview led to clearer insight into the world of the older people, which was more than the topic list on its own would have been able to accomplish. The topic of the added value of the co-researchers was raised by the academic researcher during the first reflection meeting, which empowered the co-researchers by allowing them to feel more secure in their actions and the value of their contributions to the research. This in turn stimulated them to search for more ways to help bridge the gap between the academic researcher and the frail older people. The academic researcher was no longer afraid of losing control over the interview, as she had experienced first-hand the added value of the input of the co-researchers during the interviews and had learnt to trust them in their role as interviewers.

Gender differences were also discussed by the research team. In one interview, the respondent focused solely on the co-researcher. Even when the main academic researcher asked a question, the respondent – an 80-year-old male – directed his answer to the co-researcher. For unspecified reasons, the respondent felt more at ease talking to the co-researcher; the co-researcher was quick to recognise this and assumed the responsibility of

asking the questions in place of the academic researcher. This example of a male respondent focused solely on the male co-researchers is one of the rare moments in which the research team experienced gender differences. This was a positive experience, as it showed the value of the presence and role of the co-researcher in building a rapport with the respondent. There were no analogous examples of a negative influence of gender difference between the academic researchers and the co-researchers, or between the interviewers and interviewees.

The interview described above was evaluated by the research team in the subsequent monthly meeting. The co-researcher explained to the other team members how this interview had been revealing for him, personally; he was made to feel encouraged – both by the interviewee as well as by the academic researcher – to take the lead in the interview. He felt appreciated by the academic researcher, who gave positive feedback after the interview, and empowered to take on more responsibilities during the research.

I really feel like a co-researcher now. . . . I have the feeling we are doing this research together. (Reflection meeting, co-researcher SH)

Looking back at this first interview in which a co-researcher took the lead, the main academic researcher said:

I think my fear was unjustified. Actually, I now think he [the co-researcher, JB] got to the core of the matter very well . . . Perhaps even better than I could have at that moment. (Interview, main academic researcher)

## **Discussion**

Questions have been raised concerning the legitimate representativeness in research of older people. Over the course of our project, we discovered that prejudices played an important role at the start of the project, making it difficult to assess the true value of the experiential knowledge of the co-researchers. The academic researchers focused on the representativeness of the co-researchers in terms of members of an elderly organisation speaking on behalf of others. The researchers underestimated the value of the co-researchers' experiential knowledge and their abilities to connect with the interviewees through shared experiences. The experiential knowledge of frailty became apparent after jointly interviewing the older people and reflecting on those interviews. During the monthly meetings the co-researchers began telling personal stories about their own health and the health of their loved ones. It was not until that point that researchers discovered the value of knowledge of the region, cultural habits and experience with ageing in general as valuable inputs to the research and new learning opportunities for the academic researchers. This was in line with

the findings of Barnes, Harrison and Murray (2011), who found that the fitter, more active older people tend to be the individuals most actively involved at forums for community participation. This does not imply, however, that these individuals act solely as advocates for their own self-interest; on the contrary, those active in the forums tend to be well-informed about the local situation and familiar with the needs of older people, more broadly (Barnes, Harrison and Murray 2011).

Our findings also imply that it is difficult to identify sources of knowledge at the inception of a collaborative effort which involves co-researchers. Academic researchers should be aware of the fact that experiential knowledge is very personal and it can take time for the co-researchers to feel valued and secure enough to share that information with a research team. Structural reflection of all team members on the collaboration is essential in creating such an environment, which can contribute to mutual learning about sources of knowledge, ways of collaborating and ways of making the most of bringing together the perspectives of co-researchers and academic researchers. These reflection meetings also enabled the team to adjust to the needs of co-researchers. This way of working is in line with a care-ethical approach to participatory research (Ward and Gahagan 2010). Attentiveness, responsibility, competence, responsiveness and trust are all key virtues in such an approach. Attentiveness here refers to the act of considering the experiences of both the researchers and co-researchers. It rewards flexibility when, for example, more tasks and responsibilities can be shared with co-researchers. Responsibility includes efforts at balancing participants' responsibilities as researchers and co-researchers, respectively. Competence refers to the organisation of the process, and the support afforded to and by co-researchers. Responsiveness describes the feedback process, which is sought out and considered seriously. Trust forms the foundation on which all of the other virtues rely. Establishing and building trust is of the utmost importance in asymmetric relationships (Abma, Nierse and Widdershoven 2009).

Besides the issue of representativeness, subjectivity in research is a concern of many researchers. Older people actively involved in research and policy-making can become professionalised 'users' through their collaboration with researchers, policy makers and medical professionals. Their authentic experiences, in turn, can come to be overshadowed by this new type of knowledge. In our project we have taken efforts not to lose or otherwise compromise these authentic experiences by explicitly seeking out and creating room for the co-researchers to share their experiential knowledge. Attention was simultaneously paid to the fact that the co-researchers wanted more information about the research project. As the co-researchers were included after the research proposal had been submitted and approved,

there was an initial information imbalance, and the act of providing information to the co-researchers helped them to become more equal partners.

Empowerment is a goal of many user-driven research projects (Beresford and Branfield 2006). We found that empowerment of both the co-researchers and academic researchers emerged through the course of normal interaction within the team. This fits well with the notion of relational empowerment, which stresses that one is never just someone who has power or a person in need of empowerment. Everyone involved, regardless of power position and privileges, is both an agent and a subject in the empowerment process (VanderPlaat 1999). This implies that all parties are engaged in a process of learning and action, and may gain ownership over all or part of that process. We recognised the development of relational empowerment in this research team, which occurred over the course of the journey we have described. By structurally reflecting on our collaboration and, consequently, adjusting and improving our collaborative practice, every team member gained more confidence and the relationships became more equal and mutually beneficial. Team members felt their strength and understanding of the research process increased as a result of their relationship. It was thus not a matter of researchers empowering co-researchers, which is often assumed to be necessary. The whole idea of giving power or voice is, in fact, a continuation of power relations – it implies that power can also be taken away again, thereby re-establishing the dependence of clients and older persons. The team members instead empowered each other.

Diversity continues to gain attention in literature on ageing (Mehrotra and Wagner 2009). Gender and other dimensions of diversity such as class might have played a role in this research. We did not explicitly and proactively think through, however, what it meant for two women – one young and the other middle-aged – to work with a team of three highly educated senior men. Gender is known to influence the experience of old age (Calasanti 2010). Older men and women have different financial positions, experiences of and with care providers, and different health behaviours and outcomes – for example, older women are frailer than older men, and those with lower education levels tend to be frailer than highly educated individuals (Etman *et al.* 2012; Garre-Olmo *et al.* 2012). The men in the team thus might not have been able to adequately represent or empathise with the experiences of older women and members of lower socio-economic status groups. The composition of the two-person interview team will also have had an effect on the interviews, as interviews are known to be influenced by age, class and gender. In interviews in which the interviewer and the interviewee are of the same gender, women tend to speak more

about domestic life, men more about their career. When the interviews are conducted by an individual of the opposite sex, this leads to different conversation topics. Men, for instance, speak more about their family when being interviewed by a woman (Mandersons, Bennett and Andajani-Sutjahjo 2006). From this fact we can infer that our data have been influenced by the gender of the interviewers.

We argue that a successful collaboration requires ongoing reflection and room for change. We do not think, furthermore, that there is one ‘perfect collaborative method’ applicable to all older persons and co-researchers; nor do we think that each older person should act as a co-researcher. The level of involvement should always be adjusted to the particular and changing needs and capacities of those involved, as the participatory paradigm would otherwise become dogma. This paper describes a journey and the experiences of the travellers undertaking it in order to provide readers with a vicarious experience (Abma and Stake 2001). Each such mixed research team should start its own journey from a care-ethical approach, and adjust the collaboration to the particular features of the project, the context and the people involved in the collaboration (Ward and Gahagan 2010). In doing so, each particular source of knowledge and each individual can have its own place and can be seen as valuable to the whole.

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## References

- Abma, T. A. 2003. Learning by telling: storytelling workshops as an organizational learning intervention. *Management Learning*, **34**, 2, 221–40.
- Abma, T. A. and Broerse, J. E. 2010. Patient participation as dialogue: setting research agendas. *Health Expectations*, **13**, 2, 160–73.
- Abma, T. A., Nierse, C. J. and Widdershoven, G. A. 2009. Patients as partners in responsive research: methodological notions for collaborations in mixed research teams. *Qualitative Health Research*, **19**, 3, 401–15.
- Abma, T. A. and Stake, R. E. 2001. Responsive evaluation: roots and evaluation. In Greene, C. and Abma, T. A. (eds), *Responsive Evaluation: New Directions for Evaluation*. Number 92, Jossey-Bass, San Francisco, 7–22.
- Arnstein, S. H. 1969. A ladder of citizen participation. *The Journal of the American Institute of Planners*, **35**, 4, 216–24.
- Barbour, R. S. 2001. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal*, **322**, 7294, 1115–7.
- Barnes, M. and Bennett, G. 1998. Frail bodies, courageous voices: older people influencing community care. *Health & Social Care in the Community*, **6**, 2, 102–11.

- Barnes, M., Harrison, E. and Murray, L. 2011. Ageing activists: who gets involved in older people's forums? *Ageing & Society*, **32**, 2, 261–80.
- Baur, V. and Abma, T.A. 2011. 'The Taste Buddies': participation and empowerment in a residential home for older people. *Ageing & Society*, **32**, 6, 1055–78.
- Beresford, P. and Branfield, F. 2006. Developing inclusive partnerships: user-defined outcomes, networking and knowledge – a case study. *Health and Social Care in the Community*, **14**, 5, 436–44.
- Calasanti, T. 2010. Gender relations and applied research on aging. *The Gerontologist*, **50**, 6, 720–34.
- Caron-Flinterman, J. F., Broerse, J. E. W. and Bunders, J. F. 2005. The experiential knowledge of patients: a new resource for biomedical research? *Social Science & Medicine*, **60**, 11, 2575–84.
- Caron-Flinterman, J. F., Broerse, J. E. W. and Bunders, J. F. G. 2007. Patient partnership in decision-making on biomedical research. *Science, Technology & Human Values*, **32**, 3, 339–68.
- Carter, T. and Beresford, P. 2000. *Age and Change: Models of Involvement for Older People*. Joseph Rowntree Foundation, York, UK.
- Cornes, M., Peardon, J. and Manthorpe, J. 2008. Wise owls and professors: the role of older researchers in the review of the National Service Framework for Older People. *Health Expectations*, **11**, 4, 409–17.
- Davies, S. and Nolan, M. 2003. Editorial: Nurturing research partnerships with older people and their carers: learning from experience. *Quality in Ageing and Older Adults*, **4**, 4, 2–5.
- Elberse, J. E., Caron-Flinterman, J. F. and Broerse, J. E. 2010. Patient–expert partnerships in research: how to stimulate inclusion of patient perspectives. *Health Expectations*, **14**, 3, 225–39.
- Entwistle, V. A., Renfrew, M. J., Yearley, S., Forrester, J. and Lamont, T. 1998. Lay perspectives: advantages for health research. *British Medical Journal*, **316**, 7129, 463–6.
- Etman, A., Burdorf, A., Van der Cammen, T. J. M., Mackenbach, J. P. and Van Lenthe F. J. 2012. Socio-demographic determinants of worsening in frailty among community-dwelling older people in 11 European countries. *Journal of Epidemiology & Community Health*. doi:10.1136/jech-2011-200027.
- Fudge, N., Wolfe, C. D. and McKevitt, C. 2007. Involving older people in health research. *Age and Ageing*, **36**, 5, 492–500.
- Garre-Olmo, J., Calvo-Perxas, L., López-Pousa, S., de Gracia Blanco, M. and Vilalta-Franch, J. 2012. Prevalence of frailty phenotypes and risk of mortality in a community-dwelling elderly cohort. *Age and Ageing*. doi:10.1093/ageing/afs047.
- Habicht, D. W., Witham, M. D. and McMurdo, M. E. 2008. The under-representation of older people in clinical trials: barriers and potential solutions. *Journal of Nutrition, Health and Ageing*, **12**, 3, 194–6.
- Hewlett, S., de Wit, M., Richards, P., Quest, E., Hughes, R., Heiberg, T. and Kirwan, J. 2006. Patients and professionals as research partners: challenges, practicalities, and benefits. *Arthritis & Rheumatism*, **55**, 4, 676–80.
- Janssen, B. M., Van Regenmortel, T. and Abma, T. A. 2011. Identifying sources of strength: resilience from the perspective of older people receiving long-term community care. *European Journal of Ageing*, **8**, 3, 145–56.
- Kirwan, J. R., Ahlmen, M., de Wit, M., Heiberg, T., Hehir, M., Hewlett, S., Katz, P. P., Minnock, P., Quest, E. M. and Richards, P. 2005. Progress since OMERACT 6 on including patient perspective in rheumatoid arthritis outcome assessment. *The Journal of Rheumatology*, **32**, 11, 2246–9.

- Lincoln, Y.S. and Guba, E.G. 1985. *Naturalistic Inquiry*. Sage, Newbury Park, California.
- Mandersons, L., Bennett, E. and Andajani-Sutjahjo, S. 2006. The social dynamics of the interview: age, class and gender. *Qualitative Health Research*, **16**, 10, 1317–34.
- McMurdo, M. E., Witham, M. D. and Gillespie, N. D. 2005. Including older people in clinical research. *British Medical Journal*, **331**, 7524, 1036–7.
- Mehrotra, C. M. and Wagner, L. S. 2009. *Aging and Diversity: An Active Learning Experience*. Second edition, Routledge, New York.
- Mertens, D. M. 2009. *Transformative Research and Evaluation*. Guilford Press, New York.
- Nierse, C. J. and Abma, T. A. 2011. Developing voice and empowerment: the first step towards a broad consultation in research agenda setting. *Journal of Intellectual Disability Research*, **55**, 4, 411–21.
- Nierse, C. J., Schipper, K., van Zadelhoff, E., van de Griendt, J. and Abma, T. A. 2012. Collaboration and co-ownership in research: dynamics and dialogues between patient research partners and professional researchers in a research team. *Health Expectations*, **15**, 3, 242–54.
- Patton, M. Q. 1999. Enhancing the quality and credibility of qualitative analysis. *Health Services Research*, **34**, 5, 1189–208.
- Polit, D. F. and Beck, C. T. 2008. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. Lippincott Williams & Wilkins, Philadelphia.
- Reed, J., Pearson, P., Douglas, B., Swinburne, S. and Wilding, H. 2002. Going home from hospital – an appreciative inquiry study. *Health and Social Care in the Community*, **10**, 1, 36–45.
- Reed, J., Stanley, D. and Clarke, C. 2004. *Health, Well-being and Older People*. The Policy Press, Bristol, UK.
- Reed, J., Weiner, R. and Cook, G. 2004. Partnership research with older people – moving towards making the rhetoric a reality. *Journal of Clinical Nursing*, **13**, 3a, 3–10.
- Schipper, K., Abma, T. A., van Zadelhoff, E., van de Griendt, J., Nierse, C. and Widdershoven, G. A. M. 2010. What does it mean to be a patient research partner? An ethnodrama. *Qualitative Inquiry*, **16**, 6, 501–10.
- Tee, S. R. and Lathlean, J. A. 2004. The ethics of conducting a co-operative inquiry with vulnerable people. *Journal of Advanced Nursing*, **47**, 5, 536–43.
- Thompson, N. and Thompson, S. 2001. Empowering older people: beyond the care model. *Journal of Social Work*, **1**, 1, 61–76.
- VanderPlaat, M. 1999. Locating the feminist scholar: relational empowerment and social activism. *Qualitative Health Research*, **9**, 6, 773–85.
- Walker, A. 2007. Why involve older people in research? *Age and Ageing*, **36**, 5, 481–3.
- Warburton, J. and Petriwskyj, A. 2007. Who speaks for Australia's seniors? Policy partnerships and older Australians. *Just Policy*, **45**, 38–43.
- Ward, L. and Gahagen, B. 2010. Crossing the divide between theory and practice: research and an ethic of care. *Ethics and Social Welfare*, **4**, 2, 210–6.

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