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Title: Person-centred research practice: the user involvement in research of older adults with first-hand experience of reablement

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ABSTRACT

User involvement is increasingly common in healthcare research, and the ideal is user participation and influence during all research stages. Here we describe and reflect on the processes and outcomes associated with advisory group-researcher collaboration from a person-centred perspective. When planning a study in which older adults' experiences of reablement were investigated, older adults with previous first-hand experience of reablement participated in an advisory group. We found that the fostering of healthful relationships, in which experiential and research knowledge are considered complimentary and equitable and all members have the power to exercise their unique roles, seems to be a prerequisite for the co-creation of knowledge. Also, practical arrangements and social relationships constitute important details that are crucial to ensuring contribution from older adults with health-related conditions. While such individuals may be unable to participate during all stages of a research project, their involvement on an advisory level during the initial stages can increase study quality and relevance. Input from the advisory group members contributed to the improvement of the language in the study information sheet, improvement of the study design, development and validation of the interview guide, and insight into how the interviews should be conducted. The personal knowledge and expertise of the advisory group members, which emanated from their immediate sensitivity, contributed to the person-centredness in the study.

INTRODUCTION

The World Health Organization (WHO) highlights the principle that all people should enjoy the right to the highest standard of health and that people should constitute the core of health systems service delivery. WHO defines people-centred care as, 'an approach to care that consciously adopts individuals', carers', families' and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organised around the comprehensive needs of people rather than individual diseases, and respects social preferences.' People-centred care encompasses clinical encounters and the health of people in their communities, including their crucial role in shaping health policy and services (World Health Organization, 2016). Person-centred research is based on the same values and emanates from a holistic approach with the aim to explore and support the capacity and capability of person-centeredness in healthcare on the micro-, meso- and macro levels (Dewing, Eide and McCormack, 2017). Person-centred research is underpinned by two paired key principles: attentiveness and dialogue, empowerment and participation. Reflexivity is a third, key principle, linked to process, context and outcome. Also, the formation and fostering of healthful relationships should underlie person-centred research (Jacobs, Van Lieshout, Borg and Ness, 2017). Healthful relationships facilitate human flourishing, whereby people interconnect through meaningful and intentional practices by giving and receiving (McCormack and McCance, 2017; Skovdahl and Dewing, 2017).

Patient and public involvement (PPI) in health and social research is on the policy agenda in many welfare states (Hamilton et al., 2018; National Health and Medical Research Council, 2016; National Institute for Health Research, 2019). In Norway's national strategy for research and innovation it is stated that those who receive services (users) should participate

3

in processes related to the prioritisation of, planning of and decision-making on research. The underlying rationale is that user involvement in research facilitates reflection on users' needs and improves research design, participant recruitment and research quality during all stages of the research process (Ministry of Health and Care Services, 2014). These guidelines and strategies are also reflected in the Norwegian Research Council's health research programs, in which applications for funding for research projects include a stipulation for user involvement in the project (The Research Council of Norway, 2016).

In one widely used definition of public involvement in research, research is viewed as being carried out 'with' or 'by' rather than 'for', 'about' or 'to' members of the public (INVOLVE, 2012). In that definition, public refers to the range of people and groups that may be involved in research: patients, potential patients, carers and people who use health and/or social care services as well as people from organisations who represent those who use such services. The use of the propositions 'with' and 'by' imply public involvement during all research steps: what to explore and how the research should be carried out, analysed and disseminated.

There is a long history of PPI in research related to some specific health areas, e.g. mental health and disability, and user organisations usually initiate such research. Research initiatives in which older adults are involved as co-researchers often take the form of invitations from researchers (Fudge, Wolfe and McKevitt, 2007). Participants found in this manner seldom have personal or first-hand experience of the research topic (Ward and Gahagan, 2012). Instead, the focus in such research is placed on age as an indicator of representativeness. In a review on the impact of involving older adults in research that encompassed 30 studies, most studies did not give further participant details other than that the participants were aged 50+ (Fudge et al., 2007). In another review that encompassed nine studies, older adults as co-

researchers were seen in some of the studies to have experience from the area being studied or had old-age-related conditions, but most studies did not give further participant details (Baldwin, Napier, Neville and Wright-St Clair, 2018).

Baldwin et al. found that older co-researchers experienced both benefits and challenges when participating in research: psychological and social benefits, new learning, activism and career opportunities but also demanding workloads, difficult relationships and dissatisfaction with the level of involvement. Academic researchers who included older co-researchers in their research experienced new learning and shared workloads, but also demanding workloads and difficult relationships (Baldwin et al., 2018). In their review, Fudge et al. found anecdotal evidence that the involvement of older adults as co-researchers resulted in changes on the individual level but found little evaluation of how such involvement changed research processes or outcomes (Fudge et al., 2007).

In a review of the methods used to involve older adults in health research, nine studies that fit the definition of PPI in research as delineated by INVOLVE were included. The researchers saw that while the involvement in research of older adults with old-age-related conditions is feasible, there could be specific challenges (Schilling and Gerhardus, 2017). In that review, strategies that can enhance the effective involvement of older adults with old-age-related conditions in research were identified, such as thoughtful choice of location, use of visualisation and accessible communication, building good relationships and flexible approaches. Conversely, in another review, Fudge et al. (2007) found no specific barriers to the involvement of older adults in research. The different findings may be due to the fact that Schilling and Gerhardus explicitly sought out studies that included older adults with old-age-related conditions related to the research topic.

As seen above, apart from studies where older adults were included as research objects or informants, a relatively small number of studies on involvement in research of older adults with health-related conditions and first-hand experience currently exist. Also, findings on barriers to the involvement of such groups and the impact their involvement can have on research are limited and inconclusive. This indicates that more knowledge on the topic is needed.

When planning a study investigating older adults' experiences of reablement in an urban municipality with 70.000 inhabitants in south-eastern Norway, we invited home-dwelling older adults with previous experience of reablement services to join an advisory group. Reablement is a rehabilitative intervention whereby older adults are supported in regaining or maintaining their independence in daily life (Aspinal, Glasby, Rostgaard, Tuntland and Westendorp, 2016). Unlike traditional home care services, reablement is a time-limited, intensive, multidisciplinary, person-centred and goal-directed intervention (Cochrane et al., 2016).

Aims

In this article we describe and reflect on the processes and outcomes associated with advisory group-researcher collaboration. Our reflections emanate from our experience with the user-involvement of older adults with health-related conditions and first-hand experience in an advisory group.

We placed a particular focus on the following research questions:

1) What are the important prerequisites associated with facilitating the user involvement of older adults with health-related conditions in research?

2) How can the involvement of older adults with first-hand experience improve research quality and relevance?

3) How can the involvement of older adults with health-related conditions and first-hand experience contribute to the improvement of person-centredness in research?

Note that we use the term 'health-related conditions' throughout; this is to emphasise that the challenges that older adults may face should not solely be considered 'old-age-related.'

METHODOLOGY

Creation of an advisory group

The rationale underlying our decision to create an advisory group was the assumption that individuals with first-hand experience have unique expertise, views and advice, and consequently possess a competence that we as researchers do not have. We therefore sought such knowledge to increase the accuracy and relevancy of our research. Our epistemological foundation was that knowledge is created in a dynamic process between the subjects present in a research encounter. The researcher is not a distant and neutral observer but a part of the relationships that develop in the group (Brinkmann and Kvale, 2015). Through discourse, each group member contributes their history and values. Implicit in this view is that group members supersede their roles as researchers or users. Instead each individual represents him/herself as a complete person in the context (Skovdahl and Dewing, 2017).

Recruitment process

The first author (KJ) contacted approximately twenty healthcare professionals who worked with reablement in the local municipality by e-mail, asking the professionals to recommend and initially contact older adults with experience of reablement with regard to participation in our research project as members of an advisory group. Six professionals responded, with each recommending one older adult who fit the inclusion criteria and had indicated interest in joining the advisory group. The professionals provided additional explanations for why they had asked certain individuals to join the group: '*she had a good result from reablement*', '*he will benefit from meeting other people*', '*she is outspoken*' and '*she has experience with working for organisations*'.

When using intermediaries, there is a risk that a particular type of individual may be recruited: e.g. individuals with a positive (versus a negative) experience or individuals with whom the intermediaries have a good relationship. If such occurs, critical perspectives may be lost. The professionals here demonstrated diversity in their choices, and a heterogeneous advisory group that encompassed varied personal attributes and social needs was seen. Still, this illustrates the complexity of representativeness, showing that such a small participant group cannot be considered entirely representative of the large group of individuals who have participated in reablement (Martin, 2008).

KJ contacted the six potential advisory group members by phone and invited them to a meeting. While three immediately said they would participate, one rejected the invitation, two expressed uncertainty and asked for more information. To provide more information, KJ made home visits to two individuals, during which they stated that they doubted they could participate in the group because of practical circumstances and health conditions: help getting

dressed or with transportation was needed; limited hearing, physical and/or mental capacity. As one noted, *'I can get outside with my wheelchair and wait for the taxi, but it is impossible for me to get [my] heavy winter coat on without assistance'.* To remove this obstacle, KJ suggested that she could come to the individual's home to assist, followed by a shared taxi journey to the meeting. Once the practical obstacles were identified and solutions found, the two initially uncertain individuals decided to participate. A total of five older adults agreed to participate and become members of the advisory group, four women and one man, aged 72 – 94.

These five members all had first-hand experience of reablement, were pensioners and lived at home alone. All received home care services, but the level of service varied: from several times a day to once every second week. Four had limited mobility and used a wheelchair or other mobility aids. One had visual difficulties while another had severely impaired hearing. The broad age range and differing health situations of the members showed that, as a category, older adults are not a homogenous group and that, consequently, the advisory group should not be considered as such.

When seeking members for the advisory group, we saw that seemingly small obstacles could comprise a barrier to participation, with consequent loss of experience and knowledge. In this respect, the members could be described as frail and, as such, representatives of a 'hard to reach group' with regard to involvement in research. Such representatives are often excluded from participation in user panels (Oldenhof and Wehrens, 2018).

The meetings

Four advisory group meetings were held over a period of six months, all led by KJ. Each meeting lasted 1.5 hours and was held in the local municipality's town hall. This location was chosen to suit the needs of the advisory group members; the meeting rooms were easily accessible and public transport and a taxi stand were nearby. Still, one meeting was rescheduled due to the weather; on the day originally scheduled, three members were not comfortable leaving their homes due to snow.

Each meeting started with small talk, followed by a short summary of what had occurred during the previous meeting. The topic of the day was displayed on a projection screen and/or on paper. Following each meeting, KJ wrote a summary of what had occurred during the meeting and recorded reflection notes. Between meetings, KJ sent the advisory group members letters that included information on the status of the project and topics for the next meeting, which helped members stay informed. KJ called the members the day before each meeting to confirm the meeting and ask members if they needed help with any practical matters. Close follow-up ensured that the members could attend meetings and signalled that their participation was important and appreciated. This follow-up was balanced by respect for the individuals' autonomy, shown through understanding and acceptance of the members' decisions regarding whether they could attend a meeting or not.

Four months after the last meeting, the members were invited to a dialogue meeting to reflect on their experiences of participating in the advisory group. This meeting was conducted by KJ together with second author (BL), with the dialogue audio recorded and transcribed by KJ. By the time of this final meeting, one member had passed away and two members were unable to attend because of illness; thus only two members participated. Consequently, the diversity of

experiences that could have emerged if all members were present was not realised. This shows that continuity with regard to the involvement of older adults with health-related conditions may be challenging due to the progression of illness (Schilling and Gerhardus, 2017). This is an inevitable risk that could have been reduced if the meetings had been held more frequently over a shorter period. Nevertheless, relational processes require time and the actual period can therefore be considered justifiable.

Building relationships – caring for one another

During the first meeting, KJ presented herself by telling about her professional and personal background. Thereafter, the members presented themselves and time was given to becoming acquainted. This was followed by KJ providing information about the planned study, including the motivation underlying why the members were invited to join the group. Clarifications were made concerning practical matters related to meeting times, frequency and transportation. The opportunity to become acquainted gave the members the chance to familiarise themselves with the other members of the group, i.e. the person behind the role. The members were open about their situations and sought to share information about their health and the challenges they faced in daily life. When reflecting on this first meeting, two members noted that: '*We became a tight-knit group immediately*', and '*We quickly made a connection and also talked a lot about things outside of [the scope of the study].*'

During each meeting KJ, in her capacity as researcher, sought to create an environment of attentiveness where everybody was seen, heard and experienced a sense of belonging in the group (Jacobs et al., 2017). KJ observed in a reflection note that, *'It is remarkable how they care for one other - and me.'* Knowing each other as unique individuals, with own values and

individual backgrounds, appears to have created a group relationship that was based on mutual respect and responsibility for one another (Skovdahl and Dewing, 2017).

FINDINGS

'Experts in experience'

When asked why they had decided to participate, the members stated that they would be happy if their experiences could help improve future healthcare services for others. They also expressed that they would consider their participation meaningful if their contributions could help KJ succeed with her research. When referring to themselves, they used the term 'volunteers' and maintained that they represented only themselves and own experiences. When asked what they associate the concept user involvement with, one member replied: '*I have no relationship to that word. I am myself.*'

The members wondered whether and to what degree their contributions to the research project would be useful. One stated, '*I cannot understand what you get out of talking with us.*' Another noted, '*My generation is not used to being experts. The healthcare providers are experts*.' Their perspectives can be understood if one takes into consideration the hierarchical nature of the healthcare system that the members grew up with. Previously, a total respect for authority was assumed and users' experiences and knowledge were either not appreciated or not taken into consideration (Armstrong, 2014). Older adults have also traditionally been excluded from research, because they are considered to be a vulnerable group (Littlechild, Tanner and Hall, 2015). Consequently, their voices are seldom heard and their knowledge hitherto ignored. The members experienced their involvement in research as being strange and

new. Through their comments, the relationship underlying user involvement in general was illuminated: most older adults are not used to saying what they want or wish and thus do not perceive the importance of own experience as the basis of knowledge. This underpins the notion that their role as users in user involvement research is influenced by their lived experience (Skovdahl and Dewing, 2017). We saw that despite members expressing doubt about own knowledge, they nonetheless contributed and provided significant input.

Topics shared with the advisory group

The topics presented during the four advisory group meetings included: study information sheet, study design, interview guide and how to conduct the interviews. Below, the contributions of the advisory group members are briefly presented.

Study information sheet

KJ presented a draft of an information sheet intended for individuals participating in this study, which was drawn up in accordance with guidelines from the Regional Committees for Medical and Health Research Ethics (REK). The members were asked whether the language was understandable and the necessary information included. KJ chose this as the first topic because it was concrete and therefore considered easier for the members to have an opinion on. The members noted that while the information sheet was understandable, the information provided was quite extensive and that some of the language it contained could be considered somewhat alienating. We accordingly concluded that the information as initially presented in the draft could be construed as an obstacle to participation in the study and simplified the text so that it had a more personal tone. We also made some small adjustments to the headings and layout in the information sheet to improve the text's readability.

Study design

KJ presented a proposal for the study design based on two individual interviews in participants' homes, which would occur at the start of and at the end of a reablement intervention. The members were asked if they perceived that such a design would elicit participant experiences with reablement. While the members expressed that individual interviews were suitable, they also noted that the phase following a completed intervention was 'critical' and that it would be interesting to gain more information about this phase. Based on this input, we decided to include a third interview in the study that would take place a few weeks post-intervention.

The members were also asked if there were any conditions that should be stipulated when recruiting for the study. The members expressed concern that some older adults might find participating in a study too challenging and that we as researchers should address this issue. To these means we asked the healthcare professionals responsible for the recruitment of participants for the study to consider whether simultaneous participation in a reablement intervention and the study would be an excessive burden and whether such might negatively influence the reablement process.

Interview guide

KJ presented a draft of the interview guide, followed by questions about whether the themes were suitable with respect to eliciting important content related to participants' experiences of the reablement intervention. During a first round of discussions, the members expressed that, '*[the interview guide] looks good.*' When KJ asked for suggestions on which questions should be asked or which themes should be emphasised, the members' replies were almost non-existent. However, the members mentioned what they themselves had experienced as being

important during their own reablement intervention. They revealed that their motivation, daily mental and physical condition and strength could vary. They furthermore mentioned that they would have liked to determine (or limit) the frequency, scope and intensity of the intervention. We compared their statements on what they had experienced as being important during own rehabilitation with the themes included in the draft version of the interview guide. When 'translating' the members' descriptions of what they considered to be important, we received confirmation that the interview guide contained relevant themes. We furthermore used the members' input to identify if any eventual follow-up questions were needed for specific themes. One noted that, '*Arriving on time is important!*', which led to an explicit focus in the interview guide on participants' collaboration with the reablement team. Another stated that, '*I experienced that they got me to put myself in the driver's seat during my rehabilitation*', which led to the inclusion of questions in the interview guide about what roles are played (if any, and by whom) and individuals' own responsibility during an intervention.

The members emphasised that they perceived participation in a reablement invention as something that could not be refused, stating that a person has a moral obligation to 'make a greater effort' if healthcare authorities allocate resources. They suggested that KJ should tell study participants that they were obligated to follow the information, instructions and programs they were given during their reablement intervention. We chose not to follow the members' advice literally, because, from a research perspective, this was a matter to be discussed between the reablement team and the users. Instead, during the first interview KJ asked the participants what their thoughts were on the issue of 'self-effort' in relation to the intervention that lay ahead of them.

The members were not as specific in their feedback on the interview guide as they were on how to conduct the study interviews. This can be clearly seen in KJ's reflection notes from the third meeting: '*They have talked a lot about own experiences, I have to keep trying to challenge them to think generally, with a little more distance. At the same time they provide good examples from [their] own reablement experiences*.' KJ experienced that when she confirmed and repeated members' statements or asked questions such as, 'Then I understand that it would be wise to ask about…?', the members indirectly provided input, even if the input was to an extent plucked from the members' first-hand experiences.

When developing the interview guide, we could have chosen to conduct pilot interviews and thereafter adjusted the guide in accordance with the interviewer's experiences of what had 'worked' or 'not worked'. In a 'worst-case scenario', some users could have experienced such interview situations as being uncomfortable due to being asked questions that they did not understand. Gaining input from an advisory group allowed us to adjust and alter the interview guide prior to the start of the interviews.

How to conduct the interviews

We considered the study participants to be in a vulnerable position, because they needed healthcare services due to a recent change in functional ability that could lead them to perceive that daily life was challenging or unpredictable. The advisory group members were therefore asked to provide their views on how the study's individual interviews should be conducted. They provided very specific advice, stating, '*Do not be afraid to ask direct questions. The majority have the need to talk. You can ask about anything you like as long as you demonstrate that you are genuinely interested.*' The members furthermore articulated that older adults have life experience and are capable of demonstrating that there are limits to what

they wish to share. Subsequently, emanating from the members' advice, we sought to be neither overly careful nor overly restrained when asking participants follow-up questions during the interviews. One member also provided another important piece of advice, stating that, '*You run risk that [the participants] are not honest, because they do not wish to hurt anyone's feelings. Use time therefore to reassure them that you [will not breach your] duty of confidentiality.*'

DISCUSSION

In this article we have sought to describe and reflect on the processes and outcomes associated with advisory group-researcher collaboration. A particular focus was placed on the following research questions: What are the important prerequisites associated with facilitating the user involvement of older adults with health-related conditions in research? How can the involvement of older adults with first-hand experience improve research quality and relevance? How can the involvement of older adults with health-related conditions and first-hand experience contribute to the improvement of person-centredness in research?

We found that practical arrangements and social relationships constitute important details that are crucial to ensuring contribution from older adults with health-related conditions, i.e. a hard to reach group. This strengthens the findings by Schilling and Gerhardus (Schilling and Gerhardus, 2017). We saw that weather conditions, transportation or concern about own capacity may be enough for individuals to rule out joining a project. To ensure participation, it was essential that we as researchers showed flexibility in planning and followed up on the advisory group members individually.

We saw that building relationships was a crucial factor in collaboration and co-creation. Here the researcher and advisory group members respected, took responsibility for and related to one another in a personal way, and we maintain that such behaviour facilitated relationships and may be a prerequisite for being able to contribute in a group. Other researchers have shown that people, despite individual opportunities and limitations, are self-creating social agents who flourish in relationships where all actors give and take (McCormack and McCance, 2017; McCormack and Titchen, 2014; Skovdahl and Dewing, 2017). Still, being too close can stress participants, because this might entail a moral obligation to be present and share more than they initially intended. We maintain that researchers should address the rights of participants to become involved to the degree that the participants themselves feel comfortable with, which requires continuous sensitivity and attention from researchers that supersedes learned skills and techniques.

We discerned that the involvement of individuals with first-hand experience appears to increase the quality and relevance of a study. Input from the advisory group members contributed to the improvement of the language in the study information sheet, making it more suitable for the intended target group. Their input also improved the study design, because their suggestion to add an interview following a completed intervention provided better insight into the topic of the research. Their first-hand experiences even helped us develop both the interview guide, through identification of themes for follow-up questions, and how the interviews should be conducted, encouraging us to be neither overly careful nor overly restrained when asking follow-up questions. Subsequently, in contrast to Fudge et al. (2007), we argue that user involvement, as seen here, does have an impact on research processes and outcomes.

Given the background and health conditions of the advisory group members, we experienced that their contribution and involvement on a consultative and advisory level during the initial stage of our research project were most appropriate. We saw that the members used their strengths on the level and to the extent that they were capable of. Several user organisations and research communities maintain that the public should be involved in all research steps, including decisions about what to explore and how the research should be carried out, analysed and disseminated (de Wit et al., 2011; INVOLVE, 2012; Popay and Collins, 2014). With great likelihood, the members would not have wanted to join the advisory group if we had expressed that they were to participate in several research phases. One reason was that their participation in the collection of data, i.e. interviews, would have been virtually impossible. For example, some of the physical difficulties the members faced (reliant on a large, electric wheelchair; needed assistance dressing and undressing) would have hindered them from entering others' homes when performing interviews. In accordance with Arnstein's ladder of participation, the involvement of an advisory group on a consultation level is considered tokenism (Arnstein, 1969). Yet other researchers suggest that educational programs that prepare older people to be equal partners in research can inhibit tokenism (Dewar, 2005). The overall health situation of the older adults here constituted a barrier to participation in concrete research activities. Also, we did not expect the advisory group members to possess or acquire research skills and competence, because their expertise lay in their first-hand experience.

Some researchers assert that individuals with first-hand experience bear within themselves a proximity and subjectivity that are incongruent with research ideals such as objectivity and distance, and that researchers possess a knowledge that cannot be replaced by experiential

knowledge (Ives, Damery and Redwod, 2013; Malterud and Elvbakken, 2019). Other researchers contradict this view, maintaining instead that proximity and subjectivity strengthens the quality of research (Beresford, 2013; Staley, 2013). We perceived that our research knowledge and the members' experiential knowledge were complementary domains, with neither superior to the other. We experienced that the two types of knowledge met in a co-creation process where the actors in the process were considered equal despite different positions (Greenhalgh, Jackson, Shaw and Janamian, 2016; Tritter and McCallum, 2006). Prior to the start of this project, we were uncertain how user involvement could help create something more complete than researchers by themselves could. Yet by being open to collaboration and facilitating the development of relationships and an environment that allowed the advisory group members the 'power' to exercise their role and flourish (Skovdahl, Kihlgren and Kihlgren, 2003), we found that new and valuable knowledge was created. This illustrates what Greenhalgh et al. describe as co-production: creating a whole that is greater than the sum of individual parts (Greenhalgh et al., 2016).

We found that the user involvement in research of older adults with health-related conditions and first-hand experience contributed to the person-centred approach. In accordance with a person-centred perspective, the expertise of all actors involved should be appreciated, because each human being is unique and has his/her own unique lived experiences, values and beliefs. This was confirmed when the members stated that they represent themselves, and it was illustrated in KJ's reflection note when she concluded that despite the members not having a distanced approach (i.e. they did not generalise their experiences) they contributed valuable knowledge derived from unique personal experience. Accordingly, the experiences revealed here should not be considered to represent all individuals participating in a reablement intervention, and the members of the advisory group should not be considered representatives

for the entire group (cf. Martin, 2008). This is in line with a person-centred research perspective, where the views of the individual are valued as a legitimate basis for the co-creation of knowledge (van Dulmen, McCormack, Eide, Skovdahl and Eide, 2017).

We found that the advisory group members provided important and unique perspectives, and their input both corrected and challenged our preunderstanding, values and epistemological stance as researchers. We initially believed that older adults should be considered a vulnerable group, and were concerned that asking too personal questions during interviews might possibly cause offence. Instead, the members of the advisory group revealed that researchers need not be too restrained when interviewing older adults. They maintained that not asking important, personal questions would offend, the opposite of what we intended. Such new understanding is 'knowledge in context', the insight and learning we as researchers gain when collaborating with users in research (Staley, 2015). Subsequently, we confirmed our assumptions that the members possessed valuable, unique expertise from first-hand experience. Their insight, perspectives and experiences contributed to our development as researchers and improved the person-centredness in our research.

CONCLUSION

We experienced that user involvement in research is not a linear, instrumental process comprised of tasks and a checklist, but is instead a fluctuating, dynamic process.
We maintain that inviting older adults with first-hand experience of reablement to join an advisory group can be seen as a recognition of their personal knowledge and expertise,

emanating from their immediate sensitivity. Valuable experience and knowledge would have been lost if we had not embraced the idea of user involvement in research and included the advisory group. We hold that our project illustrates that user involvement in research on a consultative and advisory level during the initial phase of a research project should not be considered tokenism. We furthermore suggest that that the ideal of user involvement in research, seen as involvement at every stage in a research project, should not supersede a realistic-pragmatic approach to what is possible through the involvement of older adults with health-related conditions. We found that engaging older adults with first-hand experience of reablement in an advisory group on a consultant level in the initial phase of a research project was highly beneficial and therefore can be advocated. The members in our advisory group had first-hand experience of reablement, but our findings and experiences may be relevant to other similar person-centred research projects where older adults with health-related conditions are involved as co-researchers.

Declaration of contribution

KJ, BL and KS were responsible for the conception and design of the study. KJ was responsible for the recruitment and the collection of data material. KJ wrote the draft manuscript and KS and BL revised the manuscript critically for intellectual content. All authors read and approved the final manuscript and agreed to be accountable for all aspects of the work.

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Ethical approval

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Conflicts of interest

The authors have no conflicts of interest to declare.

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