

## *A brief account of the PhD project:*

# Involving Citizens and Professionals in Research on Ageing and Health

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The current 'participatory turn' (Saurugger, 2010) or demand for public participation in various societal decision-making processes, has its origins in the intertwined quest for a more just society, and the successful management of the uncertainty and complexity that characterises many of today's social and environmental issues (Hronszky, 2005). The idea that public participation will improve the decision-making processes has also been directed at research on ageing and health in light of a prevailing ageism that interferes with healthy ageing (Nelson, 2016) and a demographic development that requires innovative solutions.

However, the emergence of participatory approaches in research is varied and equivocal, and the conceptual apparatus is confusing and far from unambiguous (Adelman, 1993; Bergold & Thomas, 2012; Bjerknes & Bratteteig, 1995; Hall, 1992). As an example, the terms *Participatory Research* (PR) and *Participatory Action Research* (PAR) can be mentioned. Here, some claim that they refer to the same phenomenon (Hall, 1992), others argue that while PR concentrates mainly on the process and the exchange that occurs within it, PAR has a strong focus on the outcome and impact "in real life" (Bergold & Thomas, 2012). Furthermore, while some use *involvement* as an umbrella term and see *participation* as one form of involvement (innovAge, 2014), others argue that it is the other way around (Bammer, 2019). The term *user* (as in *user involvement* or *user participation*) is ambiguous as well. In research that is linked to social work, it refers to the user of health and social care services (Beresford, 2007; Cotterell et al., 2012); in design research to the user of products, services or systems (Eason, 1995; Kujala, 2003) and in the health sciences it can refer to either the user of health and social care services (Tritter & McCallum, 2006) or to the intended user of the knowledge being produced (Iwarsson et al., 2019).

In addition to the terminology, the purposes of employing a participatory research process seem to vary as well. Whilst in the health sciences, there is a strong focus on the research process as such and the mutual learning that occurs within it (Bergold & Thomas, 2012; Hanson et al., 2006; Tritter & McCallum, 2006), in research linked to social work and design the emphasis is more directed towards the actual outcome in terms of societal impact or the intended users' satisfaction with the end product (Beresford, 2005, 2007; Cotterell et al., 2012; Essén & Östlund, 2011; Kujala, 2003; Raviselvam et al., 2016). That the process itself is highlighted in the health sciences is further indicated by the explicit requirements for user involvement by the funding bodies in this area of research (Cook, 2012). Hence, the primary goal seems not be to change the practice but to produce knowledge in collaboration (Bergold & Thomas, 2012). Since participation can look different, attempts have been made to rate the participants' engagement and impact. Here, Arnstein's (1969) *Ladder of participation*, with a range from nonparticipation to citizen control, has been influential (Tritter & McCallum, 2006). However, criticism

has been directed from a health scientific perspective to Arnstein's ladder for the unanimous focus on outcome and the inability to attribute a greater intrinsic value to the participatory process (Tritter & McCallum, 2006). Consequently, several attempts have been made to more fully describe levels of participant influence in various types of research activities (Greenhalgh et al., 2019; Hanson et al., 2006; Tritter & McCallum, 2006).

Although research with participatory aspirations may seem disparate, it does have a common ground in that it is rooted in the epistemological assumption that knowledge is socially constructed (Gergen & Gergen, 2008; Hall, 1992). This means that the choice of participatory approach or method for a particular research study usually reflects the potential it is considered to have to acquire knowledge in a social or collective way (Hall, 1992). However, the emphasis on acquiring knowledge in a collective way does not necessarily imply that the knowledge needs to be shaped into an integrated unity. It can also, as Lawrence (2020) has recently pointed out, be thought of as forming a synthetic wholeness in which professionals' know-how, citizens' ways of knowing and disciplinary (and interdisciplinary) knowledge complement each other. Regardless if the pursuit is to create a unity or a synthetic wholeness of the acquired knowledge, this form of learning and problem-solving, involving cooperation between different parts of society and academia, is usually referred to as *transdisciplinary research* (TR) (Doucet & Janssens, 2011; Lawrence, 2015; Thompson Klein et al., 2001). In its knowledge creation ambitions, TR has also points in common with the aim of obtaining *socially robust knowledge*, i.e. knowledge that is valid both inside and outside the university walls, that has been suggested as a response to increased demands of accountability directed at universities and as a way to democratise expertise (Nowotny, 2003).

Still, involving users such as citizens and professionals in research requires careful considerations since such efforts carry a potential for unjust exercises of power (Hickey & Mohan, 2004) and entails risks of reproducing existing inequalities rather than addressing them (Buffel, 2015). Moreover, there are several methodological challenges including how to appropriately recruit representatives (Gradinger et al., 2015) and adequately involve users in data collection (Priestley et al., 2010) and in the analysis of the findings (Cotterell, 2008). Further research is also needed on how to convert expressed concerns and ideas into proper research questions (Erdtman et al., 2012). Overall, there remains a scarcity of studies about involving various users, including citizens and professionals, in ageing and health research (Kylberg et al., 2018).

### *Project context*

The UserAge research program is a six-year, four-node endeavor with international collaboration, coordinated by Lund University. Involving user representatives and international scientific experts, the program builds upon our previous/ ongoing research with user involvement. The ultimate goals of UserAge are to maximize the impact of user involvement; enhance the execution of high-quality research; increase the knowledge about what difference user involvement can make and evaluate the extent to which research about and with user involvement makes an impact on practices and outcomes. This project is one out of four PhD student projects in the UserAge program.

### *Study aims*

The overarching aim of this PhD project is to increase the understanding of the involvement of professionals and citizens in research on ageing and health; how such efforts are perceived and how

professional know-how and citizens' ways of knowing could contribute to the knowledge development in research on ageing and health. An additional overarching ambition is to gain insights of the potential and pitfalls of various participatory approaches and thereby contribute to the methodological development in the field.

### Specific aims

- To explore the wicked problem of providing accessible housing for the ageing population in Sweden, with a specific focus on the identification of critical aspects in decision-making (Study I).
- To investigate the awareness of and attitudes towards public involvement in research on ageing and health among 60+ citizens in Sweden (Study II).
- To inquire how senior citizens in Sweden experience being involved in a mass experiment targeting housing accessibility (Study III).
- To elucidate potentials and pitfalls related to the establishment and maintenance of mechanisms for involving professionals and citizens in the context of a research centre for ageing research (Study IV).

## Methods

### *Study I*

This study was based on empirical material from the first work package (WP1) of the project *Decision Support System (DSS) for Improved Accessibility in Multi-Family Housing* (Jonsson et al., 2018). The aim of WP1 was to involve representatives for future potential users of a DSS in order to gain an understanding of the potentials they saw in such a system (Jonsson et al., forthcoming). The Research Circle (RC) methodology (Härnsten, 1994) was chosen as it encourages and provides opportunities for sharing knowledge and experience for mutual learning in the form of group dialogues on equal terms (Haak et al., 2015; Löfqvist et al., 2018).

For details, see Study I, submitted.

### *Study II*

This study is based on data collected within a national *Panel Study* within the UserAge program. It is an ongoing survey study about user involvement in research, addressed to four different samples, including one targeting the 60+ population. A draft set of questions was initially created based on existing instruments (Patterson et al., 2014; Tullo et al., 2015; Vale et al., 2012) and input from other researchers. Further, a *user forum* was established to adjust the questions to the target group. The questionnaire was

sent out to 3000 persons, randomly selected from the Swedish national population registry and stratified by sex.

For details, see Study II, manuscript in progress.

### *Study III*

The last Friday in September has since 2005 been announced as “European Researchers’ Night”. Through activities in more than 370 cities in Europe, researchers then strive to bring science closer to the public by showcasing its diversity and impact on our daily lives (EC, 2020). In Sweden this day is referred to as *ForskarFredag* [Research Friday] (VA, 2020b) for which *Vetenskap & Allmänhet (V&A)* [Public & Science] annually coordinates a mass experiment (Kasperowski & Brounéus, 2016). In 2021, *Bostadsförsöket* [The Housing Experiment] will be the annual the mass experiment (VA, 2020a), which is an initiative from the Centre for Ageing and Supportive Environments (CASE) at Lund University. In this project, teaming up with school pupils, senior citizens will be engaged to collect quantitative data on housing accessibility in their homes. To collect the data, they will use an app (under development) based on the Housing Enabler methodology (Iwarsson et al., 2012).

The senior citizen participants (N=3000) will be recruited via the two major senior citizens’ NGOs in Sweden using established participant recruitment strategies (Kasperowski & Brounéus, 2016). In addition, making use of V&A’s well-established networks of schoolteachers engaged in annual mass experiments since 2009, school pupils will be encouraged to participate together with older people (grandparents, other family members, neighbors, etc.). The participants will be offered guidance through a helpdesk line and a Facebook group. In both fora, I will take on an active role. In addition to addressing feasibility and reliability issues, participant feedback data will be collected (by means of online communication, interviews, questionnaires) within the frames of the project.

Study III will focus on how senior citizens experienced to be part of the mass experiment, with an emphasis on learning outcomes and experienced difficulties. Tentatively, a mixed methods approach (Creswell & Clark, 2017) will be used. The feedback data from the helpdesk and Facebook group will be used to develop questions for questionnaire that will be sent out to a sub-sample of mass experiment participants.

An application for ethical approval for the study will be developed during the autumn of 2020 and I will take on the leading role in that process supported by my supervisors.

### *Study IV*

Since the inception of CASE at Lund University (2007), applying participatory approaches and methods has been a conscious ambition and concrete element of the research at the centre. In 2010, a User Board was set up consisting of senior citizens with interest to assume the role of representatives of the heterogeneous group of ‘older persons’, as well as representatives of other categories representing users of research, such as professionals, officials and politicians from the health care, social services, building and planning and transportation sectors. Over the years, this User Board has taken on the task to assist and collaborate with the researchers at CASE, during the research process in various ways. As yet, no study has been made of how the User Board and their activities have evolved, and what forms it has adopted over the years. Nor has any in-depth study been done of what its function could and should

be in relation to the research being conducted, and to what extent the User Board has succeeded in fulfilling its commission.

Tentatively, for this study we will use a qualitative abductive method (Tavory & Timmermans, 2014; Timmermans & Tavory, 2012) where data collection and analysis is seen as a successive and iterative process that takes place in dialogue with relevant theory. The material that forms the basis for the analysis is archived documentation (e.g., meeting minutes, websites, conference/seminar programs) from CASE's history of involving the User Board in research projects. Additionally, and in parallel with the documentation material being analyzed, qualitative semi-structured individual interviews with former or current members of the User Board will be conducted and analyzed. This study will not require a formal ethical permit, but the principles of the Helsinki Declaration will nevertheless be adhered to. All data will be handled in accordance with GDPR standards.

## *Preliminary results*

### *Study I*

The findings indicate that decision-making regarding accessible housing is dominated by the socioeconomic dimension as described in a framework developed by Brown et al. (2019). Findings in the biophysical dimension elucidate well-known challenges pertaining to the definition of the concept of accessibility and its operationalization. The multiple dimensions of the wicked problem of providing accessible housing for the ageing population in Sweden are intertwined in a complex manner, which is critical for decision-making. For a more detailed description of the findings, see manuscript for Study I (Frögren, Jonsson, et al., submitted).

### *Study II*

Despite the low response rate (29%), through which the representativeness of the results can be questioned, the study showed some interesting results. For a more detailed description of preliminary descriptive results, see manuscript for Study II (Frögren, Schmidt, et al., in progress).

## *Relevance*

With this doctoral dissertation I aim to increase the understanding of how the involvement of citizens and professionals can enhance the relevance and quality of research on ageing and health. Although a participatory research process might in itself be enriching in terms of the exchange of ideas it brings, it is still crucial that there is an added value beyond that, considering the time and resources invested in such a process. Within the framework of this PhD project, the intention is to be able to show examples of when such investments are worth the efforts, and similarly address when and if they seem not to. The dissertation also aims to provide knowledge of the existing awareness and attitudes towards public involvement by an essential target group of our research efforts, namely the 60+ population. Few studies have investigated this group's interest in public involvement in research. However, their interest plays a crucial role in order to be able to conduct the participatory ageing research that we strive to

conduct. There are likely to be factors and aspects that affect both awareness of and interest in this type of research, but the current knowledge about it is lacking. Expanding knowledge here gives us indications of which categories of people are harder to reach but also hints on how we can direct our efforts to better reach these persons in order to facilitate representativeness in future studies. In addition, my PhD project will provide knowledge about different types of participatory approaches and methods; their potential, what one should keep in mind when using them and not least how they are perceived by the citizens and professionals employing them. To summarize, in addition to the theoretical contribution, this PhD project strive to facilitate future deployment of similar participatory efforts and thus contribute to the relevance and quality of research on ageing and health.

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