

Understanding User Participation in Research on Ageing and Health -- Experiences and Emerging Findings from the UserAge Program

Chair: **Susanne Iwarsson**, Sweden

Session Type: Symposia

User participation in research is a hot topic, but the knowledge about the phenomenon as such and the outcomes of research involving users is insufficient. The goals of the UserAge program are to maximize the impact of user participation, increase the knowledge about what difference user participation can make, and evaluate the extent to which such research makes an impact on practices and outcomes. Three presentations report ongoing PhD student work with different categories of users at the core. The fourth describes a consultation process involving senior citizens in the development of a forthcoming panel study.

Little is known about how culture, frailty and gender intersect and affect older people's possibilities to participate as partners in research. The first presentation reports on the limitations and benefits elicited through a grounded theory (GT) study where frail older people shared their experiences and meanings of participation in research. Presentation 2 focuses on carers' involvement in research, where a qualitative study aimed to explore their views and experiences of research and development work, in particular in the co-creation of a national carer strategy. As involvement of health care professionals in research may ensure relevant and sustainable research, the third presentation reports the findings from a case study aiming to explore professionals' experiences of being involved in a research project. A GT approach included interviews, observations and documents of meetings, and revealed a theoretical model describing such user involvement. Lastly, the involvement of senior citizens consulted in a user forum aiming to construct a panel study questionnaire targeting awareness, understanding of and attitudes to user participation in research on ageing and health among different categories of users and researchers will be presented. Involving users in this development had many benefits, especially in terms of enhancing the data collection method, wording, format and instructions of the questionnaire.

Frail Older People's Voices on Their Participation in Research

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Background: Age is often an exclusion criteria from involvement in health research (clinical trials), often without a clear motivation from the aim of the research but based on negative assumptions about older people as more demanding and less competent. A more active engagement of frail older people in research that means more than tokenistic representation could, however, lead to empowerment of the frail older people's representation as a group in research. Research has also often failed to hear the voices of frail older people, and decisions are therefore often made without their participation. This has led to a shortage of knowledge on how to overcome challenges to participation in research with this group of people. The aim is therefore to explore the experiences and meaning of participation in research from the perspective of a diverse range of frail older people.

Methods: This is the first study in a research program with the goal to reveal narratives that have previously been ignored by mainstream discourses and to develop a model for implementing research participation in partnership with frail older people. In this study we have invited people, 75 years of age or older screened as physically frail and who have previously participated in a study, to share their experiences by in depth interviews. Data is collected and analyzed in parallel with a Constructing Grounded Theory approach.

Results: Our preliminary results suggest that frail older persons have an urge to be involved and to participate in something that are benefitting the society and acknowledge their capability to contribute. They express the value of being able to share ideas with and be respected by researchers.

Conclusion: It seems like frail older people's opportunities to participate in research are limited by their own view of what research is and how they could contribute, as well as by their frailty and current way that research is structured. We are, however, still early in the analysis process, and by the time of the symposium we will be able to present our final c

Consulting Senior Citizens in a User Forum: An Early Construction Phase of a Panel Study Questionnaire on User Participation in Research on Ageing and Health

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Objectives: Applying a user participation approach, the aim of the user forum was to construct a questionnaire and design a panel study for longitudinal data collection as part of the overall capacity-building ambition of the UserAge program. The aim of the panel study is to identify and produce knowledge on awareness, understanding and attitudes toward user participation in research on ageing and health among different types of users and researchers. A national sample of 1,500 people will be recruited in Sweden. The panel study questionnaire will be administered every second year.

Method: The user forum met three times to consult senior citizens in the early methodology development phase. The Chair of the User Board of the UserAge program recruited seven people aged 70-84 and co-led the user forum with a researcher. In total eight senior citizens and three researchers participated in three meetings that each lasted for three hours. Based on an existing pool of questions originating from a literature review and the experiences of the UserAge consortium, the tasks were to give input to the delivery method and invitation letter and to stepwise construct a questionnaire targeting the general population aged 60+.

Results: The user forum made key developments related to time/length of the questionnaire, readability, tone-of-voice, understandability and putting questions into context. Users and researchers were very engaged in the discussions, which contributed to a positive and effective working climate. Disagreements among forum participants were common and dealt with through consensus discussions. The final set of core questions was used to construct questionnaires aimed for other categories of users such as informal carers, health care professionals, policy-makers as well as researchers.

Conclusion: Through a mutual learning process we developed a panel study questionnaire in a stepwise manner. Consulting senior citizens in this phase of the research process had many benefits, especially in terms of enhancing the format and the wording of the questionnaire.

Carers' Views and Experiences of the Co-Creation of a National Carer Strategy

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In Sweden, increasingly the care of older people is carried out by informal/family carers. That is, family members- adult children and spouses, but also relatives and friends. In the move towards people-centred, integrated care systems, there is a growing argument for carers to be seen as partners in care alongside the person they are caring for and health and care staff. Whilst there is an increasing awareness of carers' role within service systems and their own needs for support, their involvement in research has not been systematically explored. One of the university nodes within the UserAge research programme, focuses on this theme.

This presentation will examine recent research to create a national carer strategy in Sweden. In particular, to examine carers' involvement during the research and development (R&D) process. An overview of the initial stages of the design process will be given drawing on the theoretical foundations for the work with reference to the temporal model of family caring and the carer as expert model. The presentation will focus on findings from a qualitative study (n=12) that explored how carers perceived R&D work and their own experiences of being involved in the development of a national carer strategy. Interview participants were purposively selected from those carers that participated in focus group interviews conducted in the earlier design phase. Main findings include the challenges and benefits of carer involvement in research and their aspirations and concerns regarding their involvement in research generally, and with regards to the national carer strategy.

The discussion will examine the level of carers' involvement and the significance of their involvement in the co-creation process of the national carer strategy. Concluding comments will highlight that genuine carer involvement in research also demands a high level of engagement from involved researchers and policymakers during the entire process.

Health Professionals' Experiences of Being Involved in a Research Project - a Case Study

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Involvement of health professionals in research on ageing and health may ensure relevant and sustainable knowledge, applicable in practice. However, knowledge is lacking about the process of involving health professionals in research on ageing and health. Therefore, the aim of this study was to explore health professionals' experiences of being involved in a research project. The case study methodology was applied to explore a group of health professionals' experiences in the development and implementation of an evidence based model, for preventive home visits to senior citizens, in collaboration with researchers. A grounded theory approach was used in order to theorize health professionals' experiences of being involved. Seventeen interviews together with observations and documents from meetings were analysed. A theoretical model emerged illustrating health professionals' experiences of participation in an adaptation process, e.g. adapting practice and research to facilitate collaboration and the ability to co-learn. During the adaptation process, the professionals and the researchers were influenced by circumstances, by being subjected to political, research and organisational prerequisites. While the health professionals advocated for practice by making sure the project took a direction applicable in practice, they also experienced being led by the researchers, who drove the project forward and facilitated collaboration. Through ongoing negotiations and breakthroughs they experienced co-learning which was based on the health professionals' and researchers' trustful relationships. In conclusion, this theoretical model can be useful in designing and implementing future studies that involve health professionals in research projects on ageing and health.