



United for Participation in Society - exploration of an ongoing research process in a participatory health research project

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The creation of supporting environments for collaborative processes between researchers and people with ABI is facilitated by frequent meetings, legitimation of experience-based knowledge, appropriate work tasks and the courage to try collective working methods and reconsider these when necessary.

Introduction

At Karolinska Institutet (KI), an ongoing research project explores aspects of participation and sense of belonging for adults living with acquired brain injury (ABI). This is a participatory project with the ambition to perform scientific inquiries together with people with ABI integrating their experience-based knowledge throughout the co-creation of new knowledge. However, more knowledge is needed about how environments for co-creation and involvement can be initiated and maintained.

The purpose is to increase the knowledge about challenges and opportunities involved in the creation of a dynamic and supporting environment for co-creative processes in research involving researchers and people with ABI.

Organization of the co-research group

- Three co-researchers with lived experience of ABI and two academic researchers
- Co-researchers employed at KI (2 hours/week)
- Meeting 1,5-hour/week
- Most meetings digital using Zoom
- Co-researchers involved in grants application
- Work tasks include deciding study contexts, developing interview guides and strategies for recruitment of participants, data collection and analysis, and dissemination activities

Methods

- Interviews with academic researchers and co-researchers, reflections and notes from meeting were analysed using thematic analysis

Results

- The mixing of digital and physical meetings provided the opportunity to meet weekly
 - Building collaboration took time
 - Travel to meetings could be tiring
- Employment gave legitimacy to, and enabled the integration of experience-based knowledge
 - Conditions for participation more equal between co-researchers and academic researchers
- Challenging to balance between time, tasks and level of involvement
 - Continuous dialogue to identify work tasks for the co-research group that fitted the group's limited time, and enabled greatest possible involvement
- Flexibility and continuous search for ways to conduct meetings and perform tasks that supported individuals with e.g., aphasia, fatigue
 - Openness to try, change and try again

Analyses of data collected in Facebook groups to explore aspects of sharing of experienced-based knowledge and belonging is initiated in May 2022.

