# Practices of Participation and Co-Creation in Healthcare: Lessons Learned and Advancements of Established Methodologies

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**Abstract.** Participatory research in the healthcare sector is fraught with obstacles. In particular, choosing appropriate methods to involve the heterogeneous stakeholders in the healthcare system can be difficult. Not only are time constraints and hierarchies between professional (and non-professional) healthcare actors a challenge, but also dealing with patients who may have different physical and psychological limitations. Accordingly, not all qualitative methods are applicable to all stakeholder groups. Limitations such as impairments and low literacy levels can make it difficult to participate in focus groups or design workshops. In this workshop we will discuss experiences with participatory methods in the health sector and explore how established methods can be made more inclusive so that they can be adapted to a wide range of stakeholders.

# Introduction

In healthcare, involving a diverse group of stakeholders, including end-users, patients, relatives and health professionals, is crucial for the successful development and acceptance of technology (Symon and Clegg 2005; Wallerstein and Duran 2010). In the context of eHealth, co-creation involving technology developers, researchers and other stakeholders is both a necessity and a particular challenge for understanding and addressing complex problems in dynamic and complex environments (Hartley and Benington 2000; Rittel and Webber 1974; Jackson and Greenhalgh 2015). Qualitative methods are frequently utilized in co-creation to gain a comprehensive understanding of the socio-cultural context, including the needs and perspectives of all stakeholders involved. This approach not only leads to the development of better products but also provides direct added value to doctors, patients, caregivers, relatives, and others (Ogonowski et al. 2018). To ensure success, it is necessary to not only carefully select methods but also to integrate various interdisciplinary perspectives and needs. Despite the high relevance of user involvement in the technology development process, the conception and handling of participation within research projects is very heterogeneous (Osterheider et al. 2023). This is not least due to the unique challenges brought by the various stakeholders involved. Healthcare professionals, such as doctors and nurses, may face resource constraints (Gulland 2016; Younger 2010), while patients' participation in research projects may be hindered by limitations and vulnerabilities (Lazar et al. 2017; Bittenbinder et al. 2021). In this context, vulnerabilities refer to health-related aspects and include groups such as the young, old, sick, or disabled. Researchers often encounter challenges when working with these groups.

van der Meide et al. (2013) describe the challenges faced by participants in interviews to keep up with researchers and express themselves verbally.

Conversely, in observations, researchers must adapt to the pace of participants. The study focused on older individuals with illnesses. The participants frequently mentioned feelings of fatigue, sluggishness, disinterest, discomfort and tedium, which varied depending on the time of day. These factors hindered the research conditions and made it challenging to gain insights into their lives. Additionally, the researchers experienced discomfort and a sense of being out of place, particularly when sitting in silence for extended periods next to a bed. Working with participants experiencing depression can also be overwhelming for researchers (Kim et al. 2020). However, ethical concerns can be multiplied when working with vulnerable populations, as demonstrated in Sharkey et al.'s (2011) study of internet-based discussion groups with young people who self-harm. Research has shown that there is an increased risk of displaying or engaging in unwanted responses as a result of the research. Additionally, the burden of research participation is high, both when participants are highly symptomatic and when they report traumatic events (Alexander et al. 2018). Furthermore, there are often difficulties in recruiting and involving participants (Lindsay et al. 2012) and in building trust (Amann and Sleigh 2021). In HCI, a significant challenge is the literacy of the communities involved. When using methods like surveys or cultural probes (Gaver et al. 1999), it is important to consider different literacy levels. Additionally, the digital literacy of participants is crucial in HCI. This results in additional expense to enable participants to participate in technology development projects. (Müller et al. 2015). Although there are risks and challenges, it is crucial to ensure that the voices of vulnerable groups in our society are not ignored. Vulnerable groups often express a desire to discuss sensitive issues for reasons such as altruism, gaining new knowledge, and feeling relieved to share their story with an interested listener (Alexander et al. 2018). Additionally, involving vulnerable groups can have an empowering and self-actualizing effect (Davidson and Jensen 2013; Knight-Davidson et al. 2020; Schepers et al. 2018). This can have a positive impact not only on the final product but also on the people involved. However, appropriate and sensitive methods must be chosen to minimize challenges and risks and to achieve a positive outcome for all involved.

CSCW research has been addressing the sensitive selection of co-creative-methods for involving different stakeholder groups for many years (Schuler and Namioka 1993; Gaver et al. 1999; Wulf et al. 2018). However, the rapid pace of technological advancements and ubiquitous technologies moving more and more into everyday life, the emergence of complex algorithms, machine learning, and artificial intelligence have altered the landscape (Grönvall and Kyng 2013). Merely

asking older individuals how a complex algorithm should be adapted to their needs is no longer sufficient. Participants should be empowered for co-creation (Semmann and Grotherr 2017). However, direct and prolonged participation may not always be possible, depending on the research objectives, desired level of participation, and participant characteristics.

Research in sensitive contexts, such as healthcare, requires the involvement of a broad range of stakeholders, including patients, healthcare professionals (such as doctors and nurses), hospital management, and relatives. This ensures that the entire context is taken into account and that the perspective of actual practice is understood. This interdisciplinary and interprofessional context involves various tensions that established methods fail to consider, such as hierarchies (Noyes 2022; Green and Johns 2019; Kaspar et al. 2024; Israilov and Cho 2017), power relations (Green and Johns 2019; Egid et al. 2021), differences in language and understanding (Kaspar et al. 2024), and potential limitations of individuals (Lazar et al. 2017; Bittenbinder et al. 2021), especially in large-scale projects (Hochwarter and A. Farshchian 2020). Co-creation is not merely an exercise, but it has the potential to provide added value not only for the research but also for the participants if utilized correctly (Cila et al. 2016; Vargo and Lusch 2008). According to CSCW and HCI research, this task demands more than just running workshops. It involves establishing trust (Jirotka et al. 2005; Müller et al. 2015; Carros et al. 2020), creating infrastructure (Karasti 2014; Monteiro et al. 2013), ensuring sustainability (Meurer et al. 2018; Simone et al. 2022), building long-term relationships (ibid.), and addressing other relevant aspects. It is crucial to select appropriate methods and adapt them to the context and stakeholders' characteristics. Therefore, this workshop aims to highlight and discuss current co-creative practices in the healthcare sector, including both success stories and failures, as well as lessons learned. Based on this analysis, established co-creative methods such as interviews, focus groups, participatory design workshops, cultural probes, and participatory observation will be examined for their adaptability and potential for further development. These discussions will be based on two ongoing research projects and cases from workshop participants.

## Case 1

The N!CA project focuses on the digitalization of care processes to support and empower caregivers. It is a collaboration between Joanneum Research HEALTH (JR), the Medical University of Graz, hospitals, nursing homes and health tech

companies. The goal of the project is to optimize care processes and reduce documentation effort through co-creation activities with nurses and patients. In addition, innovative AI models based on real-world data (RWD) will be developed and a digital decision support system will be created to enhance nurses' professional skills. The project aims to increase nurses' job satisfaction and retention by providing tools for evidence-based decision making and streamlining care processes. The co-creation activities include:

- re-thinking and re-designing current nursing processes
- a general data strategy is developed in a co-creative process with nursing staff, AI experts and healthcare IT experts
- Development of decision support systems (diabetes and pain management) are designed, prototyped and evaluated together with nursing staff and experts.

## Case 2

The second research project (TeleDiag@Smart) is investigating the long-term health effects of COVID-19. The project will run for 2 years and was almost 9 months old at the time of the workshop. The variety of symptoms of post-COVID syndrome makes diagnosis difficult. New diagnostic approaches are needed to better differentiate post-COVID disorders. The aim of the project is to develop an interactive system based on artificial intelligence (AI) for holistic and interdisciplinary symptom recording. This system will enable patients to record a variety of symptom descriptions and symptoms independently and continuously via voice input and passive monitoring of vital signs. The data is seamlessly transmitted to healthcare professionals to enable accurate diagnosis and early initiation of appropriate treatment. The research team uses participatory and qualitative methods to ensure that the solutions developed meet the needs of healthcare professionals and patients. The co-creation activities include:

- Developing a digital, voice-based health assistant using a living lab approach in real-world settings
- Recruiting patient households for preliminary and pilot studies to test and optimize the technology at home
- Conducting co-creation workshops with patients and physicians to ensure that the system meets the requirements and needs of users.

# Workshop Goals and Activities

The aim of this workshop is to highlight different challenges when using co-creation methods in healthcare, especially when working with heterogeneous groups like healthcare experts and patients with vulnerabilities. Therefore, we want to bring together a diverse group of researchers with experience in co-creation in healthcare, so that a discussion from different disciplines and perspectives is possible. In order to maximize interaction and networking between participants, the workshop will take place on site in Rimini for one full day. In addition to the on-site activities, we will invite a healthcare expert to join the session virtually. We expect the expert to have fruitful insights and to be an important factor in the discussion. The discussion points will be recorded and prepared in such a way that participants who are unable to attend will be able to benefit from the workshop. Upon receipt of acceptance, the workshop website will be published with all relevant information, including position papers and authors.

## Workshop introduction

The workshop begins with an introduction to the objectives, timetable, expected outcomes and structure, including paper presentations, group discussions and possible adaptations to existing qualitative methods.

Clear and concise communication from the organizers will engage and focus participants for full participation. Participants will introduce themselves and their research, building empathy and understanding for the interdisciplinary discussions that will follow.

## Presentations

Participants will be asked to prepare a max. 2-page position paper, sharing and reflecting on experiences, best practices, lessons learned and possible difficulties or even failures encountered in previous co-creation projects. The papers will be presented during the workshop. Presentations should last no longer than 5 minutes and be presented on 2-3 slides. At the end of each presentation, each participant should identify three keywords that describe the conditions for success in participatory health research.

## Brainstorming session

In a brainstorming session participants are asked to discuss the experiences from the previous presentations and what impact they have on participatory methods used. The session therefore deals with questions like:

- What other challenges might there be beyond those presented?
- Which traditional qualitative methods might not be applicable to vulnerable people without adapting the method to their needs and perspectives?
- Which vulnerabilities require which adaptation of qualitative methods?
- What are good practices in participatory research in healthcare?
- What innovative approaches or technologies might help?
- What are the reasons behind the potential failures when using existing methods?

## Designing the future

In this session the participants are divided into small groups for discussion. Each of these groups will be given one of the qualitative methods discussed earlier, with the aim of adapting it to minimize the challenges of working with the previously collected stakeholder groups and the cases presented by the organizers and participants. To do this, the groups first clearly define the problems and challenges that arise. Ideas are then generated, prioritized, and collected (e.g. in the form of a mind map, storyboard or similar). Participants are encouraged to express unconventional ideas and not to evaluate solutions immediately. The ideas are then discussed and evaluated against the background of the different stakeholders, projects, work cultures and hierarchies, institutional settings, resources and time constraints and political influences.

## Working Group

To ensure the publication of the workshop results, we have allocated the second half of the workshop solely to the joint publication. Our goal is to produce a high-quality report on co-creation in healthcare. Therefore, we will start by discussing the type of publication and where to publish. After that, we will form groups to research the literature, gather and compare case studies and reflect on discussions and the workshop itself. This will be an active writing session to support publishing results afterwards. Wrap up and next steps.

Results from the former sessions will be collectively synthesized into a methodological and conceptual "road map" of appropriate design concepts and methodological approaches for participatory work in the healthcare domain. These findings will reveal an understanding on specific actions to make co-researchers comfortable and experience co-creation as a meaningful activity while being aware of possible limitations.

**Table 1 - Workshop agenda**

| Time | Activity |
|------|----------|
| 09:00 – 09:05 | Brief workshop introduction |
| 09:05 – 09:50 | Keynote: Rob Procter |
| 09:50 – 10:30 | Project presentations |
| 10:30 – 10:45 | *Coffee/Tea break* |
| 10:45 – 11:15 | Brainstorming Session |
| 11:15 – 12:00 | Designing the future |
| 12:00 - 13:00 | Lunch Break |
| 13:00 - 15:30 | Working Group Session |
| 15:30 - 16:00 | Wrap Up and next steps |

# Submission details

Potential participants are invited to submit a position paper of no more than 2 pages, excluding references, formatted according to the ECSCW template. Authors are invited to submit methodological reflections, reflections and lessons learned of former case studies, challenges and failure stories of former case studies, ethical or political considerations, philosophical or theoretical reflections. Example cases could be problematizing the motivation for WS participants (Why should I attend? What do I gain from this?) or sustainable partnerships and collaborations beyond single co-creation projects/workshops. Following submission, the organizers will review and select papers based on their quality, innovation and relevance to the workshop.

- March 28, 2023: Workshop website is published together with the call shared in all our communication channels.
- May 03, 2023: Paper submission deadline.
- May 08, 2023: Acceptance notification.
- June 17 or 18, 2023: Participation and presentation.

We will notify participants of acceptance at an early stage so that both the early bird rate can be selected, and conference travels can be arranged.

# Post-workshop and expected outcomes

During the workshop, we will start creating a joint reflection paper on co-creative methods in healthcare with the participants. In this paper we would use the position papers of the participants and reflect on the discussions of the workshop in the form of a workshop report in collaboration with the participants or in the form of a special issue of a journal. The journal in which the report will be published will be discussed with the participants during the workshop. One suggestion would be IRSI - an open-source online journal (https://www.iisi.de/international-reports-on-socio-informatics-irsi/). This will require further collaboration after the workshop, so we will establish a communication channel with all participants for sustainable collaboration between all.

# Organizers' short bio

**Tim Weiler** is a research associate at the University of Siegen, Germany. His research focuses on PD and Co-Creation in healthcare. Hybrid interaction systems for maintaining health even in exceptional situations are analyzed and a framework for co-creative methods is to be defined.

**Stefan Hochwarter** is a senior scientist at Joanneum Research HEALTH, Graz, Austria. His doctoral thesis at the Norwegian University of Science and Technology investigated a case on moving healthcare activities into homes. At his current position, his research focuses on digitalization and digital transformation of healthcare services, mainly in hospital settings.

**Sourav Bhattacharjee** is a research associate at the University of Siegen, Germany. He studied master's in Human-computer Interaction program at the University of Siegen in Germany and completed his bachelor's degree in Computer

Science in Engineering from Shahjalal University of Science of Technology in Bangladesh. His research interests are in participatory health research and designing interactive systems for health promotion.

**Babak Farshchian** is an associate professor in software engineering. His research focuses on digitalization in service organizations, in particular within healthcare and social and welfare services, using interpretative qualitative research methods.

**Claudia Müller** is a Professor of Socio-Informatics, specializing in "IT for the ageing society" at the University of Siegen, Germany. Her expertise is PD with and for older adults, vulnerable user groups and local communities. She is a representative chairwoman of the commission of the Eighth Federal Government Report on Older People.

## Recruitment and participants selection

The workshop aims to facilitate an interdisciplinary discussion on challenges of participatory design in healthcare by bringing together experts from various fields like HCI, CSCW, health informatics and involving groups of people with diverse backgrounds. The organizers plan to accept 10 submissions and invite approximately 15 people to the workshop. The call for position papers will be sent to various interdisciplinary mailing lists including ACM, HCI, (E)CSCW, health sciences, EUSSET email list, Research Network "Ageing in Europe" of the European Sociological Association, the German Network for Participatory Health Research (PartNet), Health Geography, feminist geography and all our research partners from our current research projects. In addition, our workshop website will promote the workshop and clearly present the most important information.

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