

Weiler, T., Savage Pinto, L., Struzek, D., Klapperich, H., Huldtgren, A., Müller, C. (2023): *From empathy to gamification: Inspecting motivational and sensitive methods for participation of co-researchers in healthcare*. In: *Proceedings of the 21th European Conference on Computer-Supported Cooperative Work: The International Venue on Practice-centred Computing on the Design of Cooperation Technologies - Workshops, Reports of the European Society for Socially Embedded Technologies (ISSN 2501-2591)*, DOI: 10.48340/ecscw2023_ws05

From empathy to gamification: Inspecting motivational and sensitive methods for participation of co- researchers in healthcare

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Abstract. Methods to create inviting and motivational collaborative research settings between researchers, designers and their anticipated co-researcher groups are manifold. They appear in a wide spectrum, from creating empathy to joyful and ludic approaches. However, some research domains are more open to long-term participatory contexts than others. Specifically, the healthcare domain provides several challenges, e.g., with healthcare practitioners under time pressure and patient groups of different levels of vulnerabilities. This workshop aims at opening up a discussion of appropriate methods for increasing participants' motivation with preserving their well-being. The workshop will explore the motives of co-researchers, options and opportunities arising from co-research, and how to make co-researchers comfortable and experience co-creation as a meaningful activity but also be aware of possible limitations.

Background

Involving potential end users, patients, relatives and other stakeholders in the technology development process and research is an essential factor (Symon and Clegg 2005) for digital products' success and user acceptance, especially in healthcare (Wallerstein and Duran 2010), a highly dynamic and complex environment. In the digital driven eHealth context, involvement is particularly essential albeit accompanied by challenges. Hereby, Participatory Design (PD) (Schuler and Namioka 1993) and Socio-Informatics (Wulf et al. 2018) offer methods and frameworks for involving different stakeholder groups in the design and development process in order to take different perspectives into account in the production of knowledge and understanding (Hartley and Benington 2000; Rittel and Webber 1974). In this sense, co-research means conducted research with and by potential end-users and other possible stakeholders such as patients, doctors and relatives, rather than research for, or about, the relevant target group. This understanding is particularly important around audiences considered vulnerable, which have specific and/or unique needs based on their 'human diversity with respect to ability, language, culture, gender, age and other forms of human difference' (Inclusive Design Research Centre 2023). Due to these differences, these groups are under risk of being marginalised by public services as well as overlooked in PD activities (Hodson et al. 2023). Since healthcare often takes place in sensitive settings with vulnerable co-researchers, direct and long-term involvement may not be possible, or may be limited. These settings, which are charged with emotions and vulnerability, (Condomines and Hennequin 2014) are often associated with cultural taboos such as death, dying, sick or disabled minors, mental illnesses, etc. (Pinto et al. 2022). Research on sensitive topics can have threatening effects on participants and target audience (Crabtree et al. 2003; Renzetti and Lee 1993). In order to avoid such threats in healthcare, the participation of experts and patients is essential. Co-designing along such key stakeholders and end users allows for an appropriate interaction with end users in terms of communication as well as to achieve study aims that will in fact benefit them (Pinto et al. 2022). But how can participation in sensitive settings with vulnerable co-researchers be facilitated? Where are limits or needs for adaptations?

When asking how participation in healthcare related contexts might be facilitated, the spectrum of joyful, playful or gaming approaches is worth being examined. While workplace related research and design methods focus on production and efficiency, experts suggest research and design around everyday life topics such as healthcare should support 'ludic pursuits' (Gaver 2001). For example, when working with children in participatory design projects, fun and enjoyment seems to be a leading factor in the involvement of younger groups (Benton et al. 2012; Ruland et al. 2008; Schepers et al. 2018b). Despite the fact that we know that pleasure has positive effects on participation like trust, cooperation,

motivation, and other aspects, even in adulthood (Markussen and Knutz 2017), this point is much less common in the literature among older individuals, and could possibly add to the enjoyment and well-being of co-researchers from ‘vulnerable’ groups.

In this workshop we aim to bring together discussions on participatory work in healthcare. Therefore, we want to explore a broad range of methods for inviting and motivating healthcare professionals, patients, family members and other stakeholders to act as co-researchers. Thus, they can be part of the entire PD process, focusing on their well-being and shaping their healing processes according to their priorities.

Motivational approaches in Participatory Design for healthcare

A recent study found that understanding to utilise the full potential of co-research methods can prevent the waste of up to 85% of healthcare funds arising from non-publication, incomplete reporting, poor design and disregarding stakeholders’ priorities and needs and thereby improve health outcomes (Slattery et al. 2020). Involving healthcare co-researchers actively has additional benefits, such as end-user acceptance (Puts et al. 2017), relevance and engagement to the process (Di Lorito et al. 2018), better identification of relevant questions, credibility and context adaptation (Camden et al. 2015). In the following discussion, we will explore motivating approaches used in healthcare contexts.

Gamification uses playful elements in non-game contexts (Caponetto et al. 2014; Deterding et al. 2011) to increase motivation (Branston 2006; Deterding et al. 2011; Huotari and Hamari 2012; Weppel et al. 2012), engagement, fun, and learning success (Branston 2006) by using points, badges, leaderboards, puzzles and challenges (Kim and Werbach 2016; van der Lubbe et al. 2021). In healthcare, gamification has been used in the context of mental health, physical activity and chronic disease rehabilitation (Sardi et al. 2017) as well as for psychiatry, and neuropsychiatry (Ciornei 2021). Here, gamified methods for ‘vulnerable’ groups focus on empowerment (van der Lubbe et al. 2021), simulative training (Hiraoka et al. 2016), and learning outcomes (Sun et al. 2017) rather than enabling participation, co-researchers’ pleasure, and well-being or the appropriation of IT. However, gamification has ethical challenges, such as exploiting and manipulating workers and negative effects on moral character (Kim and Werbach 2016). Leaderboards showing participants’ individual performance can negatively impact motivation if they are lower down the leaderboard (Toda et al. 2018)

Nudging is the act of influencing decision-making or behaviour and can support a healthy lifestyle (e.g. displaying fruit instead of cake at a checkout counter). In this way researchers want to improve individuals’ decision-making around topics like health and happiness (Leonard 2008). Berg describes an app used to nudge patients to take their medications and empowers self-management. But to be able

to use nudges, we need to understand the users' perspective and context (Berg 2018). Nudging can be categorised into six types: facilitation, confrontation, deception, social influence, fear, and reinforcement (Caraban et al. 2019). Categories like "fear" may be considered manipulative and raise ethical concerns.

Cultural probes allow for less intrusive data collection in sensitive settings to better understand the sociocultural context of the target audience (Crabtree et al. 2003; Gaver et al. 1999). Co-researchers use materials like maps, postcards, diaries and cameras to actively record their observations of everyday life, fostering an open exchange and enjoyable experience through playful artefacts (Crabtree et al. 2003; Gaver et al. 1999; Schorch et al. 2017). This approach is particularly useful in sensitive settings like healthcare, for example in understanding former psychiatric patients' living conditions in residential care settings (Crabtree et al. 2003) and older adults' independence and well-being at home (Mikus et al. 2022; Wherton et al. 2012).

Creative prototyping methods like storytelling, roleplay, or Lego Serious Play can engage co-researchers and be enjoyable. Lego Serious Play, a low fidelity prototyping method, can facilitate group discussions, problem solving and decision-making while the visualisation reduces language barriers and leads to shared understanding (Hyvönen 2014; James 2013; Wheeler et al. 2020). Playful participation builds trust and relationships for successful participation through its informal and easy character (Wheeler et al. 2020) making it suitable for sensitive settings. Although promising, this approach is not yet frequently used in healthcare (Wengel 2020). Its use has been limited to training nurses (Warburton et al. 2022) and developing shared vision and strategy for maternal and newborn care (Langley et al. 2018).

Empathy for Design is a human-centred approach aiming to understand co-researchers, their experiences and contexts (Ferri et al. 2017; Wright and McCarthy 2008). With co-researchers, methods include interviews, observations, and diaries, while without them, narratives, role-playing, and watching movies can be used (Wright and McCarthy 2008). This approach is crucial in healthcare, for designing solutions that address patients' needs, and unique challenges, improve their quality of life, and promote better health outcomes. It enables the adoption of different perspectives through playful interactions (Ferri et al. 2017) and leads to user-centred design solutions, motivating students to engage in projects (Carmel-Gilfilen and Portillo 2016; Howick and Rees 2017).

Challenges in the involvement of heterogeneous stakeholder groups

Involving 'vulnerable' groups in healthcare research through PD may be challenging as the context and stakeholders involved vary. Despite the benefits such as empowerment, increased confidence and self-actualization (Davidson and Jensen 2013; Knight-Davidson et al. 2020; Schepers et al. 2018a), many designers

are still hesitant to engage with them due to possible difficulties in recruiting, engaging participants (Lindsay et al. 2012) and building trust (Amann and Sleigh 2021). Labelling a group as vulnerable can make them more vulnerable and victimised (Latif et al. 2018), rather than focusing on their strengths and possibilities (Schepers et al. 2018a). Stereotyping certain audiences as not tech-savvy or lacking valuable input can lead to doubt in their skills and value (Kopeć et al. 2019). Contacting, informing, and organising ‘vulnerable’ persons, relatives, health professionals, and other stakeholders can also present challenges. In online collaborations, technological challenges can be particularly strong due to the lack of non-verbal communication (Cerna and Müller 2021). Involving doctors and nurses is different, as the focus is on increasing intrinsic motivation to counteract their lack of time (Gulland 2016; Younger 2010). Participants should therefore have a personal motivation to participate actively, and co-research activities should be designed in a meaningful way (Sinclair 2004) taking the participants' needs into account. Co-researchers should be supported to feel competent by valuing their lived experience as their expertise through different methods (e.g. autobiographical) (Raman and French 2022).

Workshop goals and activities

To allow the highest possible interaction between participants and thus enable networking, the workshop will take place on site in Trondheim, covering one full day. In case external influences require it, a hybrid version of the workshop is also planned via Zoom¹ and Miro². The discussion points will be recorded and prepared in such a way that even those participants who could not be present will benefit from the workshop. Upon receipt of the acceptance notification, the workshop website will be published, containing all relevant information as well as the position papers and authors.

Workshop introduction

The workshop starts with an introduction to the objectives, schedule, expected outcomes and structure, including game-like methods, paper presentations and group discussions.

Clear and concise communication from the organisers will engage and focus participants for full participation. Participants will present themselves and their research, promoting empathy and understanding for ensuing interdisciplinary discussions.

¹ <https://zoom.us/>

² <https://miro.com/>

Presentations

Participants will be asked to prepare a max. 4-page position paper which they will present during the workshop. The length of the presentations depends on the number of participants but should be no longer than 5 minutes and display on 2-3 slides. At the end of each presentation, every participant should name three keywords that describe what motivates them (or not) to participate.

Method collection

In a brainstorming session, participants and organisers will collect and discuss methods based on the position papers and presentations to create inviting and motivational research settings between researchers, designers and their anticipated co-researcher groups. These methods will be connected to heterogeneous stakeholders in healthcare and the contexts and project phases they might be used in. The methods, settings and stakeholders are collected on a (online) whiteboard and connections are drawn in.

Interactive Session 1: Designing the future

In this session participants will draw a picture of a successful future 10 years after implementing a technical artefact in healthcare developed through motivational and joyful participation. In small groups, participants create a collective drawing to represent their vision using markers and a large sheet of paper. This can be done in any format including sketches, diagrams, or more elaborate illustrations by discussing brainstorming ideas, sketching out different elements, and collaboratively refining the drawing. The groups will then share their insights and discuss opportunities and challenges of using different motivational PD methods in various health settings with different groups and structures. This exercise encourages creativity, collaboration, and visualisation and helps participants reflect on learnings for their own work. This method is based on the design fiction approach, which has been successfully used in the healthcare sector (Stead et al. 2018; Tseklevs et al. 2017).

Roadmap Session

Results from the former sessions will be collectively synthesised 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 I. Workshop Agenda

Time	Activity
09:00 – 09:20	Brief workshop introduction
09:20 – 10:00	Participants' presentations
<i>10:00 – 10:15</i>	<i>Coffee/Tea break</i>
<i>10:15 – 11:15</i>	Method collection
11:15 – 12:00	Design the future
<i>12:00 – 13:00</i>	<i>Lunch break</i>
13:00 – 14:00	Roadmap Session
<i>14:00 – 14:15</i>	<i>Coffee/Tea break</i>
14:15 – 15:00	Wrap up and next steps
15:00 – 16:00	Optional networking session

Submission details

Potential participants are asked to submit a position paper no longer than 2-4 pages including references and formatted according to the ECSCW template. Authors are invited to submit case studies, empirical cases, philosophical or theoretical considerations. Upon submission, the organisers will review and select the papers based on their quality, innovation and relevance to the workshop.

- March 27, 2023: Workshop website is published together with the call shared in all our communication channels.
- April 18, 2023: Paper submission deadline.
- April 25, 2023: Acceptance notification.
- June 5 or 6, 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

After the workshop, we plan to publish the revised submitted papers in the form of a workshop report in cooperation with the participants. The journal in which the report will be published will be discussed with the participants within the workshop. One suggestion would be IRSI - an open-source online journal (<https://www.iisi.de/international-reports-on-socio-informatics-irsi/>). In addition, we plan to create and submit a journal special issue with the collected and discussed opinions and insights. This requires further collaboration after the workshop so we will create a communication channel with all participants for a sustainable cooperation between everyone.

Organisers' 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 analysed and a framework for co-creative methods is to be defined.

Liliana Savage Pinto is a HCI Master student at the University of Siegen, Germany. She conducts research to understand how governments, NGOs and citizens collaborate to build technology and then uses that knowledge to design technological solutions that empower citizens and governments in the Global South to better collaborate and build their desired societies.

David Struzek is a PhD student at the Information Systems department, especially IT for the Ageing Society at the University of Siegen. He explores how people in urban public spaces can be supported in their physical movement or motivated by technical interactive systems. Furthermore, his interests lie in the design of good usability and UX with the support of creative methods.

Dr. Holger Klapperich works as a post-doctoral researcher at the Faculty of Media at Düsseldorf University of Applied Sciences. He holds a PhD on the topic of "The compatibility of efficiency and well-being" and researches well-being-oriented design of digital technology in the eHealth sector. He led the funded project "NoStress" in the working group "Experience and Interaction" (Prof. Hassenzahl) and the EFRE-funded research project "Design for Wellbeing.NRW".

Prof. Dr. Alina Huldtgren is Professor of Digital Health and Intelligent User Interfaces at Düsseldorf University of Applied Sciences. She holds a PhD in HCI and runs a co-design lab for digital health (www.codeforhealth.de). Her research focuses on empowering, among others, vulnerable groups (e.g. people with dementia, children) in digital health development. She is PI in a project on engagement of older citizens, and partnering CoCre-HIT (cocre-hit.de), a project on co-creation in hybrid healthcare.

Prof. Dr. Claudia Müller is a Professor (Subst.) of Socio-Informatics, specialising 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 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 and CSCW and involving groups of people with diverse backgrounds. The organisers 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.

Acknowledgments

Funded by the Bundesministerium für Bildung und Forschung (BMBF, Federal Ministry of Education and Research)

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