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Practices of Participation and Co-Creation in CSCW Healthcare Research

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Practices of Participation and Co-Creation in Healthcare: A Workshop Report

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Abstract. Participatory research in the health sector is fraught with obstacles. In particular, choosing appropriate methods to involve the heterogeneous stakeholders in the health 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 speech or visual impairments can make it difficult to participate in focus groups or design workshops. With a workshop at the European Conference on Computer-Supported Cooperative Work in 2024, we discussed experiences and lessons learned with participatory methods in the health sector. The workshop showed how different challenges were dealt with and thus opened up a space for reflection on participatory projects.

1 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 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. Different stakeholders may present unique challenges. 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 who suffer from 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 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). 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.

Research in the field of Computer Supported Cooperative Work (CSCW) 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 allows 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. 2023; Israilov and Cho 2017), power relations (Green and Johns 2019; Egid et al. 2021), differences in language and understanding (Kaspar et al. 2023), 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 aimed to highlight and discuss current co-creative practices in the healthcare sector, including both success stories and failures, as well as lessons learned. Discussions evolved around these topics and were based on the insights form the two ongoing research projects and cases from the workshop participants

2 Workshop course and results

The workshop was conducted with four participants, one keynote speaker and five organizers with various backgrounds, and it took place in Rimini, Italy as part of the 22nd European Conference on Computer-Supported Cooperative Work. Although the field was consistent with participation in health care, a number of different contexts were served, such as children with anaemia or obesity/overweight, smoking pregnant women or workplace health promotion. A health researcher from Austria was also invited to give a short presentation as a starting point for discussion.

The main focus of the workshop was the exchange of experiences among the participants. After a short introduction, the workshop began with a keynote speech that explored how participatory design (PD) intersects with responsible design and responsible innovation (RRI). The keynote by Rob Procter reflected on lessons learned from various co-creation projects in healthcare and provided an overview of RRI principles, emphasising the importance of embedding critical and contextual thinking about the wider implications of research and innovation. Procter highlighted the term co-evolution as a result of PD and RRI, and emphasised the need for accountability in design, particularly in relation to the lives it impacts and the worlds it creates. Several practical examples were shared, including assisted living technologies such as fall detectors and GPS trackers, which illustrate how PD can help ensure that innovations are ethical, safe and useful for their intended users. The challenges of using cultural probes in hard-to-reach environments, such as private homes, were also discussed. These probes, which include tools such as cameras, diaries and maps, have been used to gather information and stimulate discussion, although their use with people with physical impairments presents unique challenges.

Followed by a discussion, the participants presented their position papers and discussed them in detail. The workshop showed that, despite different application contexts, we face similar research challenges, such as long-term sustainability, power dynamics and positionalities, ethical considerations when working with vulnerable populations and scalability and transferability of co-creation practices. The discussions served as a starting point for future collaborations between researchers to synthesise and share findings. The revised position papers from the workshop have been supplemented and refined for this workshop report with comments from the workshop.

3 Acknowledgements

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Reflections on Physical Factors That Influence Participation in Co-design Workshops in Peruvian Low-Resource Settings

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Abstract. Participatory Design (PD) approaches have been widely applied in different contexts and locations. However, there are still challenges when PD is used in low-resource settings in the Global South. As part of a project aiming to understand complementary feeding practices and promote nutrition of infants and young children under two years, we conducted ten co-design workshops with healthcare professionals (HCPs) and caregivers in two different low-resource settings in Peru. In this paper, we report the physical factors that influenced participation in four out of ten co-design workshops, such as the characteristics of the venue and the design materials we used during the co-design sessions to support a more active participation.

1 Introduction

Participatory Design (PD) approaches aim to engage different actors through cooperative, hands-on activities in the design and development of technologies that will impact people's everyday lives (Bødker et al., 2022). PD has been widely applied in different locations and contexts. However, there are still challenges when engaging with different stakeholders in PD activities, especially in low-resource settings in the Global South. Socio-cultural factors can affect stakeholders' engagement (Hussain et al., 2012; Till et al., 2022) as well as there is a need to create suitable design tools and materials to support creativity and enhance community participation in the Global South (Hussain et al., 2012). Our previous work has identified physical, social and temporal factors that have influenced the engagement of community participants from low-resource settings in co-design workshops (Ortega et al., 2024a). In this paper, we will further describe how physical factors and the created design materials we used during co-design sessions with caregivers and healthcare professionals in future and prototyping workshops have impacted participants' engagement in Peru (Ortega et al., 2024a,b).

2 Case study: Exploring how to support complementary feeding practices in Peru

The World Health Organization (WHO) estimates that 45% of deaths of children under five years are related to nutritional factors (who, 2020). Peru is a country in South America facing a double burden of malnutrition, affecting in particular infants and young children who are experiencing anaemia and/or obesity and overweight, especially the ones living in low-resource settings (Pradeilles et al., 2022).

We started a project aiming to address the double burden of malnutrition among infants and children aged 6-23 months in two different low-resource peri-urban settings in Peru: Manchay in Lima, located in the coastal region, and the city of Huánuco in the Huánuco district, situated in the Andean highlands.

2.1 Methods

We conducted ten co-design workshops, including four ideation workshops, two future workshops, two storyboard workshops and two prototyping workshops (Rousham et al., 2023). Here, we report and reflect only on four workshops (two future workshops and two prototyping workshops) out of the ten workshops conducted. We recruited healthcare professionals (HCPs) and caregivers of children under two years in Manchay and Huánuco. For data collection, with informed consent from participants, we recorded the audio of the workshops, in addition to observations, photos and the outcome materials from the workshops. The project received ethical approval from the Nutritional Research Institute in Lima, Peru, as well as from Loughborough University and was confirmed by Cardiff University in the UK. We analyse the data with Affinity Diagram (Harboe and Huang, 2015) and Thematic Analysis (Braun and Clarke, 2021) as reported in Ortega et al. (2024a,b).

3 Physical factors that influence participation

Based on the analysis, we identified how physical factors, such as the venue and visual and tangible design materials, played a crucial role in supporting HCPs and caregivers' participation during the co-design workshops.

3.1 The characteristics of the venue

For the co-design sessions, we needed spaces for the co-design activities to take place (e.g., including tables, chairs, and an area for children). In Huánuco, we conducted the co-design workshops in the auditorium of the healthcare centre as it was accessible for caregivers who attended the medical consultation with their children. Similarly, HCPs could attend easily as it was in the same location. In contrast, in Manchay, we previously identified that the auditorium in the healthcare centre was too small during the ideation workshops, making it difficult and challenging to participate as caregivers had to have their children in their arms, and could not move within the same space. To address these restrictions, we rented a space close to the healthcare centre that was bigger and better illuminated, making it easier for participants to feel comfortable and actively participate in workshops.

Moreover, participants brought their children with them (children younger and older than two years old). Having a bigger space enabled the arrangement of a dedicated area within the same space for children where they could be supervised during the co-design workshops to reduce distractions for caregivers and HCPs. Our data analysis showed that participants focused during the sessions but few still got distracted by children crying or when some caregivers had to breastfeed them.

3.2 Design materials used during workshops

We observed how the provided design materials supported participants' engagement by attracting their attention and helping them to build a common understanding of ideas and concepts. These pre-designed materials included sketches of clusters of ideas used in future workshops and low-fidelity tangible materials for prototyping workshops.

3.2.1 Visual design materials

In future workshops, we provided visual clusters of ideas based on the analysis of the ideation workshops that helped facilitating discussion and understanding of the ideas generated by participants. For example, the pre-designed sketches worked as a base for participants' sketches in Huánuco as they enabled HCPs and caregivers to situate themselves in the real spaces (the waiting area) that they would re-design during the workshop. Participants visualised the spatial dimensions of the physical infrastructure (e.g., existing constraints), and facilitated a sense of the current state and supported envisioning of the future state of the waiting area.

During prototyping workshops, participants co-created sketches portraying physical elements augmenting the floor and wall surfaces of the waiting area of the health centre to support play and promote nutrition. These co-created sketches enabled participants to convey their ideas on how to engage children and caregivers while incorporating the food elements to promote healthy eating. Participants illustrated familiar games and elements and even explored the materiality (e.g., cushioned surfaces) in their sketches. In addition, we gave participants paper templates and printed screenshots of wireframes of a mobile app created in Figma. With these materials, participants co-created paper prototypes facilitating the visualisation, exploration and envisioning of features of the mobile app to support parents in managing children's health and well-being.

3.2.2 Tangible materials

Besides similar properties and benefits of visual materials, such as visualising and conveying ideas or solutions, tangible materials enabled participants to explore the different ways of interaction with the prototypes. When participants co-created low-fidelity prototypes with tangible materials (e.g., 3D objects like cubes), it helped them explore, materialise, and manipulate these objects, bringing them closer to the tangible features they wished for their prototypes. In this way, participants used this tangibility to add another layer to refine resulting prototypes and provide design rules or considerations on how their games or toy ideas would be played.

In the four workshops, during the presentations of the outcomes (sketches and low-fidelity prototypes), the visual and tangible materials supported participants to engage with the audience bringing different perspectives and reminding them about particular details discussed previously within their small groups.

3.3 Limitations

One of the limitations of this study is that the target population are children under two years. Most of the time, these children depend on their caregivers for care, making it impossible for them to participate directly in the workshops. Thus, we include caregivers and HCPs as proxy co-designers due to their expertise with children under two years old and young children will be involved as users and testers of resulting high-fidelity prototypes in later stages of the process (Druin, 2002). As facilitators and external actors (Mainsah and Morrison, 2014), intentionally or unintentionally, we may have impacted participants' involvement (Dearden and Kleine, 2018), such as asking more questions or helping some participants more than others. However, we reduced our influence by encouraging active participation of HCPs and caregivers throughout the workshops.

The research team acknowledges that our experiences and backgrounds influence the way we see the world and how this may have shaped our work (Motti Ader et al., 2023; Secules et al., 2021). In spite of that, our research team has comprehensive experience conducting research in Latin America and the Global South and has followed the best practices to engage with participants from low-resource settings.

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Working with Visual Metaphors Using Physical Artefacts in Group Meetings

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Abstract. This position paper is about our work on using visual artefacts as metaphorical tools in group meetings. The use of visual artefacts in such meetings enhances equal participation, and collaboration, and eases the recollection of meeting outcomes. The participatory work process includes individual building and joined group building to collaboratively make sense of the current work task. The results of using metaphorical artefacts are presented through storytelling that engages all participants for commitment. Our studies include the use of LEGO® pieces as well as our own designed and 3D-printed artefacts. The use of these artefacts broadly covers the ways in which metaphors are expressed and therefore do not limit the use of imagination by the participants.

1 Introduction

Our study extends the HCI concept of visual metaphor (Blackwell, 2006) to group meeting contexts to enhance planning collaborations and business landscapes using metaphorical artefacts. Visual artefacts in meetings can facilitate participation, collaboration, harmonic work (McCusker and Swan, 2018), creative ideas (Ylipulli et al., 2017), and improve the recollection of meeting content (Bolognesi and Aina, 2019).

We are conducting studies of using LEGO® pieces and 3D printed artefacts to better understand the use of visual metaphors in group meetings. Although our current studies focus on visual metaphors in co-located meeting contexts, our goal is to study CSCW environments of working from distributed locations. Moreover, this research development enables to combine collaborative technologies with the use of physical artefacts to create broader collaborative landscapes. We consider this development as a relevant one for co-creation in healthcare sector while we are interested in exploring the possibilities of emotional and mood-based working with visual artefacts and metaphors.

2 The concept of visual metaphor

The concept of metaphor is defined as seeing one thing in terms of another, and these two things are commonly referred to as the *source domain* and the *target domain* (Lakoff's and Johnson, 1980; Celentano and Dubois, 2014). We applied Jung et al.'s (2017) framework of *material*, *cognitive*, and *semantic* links between source and target domains, in group meeting contexts. The *material* link refers to tactile and temporal short-term uses of artefacts as well as assigning meanings to the artefacts, which can be reinforced with gestures (Sun et al., 2022). Physical artefacts and metaphors support bridging abstract and concrete things (Bakker et al., 2012), as well as evoke memories, sensorial experiences, and support ideation (Jung et al., 2017). Physical artefacts also reduce the likelihood of getting stuck during meetings (Huron et al., 2017). *Cognitive* link refers to thought processes about visual schemas of primary metaphors, which influence how the visual artefacts are chosen and arranged on the table (Hurtienne et al., 2015; Reed et al., 2023). Finally, the *semantic* link refers to the visual characteristics of metaphors (Heath et al., 2014), and more specifically to shapes, colours, and textures. Visual communication is made by narrating a story (Dasu et al., 2024). The set of used artefacts enable using many kinds of metaphoric expression listed by Kövecses (2010) and therefore do not limit the use of imagination by the participants.

3 Conclusions

Visual artefacts provide haptic experiences and cognition relying on visual schemas of primary metaphors. Consequently, these tools are suitable for different kinds of users. While offering new and interesting possibilities for co-creation in healthcare, we are interested in learning about emotional and mood-based design possibilities for co-creation with visual artefacts and metaphors.

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Idea Development, Decision-Making and Power Imbalances in Co-Creating Web Platforms for Building and Supporting Caring Communities

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Abstract. In cooperation with a participatory action research project in Switzerland, we accompanied measures to build sustainable local caring communities. One measure was to set up digital cafés to promote digital literacy of older adults, which we supported by co-creating an e-learning platform. The second measure concerned the topic of help, which led us to develop a helping (stories) platform, addressing identified barriers of asking for, accepting and giving help. When the Swiss project funding period ended, we were faced with the challenge of transferring and adapting the platforms to other social contexts in Germany with other co-creators. It became clear that some ideas could be transferred well, but that the platforms also needed to be adapted to context-specific needs and expectations. Using the examples of the co-creation processes of these platforms, we argue for critically reflecting on one's own role as a researcher and balancing the logic of research with the logic of practice when developing ideas and making design decisions.

1 Introduction

This position paper is about the cooperative development of social measures and technical infrastructures or web platforms with the aim of improving care, social support and health. We report on various activities such as social research and iterative platform design that we carried out together with citizens, social workers and our students. We can therefore speak of “co-research”, but also of “co-design”, “participatory design” (PD) or “co-creation”. But regardless of the terminology, it can be said that it is a widespread opinion that as much as possible should be “put into the hands of the people”, e.g. idea development and decision-making. Take, for example, the famous “ladder of participation”, which proposes “citizen control” as the highest and ultimately ideal level (Arnstein 1969). Of course, this model is concerned with social measures and institutions, but not with the development of technology. However, participatory design is also often seen as a process that aims to empower users of technology or citizens in general. It was said, for example, that participatory design “empowers others and can be seen as a means to give the conditions for all involved to decide and act during the process and influence the design outcome in a way that it represents their needs and values.” (Tomasini Giannini & Mulder, 2022). But let's read carefully. On the one hand, it is about “others”, which refers to people who are not academic researchers or professional designers, and on the other hand, it is about “all involved”.

Obviously, we, the academic researchers, are also involved, and it is equally obvious that we also have an agenda, goals, ideas and even personal values. Ultimately, different interests, expectations, values, ideas, forms of knowledge, skills, resources etc. come together in a complex collaborative research and design process. In other words, the logic of research and the logic of practice meet and must be balanced. Using our example of co-creating two web platforms to build and support caring communities, we argue that self-critical reflection is helpful and important to achieve a good balance.

We will first present the research context and the concept “caring community” (2.1), then reconstruct the co-creation process of the first platform, an e-learning platform to promote digital literacy (2.2), followed by the second platform, which is designed to lower barriers to asking for, accepting and giving help (2.3). We then reflect on the co-creation processes and outline the next steps for the further development of the platforms (3). Finally, we discuss whether the processes can be understood as co-design processes at all or whether it would be more appropriate to speak of processes of “co-evolution” that no one involved can control (4).

2 Examples of co-creation

2.1 Research context

From 2019 to 2022, we cooperated with the action research project “Caring Community Living Labs”, funded by the Swiss National Science Foundation

(SNF), launched by researchers at the Bern University of Applied Sciences and the Health Research Institute Careum in Zurich. Together with representatives of five municipalities in Switzerland and representatives of local organizations and civil society, opportunities and challenges for building local caring communities were jointly explored and activities to promote such developed and implemented. The concept “caring community" can be understood as a "visionary concept", whereby the central idea is to achieve a “care mix”, which means that professional caregivers and volunteers work together in a locally defined area and cooperatively provide care and support (Klie 2016). The overall goal is to build new local and sustainable solutions for the support, care and health of people at home and in their everyday environment. In practice, this means a distribution of day-to-day (domestic) care work across several shoulders in order to reduce the burden on family carers, e.g. through neighborly networks, new support services and good networking with professional service providers and existing services.

In the following, we would like to take a closer look at two municipalities, which we see as “living labs” (Mueller et al. 2018). In one “lab”, digital cafés have been set up to promote digital literacy of older adults, which we supported by co-creating an e-learning platform. In the second “lab”, an empirical study was conducted together with citizens, and on this basis, measures were developed to overcome psychological and social barriers to asking for, accepting and giving help, which also led to the collaborative development of a platform.

It was important to us to develop sustainable measures and to continue the platforms in Switzerland, but this proved difficult when the Swiss project funding ended. In order to continue developing the two platforms and achieve a positive social impact with them, we transferred both platforms to new social contexts in Germany starting in 2023. This was accompanied by the challenge of adapting the platforms and addressing the needs, expectations and ideas of new co-researchers or co-designers.

2.2 E-learning platform

In the first “living lab” near Zurich, the involved citizens decided that they wanted to link the development of a caring community to the teaching of digital skills, as these skills are central to social participation in today’s society. Several digital cafés were set up in cooperation with the association for neighborhood help and church community centers. The digital cafés are primarily aimed at older adults aged 60 and over, but younger people are also welcome. At the digital cafés, people can bring their own device, e.g. smartphone or laptop, and receive personalized advice and problem-solving from people we call “coaches”. Some of the coaches are paid employees, but many are volunteers, and it is mainly they who keep the digital cafés running without pay or professional training. It soon became clear that some coaches needed further training in technical, didactic or social topics, which is why we decided together to develop an e-learning platform.

To best meet the learning needs of coaches, we integrated their own ideas into the platform, e.g. online courses on specific topics, a forum for exchanging experiences and knowledge, and a decision tree that shows coaches exactly what to do in which situation. The latter idea, however, has proven to be less fruitful, since the work of coaches is based largely on tacit or practical knowledge that is difficult to formalize in a decision tree. When the funding period for the project in Switzerland was coming to an end in 2022 and we were no longer traveling on site, the co-researchers' motivation decreased and they told us that they would no longer be taking part in this platform project until further notice.

In 2023, we were contacted by two initiatives in Germany that were in the process of setting up new digital cafés in the context of a political party and in welfare community centers. Since we wanted to continue operating and further developing the e-learning platform, we proposed the platform to the people and they began to participate in the project with enthusiasm.

We found that there are different needs and desires here, for example, the need to recruit new volunteer coaches or the desire for in-person workshops. Furthermore, we found that the stakeholders were in favor of scaling the platform to a regional level. And we have realized this wish, even though we actually wanted a higher level of scaling and an international exchange between coaches in Switzerland and Germany via the platform, but practitioners in Germany felt that the digital cafés in Switzerland were too far away and that they did not have enough in common with the coaches there.

It is also interesting to note that especially the political party wanted to advocate for people with disabilities, but on the other hand, there was a lack of knowledge, for example, about smartphones for blind people, so this idea was not pursued very eagerly.

2.3 Helping (stories) platform

In the second “living lab”, located in a rural area not far from Zurich, we (researchers and co-researchers/community members/55+) conducted a qualitative interview study (20 interviews, including one focus group) within the community and needs of older persons were revealed. One of the key findings was the barriers to asking for, accepting and giving help. The co-researchers then wanted to develop a helping platform and we designed a prototype together (Aal et al. 2023). As we found that platforms already exist where help can be asked for or offered, we continued to focus on overcoming barriers to help destigmatize the need for help, which we identified as a research gap. With this in mind, we focused on stories of helping to harness the benefits of the storytelling approach (Prasetyo 2017). We wanted users to use the platform to publicize positive or successful stories in the local community where they had received help. This idea remained theoretical during the “Caring Community Living Labs” project as other activities were preferred but it was taken up again by us in Germany within an urban community. As a project integrated into the university teaching context, it is currently being developed in participatory manner with different target groups (older people/63+, international students/25+). Eight semi-structured interviews were carried out so far (4 per target group) and three PD workshops, developing the platform from paper prototype to the first version of a live website.

Although the idea was not developed by the community itself, people responded positively to it and considered it promising. However, it became clear over the course of the process that our understanding of a "helping stories" platform on which citizens can share their stories about asking for, accepting and giving help to show that everyone needs help from time to time did not correspond to the expectations of the co-creators. They find that sharing such stories must also be accompanied by the actual possibility of getting help to unfold the platforms potential to improve health and social life in the community and to motivate people to use the platform at all. This is where conflicting logics emerge. On the one hand, from a scientific perspective, we find a platform that focuses on stories and changes in consciousness much more interesting because it allows us to address a research gap. On the other hand, we see the logic of practical needs, and from this perspective, such a platform is hardly useful and people would rather have a platform where they can actually ask for and offer help.

3 Reflection and further steps

It is important not to develop technology simply because you can. In both "living labs" in Switzerland, the idea of starting with the development of a platform was based on practical experience and practical needs. In the first "lab", it was particularly obvious to develop an e-learning platform; the idea was in the air, so to speak, and it is hard to say who had a greater share in it, we, as academic researchers, or the co-researchers. As has been shown, there are different forms of knowledge, e.g. more practical and more theoretical or abstract, and it is important that in participatory research, the knowledge of all those involved is well brought together and utilized (Kaspar et al. 2023). However, we believe that at the beginning of a design process, we should hold back our knowledge and ideas. The ideas of the co-designers have priority first and you should take these ideas seriously and implement them in the design, even if you yourself are not entirely convinced. Let's look at the example of the decision tree for the e-learning platform. We were not entirely convinced by this idea from the outset, but we appreciated the idea because, after all, it came from a coach with practical experience. And we think it was good to have tried out the idea, even though it ultimately did not prove successful and probably even contributed to the Swiss co-researchers losing interest in the platform.

The idea of developing a helping stories platform was not so obvious, but here too, it was important to us not to impose the idea of a platform on people. On the other hand, we had identified the psychological and social barriers together and the co-researchers were highly motivated to do something to lower the barriers. Therefore, they were very open to our platform idea and we did not have to do any convincing.

A self-critical reflection on our own role can nevertheless raise the question of whether we were too driven by research logic and did not take sufficient account of people's needs and desires. It could be argued that we have somewhat ignored the desire of people, both in Switzerland and Germany, for a platform to ask for help and give help, and instead focused too one-sidedly on the aspect of overcoming barriers through positive help stories. On the other hand, we think it was good that we didn't give up our perspective and our ideas and that we can now come to a design compromise. Now we want to combine the idea of telling and sharing stories with “a helping bazaar” where people can ask for and offer help. With this in mind, we will work with the target groups of older adults and international students in further joint PD workshops to identify best ways of combining. We will also acquire a third target group that reflects the diversity of the urban community, as the platform will ultimately be developed for the entire city, all generations, genders, nationalities and cultures.

Let's come back to the first platform. It could be argued that we promoted our e-learning platform too eagerly instead of first listening carefully to the needs and wishes of the people of the digital cafés in Germany. We were asked for help with setting up digital cafés, not for a platform. But what speaks against wanting to pursue one's own research interests and keeping an idea alive and continuing it in a new social context? The people agreed and, in addition, we are now addressing also other needs and wishes, e.g. the need to recruit new volunteer coaches by not only targeting coaches with the platform, but also visitors of the digital cafés, so that they can further educate themselves and become coaches themselves. We are also now working together with the practitioners of the digital cafés to create and implement in-person workshops.

Regarding the topic of values and goals, we have an interesting example to reflect on. At the digital café of the political party, people had the goal of supporting people with disabilities and then didn't really do it. It can be said that it is problematic when academic researchers want to enforce their own values and goals, but what we can do here, of course, is remind people that they themselves wanted to advocate for people with disabilities.

For the future, we are considering merging or at least connecting the e-learning platform and the helping platform. In this context, we find an idea from the first workshop on the helping (stories) platform exciting that came from an older participant. The idea is about “social scouts” (similar to boy scouts) who would be volunteers who are easily recognizable in the city by means of certain symbols, e.g. buttons, and to whom people who need (ad hoc) help can safely turn. This would increase inclusivity and the ‘Everyone needs help sometimes’ campaign;

and its desired destigmatizing effect would gain more reach. It would also be worth considering whether coaches from digital cafés could also take on the role of a social scout (and vice versa). This can strengthen the integration of different social services and promote local care and support in line with the caring community concept. However, we will not decide on the possible platform merger ourselves, but will explore it step by step together with practitioners. It is important not to use our power as academic researchers to force ideas that we find exciting from our perspective on co-creators. On the other hand, one should not forget that the co-researchers also have power and can always say “no” or even end the collaboration.

4 Conclusion

There are many questions about the boundaries of roles, their perception and protection, about what is important from a research perspective and what for the people on the ground or what counts more: PD in its execution or the research gap identified. The two examples described in this paper show how important it is to constantly reflect on our own role as researchers within PD processes to achieve just and useful design outcomes.

Finally, we would like to ask whether it would be more appropriate to speak of “co-evolution” rather than “co-design”. The word “design” implies goals, plans, intentions and the possibility of controlling the outcome. The word “evolution”, on the other hand, refers to processes in which the outcome cannot be predicted. Since many different people were involved in our examples, citizens from Switzerland and Germany, social workers, our students and ourselves, each contributing different ideas, it is ultimately difficult to say who the originator or creator of the two platforms is and who they belong to. These are joint products that no one involved could have foreseen or planned in advance. In a way, the question of who should be in control no longer arises, because in this view, no one is in control, at least no one has full control.

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Challenges in Participation of Vulnerable Groups in Design Processes

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Abstract. This position paper is based on experiences of and analyses from two different research projects, as the source from which challenges are drawn and solutions suggested for discussion of the design and development of systems for vulnerable groups.

1 Introduction

In design collaborations, a number of participants can work hand in hand with one another in as many stages as possible in order to realize an end goal. This is very much dependent on communication between participants, mutual respect, and a shared understanding of objectives.

The generic process of collaborative designing with requirements among the actors in ensuring success can be described as follows: The initiation and alignment, which will have a clear objective setting and role and responsibilities definition; research and exploration as information sourcing and collective share and synthesis; ideation and conceptualization, by use of a brainstorming and co-creation workshop; prototyping and testing through the development of prototypes with iterative feedback. This follows the finalization of design and refinishing of development, which follows the assessment of the outcomes and planning of how best to improve in the future.

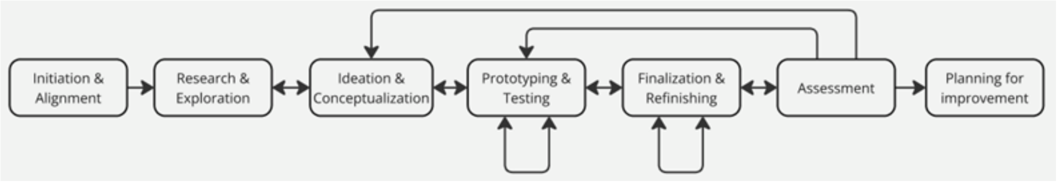


Figure 1 - The process of collaborative designing.

In design collaborations with vulnerable groups, the described collaboration situation is a little bit more challenging. Even if one can argue that the collaboration with end users should happen on an equal footing if the end users are people with special mental or physical needs designers have to consider several collaboration aspects and prepare the base for a smoother and easier cooperation.

This short paper refers to previous projects with vulnerable groups, by extracting the communication and collaboration issues during the design and development of solutions for the target group. The insights of these projects help to identify several aspects which are crucial for the participation of vulnerable groups in design processes. These are briefly described in the discussion of the paper.

2 Research Setting

The following aspects are the result of the analysis of collaboration work with vulnerable groups in two different research projects: PHOBILITYaktiv and “Skill-sharing for young people with disabilities”.

2.1 PHOBILITYaktiv (2018-2020)

An open traffic system, enabling equal mobility to all social groups is a fundamental prerequisite of democratic societies. The preceding project, PHOBILITY (FFG project number 849032), investigated the traffic participation of road users who suffer from fears, compulsory disorders, or phobias for the first time. Research estimates that the lifetime prevalence of persons among the population who suffer from fears, phobias, and compulsory disorders is 10% to 25%. Situational conditions, psychic barriers, and lack of information make persons affected believe that they are unable to control the routine situations of their daily lives. A precondition of full traffic participation is the ability to control fears that are related to this situation to a sufficient degree. In the worst case, affected persons withdraw completely from social and occupational life. These persons themselves, as well as traffic- and health experts, reported that one of the most important supportive measures are tools for self-distraction, self-calming, and self-manipulation, as well as information for traveling and planning trips. These tools help reduce anxieties if they are combined with therapeutic principles. Knowledge derived from the PHOBILITY project was the basis for its successor, PHOBILITYaktiv which aimed at developing and testing these solutions. The aim of PHOBILITYaktiv was to enable equal mobility for persons who suffer from anxieties, phobias, and compulsory disorders which also implied equal participation in social life. It helped them to regain and maintain their usual forms of mobility and their active participation in public transport as long as possible. In order to achieve this aim, recent developments in the field of mental health apps and cognitive therapy have been combined (Figure 2).

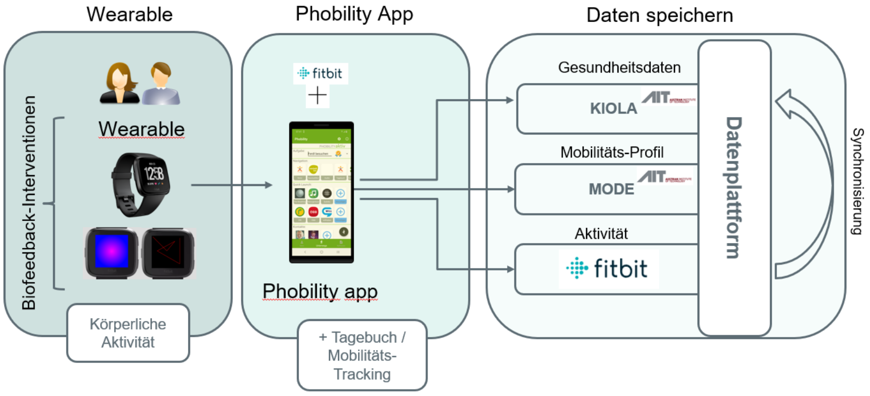


Figure 2 - The system architecture of the PHOBILITYaktiv system developed in the project.

Figure 3 shows some illustrations of the Phobility App we have designed and developed together with the users.

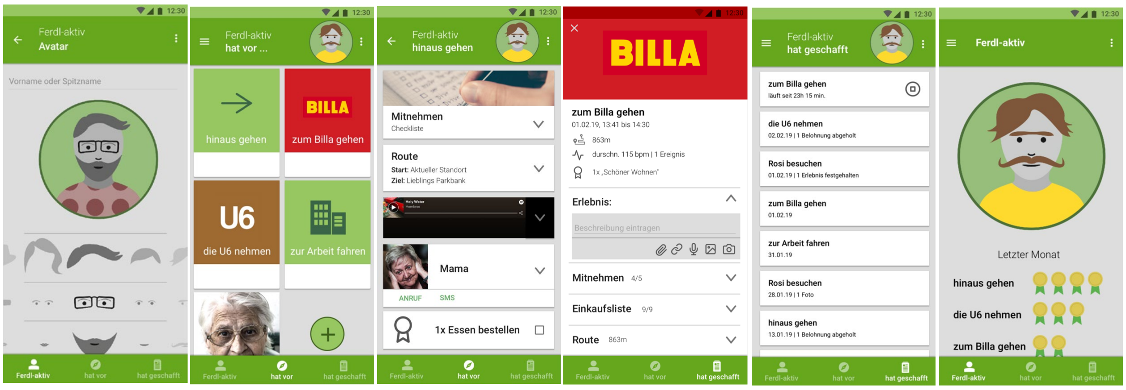
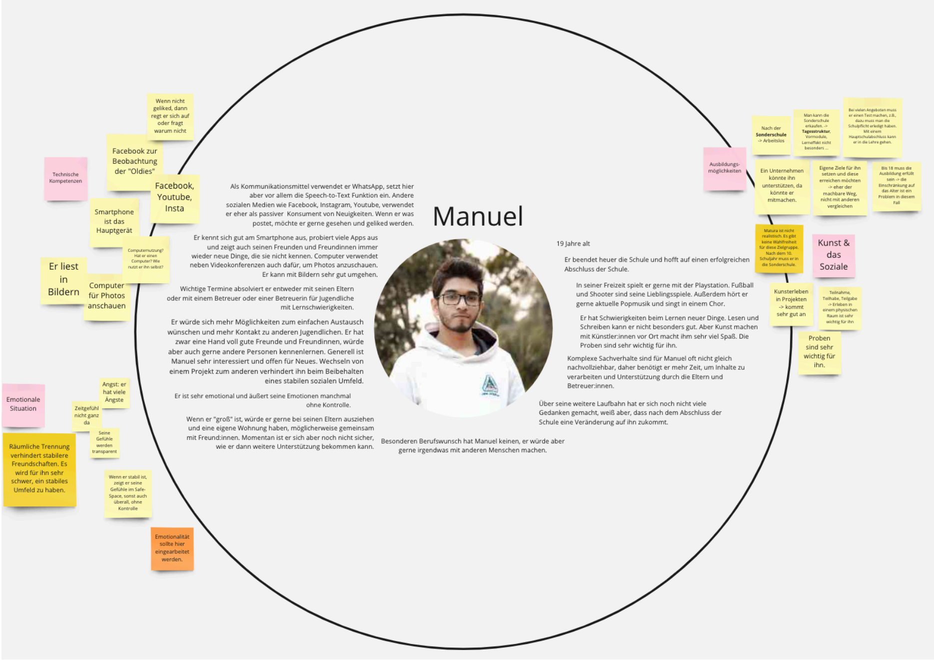


Figure 3: Illustrations of the Phobility App developed collaboratively with the end users in the project.

2.2 Skill-sharing for young people with disabilities (2022)

The thematic-content framework of the project was to explore ways in which youth and young adults with disabilities can be supported in passing on their skills. In doing so, the perception of one's own digital competencies is to be built up and further developed in a strength-oriented manner, and these competencies are to be transmitted to other people who do not yet have them. In this way, the self-confidence, self-esteem and communication skills of the young people concerned should also be developed and support provided for career orientation. In the course of the research project, approaches, technologies, and forms of interaction have been described and tested, which supported this transfer so that this can take place structurally and possibly institutionally. Both the adolescents and young adults will benefit, as the structured transfer can promote self-esteem and communication skills, and the recipients, whose digital skills will be strengthened.



Wenn nicht geliked, dann regt er sich auf oder fragt warum nicht

Als Kommunikationsmittel verwendet er WhatsApp, setzt hier aber vor allem die Speech-to-Text Funktion ein. Andere sozialen Medien wie Facebook, Instagram, Youtube, verwendet er eher als passiver Konsument von Neuigkeiten. Wenn er was postet, möchte er gerne gesehen und geliked werden.

Er kennt sich gut am Smartphone aus, probiert viele Apps aus und zeigt auch seinen Freunden und Freundinnen immer wieder neue Dinge, die sie nicht kennen. Computer verwendet neben Videokonferenzen auch dafür, um Photos anzuschauen. Er kann mit Bildern sehr gut umgehen.

Wichtige Termine absolviert er entweder mit seinen Eltern oder mit einem Betreuer oder einer Betreuerin für Jugendliche mit Lernschwierigkeiten.

Er würde sich mehr Möglichkeiten zum einfachen Austausch wünschen und mehr Kontakt zu anderen Jugendlichen. Er hat zwar eine Hand voll gute Freunde und Freundinnen, würde aber auch gerne andere Personen kennenlernen. Generell ist Manuel sehr interessiert und offen für Neues. Wechseln von einem Projekt zum anderen verhindert ihn beim Beibehalten eines stabilen sozialen Umfeld.

Er ist sehr emotional und äußert seine Emotionen manchmal ohne Kontrolle.

Wenn er "groß" ist, würde er gerne bei seinen Eltern ausziehen und eine eigene Wohnung haben, möglicherweise gemeinsam mit Freund:innen. Momentan ist er sich aber noch nicht sicher, wie er dann weitere Unterstützung bekommen kann.

Besonderen Berufswunsch hat Manuel keinen, er würde aber gerne irgendwas mit anderen Menschen machen.

19 Jahre alt

Er beendet heuer die Schule und hofft auf einen erfolgreichen Abschluss der Schule.

In seiner Freizeit spielt er gerne mit der Playstation. Fußball und Shooter sind seine Lieblingsspiele. Außerdem hört er gerne aktuelle Popmusik und singt in einem Chor.

Er hat Schwierigkeiten beim Lernen neuer Dinge. Lesen und Schreiben kann er nicht besonders gut. Aber Kunst machen mit Künstler:innen vor Ort macht ihm sehr viel Spaß. Die Proben sind sehr wichtig für ihn.

Komplexe Sachverhalte sind für Manuel oft nicht gleich nachvollziehbar, daher benötigt er mehr Zeit, um Inhalte zu verarbeiten und Unterstützung durch die Eltern und Betreuer:innen.

Über seine weitere Laufbahn hat er sich noch nicht viele Gedanken gemacht, weiß aber, dass nach dem Abschluss der Schule eine Veränderung auf ihn zukommt.

Räumliche Trennung verhindert stabilere Freundschaften. Es wird für ihn sehr schwer, ein stabiles Umfeld zu haben.

Wenn er stabil ist, zeigt er seine Gefühle im Safe-Space, sonst auch überall, ohne Kontrolle

Emotionalität sollte hier eingearbeitet werden.

Man kann die Sonderschule erkaufen. -> **Tagesstruktur**, Vormodule, Lerneffekt nicht besonders ...

Bei vielen Angeboten muss er einen Test machen, z.B., dazu muss man die Schulpflicht erledigt haben. Mit einem Hauptschulabschluss kann er in die Lehre gehen.

Ein Unternehmen könnte ihn unterstützen, da könnte er mitmachen.

Eigene Ziele für ihn setzen und diese erreichen möchten -> eher der machbare Weg, nicht mit anderen vergleichen

Bis 18 muss die Ausbildung erfüllt sein -> die Einschränkung auf das Alter ist ein Problem in diesem Fall

Matura ist nicht realistisch. Es gibt keine Wahlfreiheit für diese Zielgruppe. Nach dem 10. Schuljahr muss er in die Sonderschule.

Teilnahme, Teilhabe, Teilgabe -> Erleben in einem physischen Raum ist sehr wichtig für ihn

Figure 4: Persona "Manuel" was created and agreed upon together with all stakeholders including the representatives of the target group in several workshops.

During the project, we could create a persona, "Manuel" (Figure 4), and put him into several scenarios to understand the requirements and circumstances under which the technology support should be given. After the conclusion of the project, we have noticed that there is still a great need for action in the support of young people with disabilities, not only in Austria but also internationally. There are many well-established projects that mainly offer help to those affected without imparting knowledge to enable them to help themselves. Solutions should be developed and implemented for this purpose. Since the target group of young people with disabilities is not a homogeneous one and therefore very different conditions and challenges arise, it is relatively complex to find common ground to develop and offer uniform holistic help. Platforms make a lot of things possible. Playful access is the other aspect that could be very helpful in this context. Therefore, it is necessary to approach this topic with well-founded research questions and approaches and to develop and evaluate relevant and, above all, feasible solutions in a participatory manner through the participation and involvement of those affected and all other supporters.

3 Discussion

Seeing the different approaches – though both are cooperative and participatory – we identified several issues that are special for the vulnerable target groups. The design and development process remains the same as presented above (see Figure 1). But the qualities of interactions with users in such settings and the cooperation modes and aspects need to be adapted and enhanced by considering the following aspects:

Open communication about the issues of design is important to provide effective channels and regular schedules for communication to ensure everyone is updated and misunderstandings are minimized. In the case of cooperation with a vulnerable group, the ways of open communication need to be considered each time carefully in order not to promise too much about the features or possibilities in interaction with the system-in-development.

A successful collaboration is based on the *trust* vested in the abilities and inputs of each of the collaborators and *respect* for their differing perspectives and expertise. One can, in a manner either consciously or unconsciously, underestimate the abilities and inputs of participants with disabilities. This will not be due to a scrutiny of the actual abilities and capabilities but a preconceived notion of their limitations. For example, they could communicate in a different way. For instance, one is bound to meet a participant who has a cognitive disability that is unable to articulate ideas in usual ways, a participant who has a speech impairment that is not understandable during spoken conversations, among others, and other communication variations that can constrict views. The last group of people may not express or have their views supported well. Disabled participants can be perceived differently and can be treated in a certain way by other team members. The stigma of biases related to disabilities can reflect how other team members perceive and act toward the disabled participants. It can create a feeling of disesteem or lower self-confidence in professional capabilities.

A *shared vision* and *mutual goals* permit a common view of what the project is supposed to achieve and are therefore used to direct all the effort toward these common goals. The format and language for these visions and goals may differ. All these translations must ferret out concerns being expressed by participants on some matter or value, out of which an effective design solution could be derived for system design. This might take some time, but the result is very worthwhile.

Working with people with special needs requires an appreciation of different opinions and backgrounds in a bid to foster creativity and innovation. There are several challenges to the *appreciation* of such *diversity*. It is often challenging to ensure proper integration of the different insights due to the possible barriers in communication, accessibility, and underrepresentation. Such challenges would work against a group benefiting fully from unique perspectives that enhance creative outcomes.

Challenges in Applying Participatory Approaches for Workplace Health Promotion Research in Small and Medium-Sized Enterprises

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Abstract. Workplace health promotion (WHP) is gaining attention as a critical factor in enhancing employee well-being and organizational productivity. However, applying participatory approaches in WHP research within small and medium-sized enterprises (SMEs) presents substantial challenges. These challenges raise important questions about the feasibility and appropriateness of such approaches in SMEs, and about the broader context of workplace health as an individual and social construct.

1 Introduction

Workplace Health Promotion (WHP) requires a range of strategies designed to improve an employee's health and wellbeing, reduce physical and mental stress, and enhance overall job satisfaction (Lassen et al, 2018). When the context of WHP is researched in practice-centered research, the participatory research methods or participatory design (PD) methods become particularly relevant, where the success of interventions often hinges on their relevance to employees'

daily work lives and their ability to engage and motivate participants (Muller & Kuhn, 1993, Schuler & Namioka, 1993).
Small and Medium-Sized Enterprises (SMEs), which form the backbone of many European economies, face unique challenges in implementing WHP initiatives due to limited resources, flatter organizational structures, and the close-knit nature of their work environments (Harris et al., 2011; Syed et al., 2024). In this position paper, we outline some challenges faced by our research team while conducting research on workplace health promotion and interventions in SMEs.

2 Methodology in practice

The research is conducted in a small company with 35-40 employees in the north-west region of Germany. The company is a service provider for print and media solutions, and the employees mostly work full-time or part-time desk jobs with computers. During the research period, participatory methods (Muller & Kuhn, 1993) were planned but were adapted differently due to the challenges listed in the later sections. Initially, it was planned to conduct participant observations, which were not possible, so only interviews were conducted. These were followed by online questionnaires to collect more data and fill the information gaps in the interviews. The company requested that all interviews be conducted in one day, in one room, with 30-40 minutes time slots, where one participant would engage with us for the time and then be replaced by the next person. The participatory mapping and co-design workshops were replaced with focus groups, where design ideas were demonstrated, and feedback was collected.

3 Challenges

On the completion of the first design iteration and evaluation, we analyze and recall some of the noticeable challenges in employing participatory methods in SMEs, especially in the context of workplace health, which are as follows:

3.1 Gatekeepers, gateways and power imbalance

In establishing contact with small and medium-sized enterprises (SMEs), interaction often revolves around designated contact persons who serve as liaisons between external entities (such as research institutions) and the company. These individuals play a crucial role not only in facilitating communication but also in shaping the flow of technology and research within SMEs. Acting as gatekeepers or gateways, they control access to resources, information, and opportunities for collaboration and participation in research (Pettigrew, 1972, p.190). Their influence extends beyond mere communication facilitation, as they possess the authority to direct inquiries, proposals, and partnerships towards the individuals of their choice within the organization. Thus, the effectiveness of engaging with SMEs often hinges upon the relationships forged with these key contact persons, who wield considerable influence over the integration of technology and research initiatives within the company.

Parallelly, SMEs often have flatter organizational structures, which can lead to power imbalances where senior management disproportionately influences the co-design process (Pfeffer, 1981). Participatory methods, on the other hand, bring a sort of democracy and activism to the field, requiring SMEs to find ways to ensure that all employees' voices are equally heard (Ludwig et al., 2018).

3.2 Blurred boundaries in private vs. workplace health choices

In the broader context of workplace health, the conflicted positioning of this as both an individual and social construct is often overlooked, leading to debates about the collective versus private responsibility for health measures. Traditionally, health has been regarded as a private matter, but with the integration of health promotion initiatives into the workplace, personal health concerns are brought into the professional sphere (Chung et al., 2017). As employers seek to create healthier work environments, they may implement various programs and policies that encourage behaviors such as exercise, healthy eating, and stress management. While these initiatives are well-intentioned, they can inadvertently encroach upon employees' personal time and space. For instance, wellness programs may involve activities during lunch breaks or after work hours, blurring the distinction between work and leisure time.

The smaller workforce in SMEs means that individual differences in health needs and perspectives can be more pronounced. Thus, participation in workplace health research can contribute to a culture where personal health issues are not only discussed but also monitored and managed within the professional context (Stephanie, 2016). This blurring of boundaries may result in employees feeling exposed or uncomfortable discussing health concerns with their employers, researchers, or colleagues, further complicating the delicate balance between work and personal life and making participatory research a complicated endeavor.

3.3 Operationalization of participatory research

SMEs like ours operate with limited financial and human resources. Unlike larger corporations, they may lack dedicated health promotion staff or a sufficient budget to support workplace health initiatives (Hall and Clark, 2013). Participatory research approaches in such a health context require engaging employees in co-design, demanding their willingness to adopt new behaviors and interventions. The operational flexibility of SMEs, often touted as a competitive advantage, paradoxically hinders participatory approaches because employees frequently juggle multiple roles. This leaves little time for participation in research endeavors, creating an additional burden on their daily work. Furthermore, participatory data collection requires skills that may not be readily available in SMEs. Without proper training, the quality of data collected can be compromised. It may not be realistic to expect SMEs to develop these capabilities internally, so support from external organizations, like research institutions, is needed to bridge this expertise gap. Even if researchers are available to invest time and bring along this expertise, operationally bound employees have very limited time, capacity, and zeal to learn these methods.

4 Conclusion

We conclude the position paper with the following open and leading questions for conducting participatory research in SME companies.

- How can SMEs balance the need for employee participation in research with their operational demands?
- Is it fair to ask employees to take on additional responsibilities in the name of participatory research?
- Should SMEs be responsible for developing the expertise required for participatory research internally?
- Who bears the responsibility for ensuring the quality and validity of participatory research data?
- How can SMEs address power imbalances in the co-design process to ensure genuine participation from all employees?
- Does the existing hierarchical structure inherently undermine the participatory approach?

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Designing the Future to Empower and Unburden Nurses – Anticipated Challenges in a Multi-Stakeholder Healthcare Project

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Abstract. Currently, healthcare systems are facing a lack of nursing staff. This situation will intensify in the coming decades. Through the “N!CA” research program, nurses should be unburdened by optimized care processes and reduced documentation burden. New tools will be co-created together with the users to allow evidence-based decision making by using accurate data that lead to informed decisions. Through the entire N!CA program users, i.e. the nurses but also patients and other user groups, will be put into the center of all considerations. In this paper, we will present some anticipated challenges in a multi-stakeholder healthcare research program.

1 Introduction

Demographic developments, chronic illnesses, multimorbidity and a variety of other health-related aspects are leading to an ever-increasing need for care and treatment among the population (O’Connor et al. 2018; Holman 2020). By 2050, for example, there the number of care allowance recipients in Austria will be significantly increased (BMSGPK 2024). At the same time, there has already been a shortage of nursing staff for years. Forecasts estimate that there will be a shortage of around 51,000 nurses and caregivers in Austria by 2030 (Juraszovich et al. 2023). Healthcare facilities face the challenge of recruiting qualified staff and maintaining them in the profession in the long term. One of the main reasons for leaving the profession is a lack of time: too little time for patients/clients and too little time for nursing activities. Nurses spend a large amount of their working time on unattractive documentation activities and administrative tasks. The average amount of time spent on nursing documentation in the acute inpatient sector is up to 25% of the daily working time of nursing staff (Yen et al. 2018). An efficient way to relieve nursing staff is by optimizing nursing processes, thereby reducing the workload and empowering nurses.

Our vision with the program “N!CA” is to unburden nurses by optimized care processes and reduced documentation burden, and to empower them by co-creating new tools that allow evidence-based decision making at the point of care at the right time, using accurate data that lead to informed decisions. As a result, nurses' job satisfaction and job retention will be increased.

2 Objectives

To achieve N!CA’s vision of unburdening nurses by optimized care processes and reduced documentation burden, and of empowering nurses by giving them tools at hand that allow evidence-based decision making at the point of care at the right time, using accurate data that lead to informed decisions we will follow these main objectives:

1. Investigate the potential of unburdening nurses by re-thinking and re-designing current nursing processes
2. Develop multiple new and innovative AI (Artificial Intelligence) models by using Real World Data (RWD)
3. Empower nurses regarding their professional skills by developing evidence-based digital decision support.

Within this program, we want to close the gap between high-tech possibilities and previous “old school” practices. Outdated processes and structures will be broken up in order to reduce the time and need for nursing care documentation. The quality of the documentation will be increased through the prompt documentation directly at the patient’s bedside. RWD will be used intelligently as well as existing IT solutions to create standardized documentation tools. Furthermore, decision support and AI will be integrated throughout the whole program. It is important to consider social, legal, ethical, and organizational factors to pursue an agile, user- and patient-centered approach.

3 Planned Projects in N!CA

Within the research program N!CA, evidence-based digital tools are investigated, developed, evaluated, and implemented. The three planned, closely linked projects within the research program N!CA are:

3.1 Streamline processes & unburden documentation

Nurses often need to follow burdensome and outdated processes and structures that evolved over time. This project aims to simplify and streamline these processes with the help of innovation and digitalization. Many technological solutions are already available to simplify the day-to-day work of nursing staff but they have not yet reached nursing practice. The following steps will be applied in this project: in-depth analysis of the current nursing care processes/documentation, investigation of the potential for simplification/ automation/ AI implementation, development of innovative data collection, development of processes and solutions which should then be adapted as well as the evaluation and validation of a new tool for patient self-assessment. Users will participate in all of the before mentioned steps. Findings from the process analysis and the legal framework for the use of digital tools will serve as a basis for the other two projects.

3.2 Beneficial use of RWD

A huge amount of data is currently being generated in hospitals and nursing homes, but it is not properly utilized. The data generated should be used to develop new systems that support and improve the nursing care process. In this project we will assess and implement several necessary steps:

- Data extraction and conversion into a standardized format
- Definition of a standardized data format for hospitals & nursing homes
- Development of AI models for
    - prediction of personalized risks
    - semi-automated care assessments, and
    - the automated classification of the need for care.
- Integration of evidence-based knowledge and recommended guidelines into existing electronic care systems
- Evaluating the performance, trustworthiness, usability and effectiveness of AI models in hospitals and nursing homes

3.3 Decision support for empowerment

This project is focused on the empowerment of nursing staff to work independently on the basis of evidence-based knowledge. This can be facilitated through decision support systems and will be investigated in use cases for diabetes and pain management. Diabetes and pain management are complex processes that are very time consuming. Nursing staff should be empowered by using digital systems to support clinical decisions. The project will (a) analyze current processes. (b) identify evidence-based parameters for pain/diabetes management, (c) develop a prototype for decision support, and (d) implement and evaluate novel developed decision support systems regarding the empowerment/unburdening of nursing personnel.

Data sets from the second project will be used to develop decision support applications. The legal aspects and the possibilities for autonomous work of the nursing staff from the first project will be incorporated into this project.

4 Co-creation activities in N!CA and anticipated challenges

In the whole N!CA program, nursing staff, patients, healthcare providers, decision makers, scientific as well as company partners will be involved. The goal of the program is to optimize care processes and reduce documentation effort through co-creation activities with nurses and patients. The co-creation approach is implemented in all research program phases:

- Proposal planning
- Development and design of concepts, innovative processes and technical prototypes
- Evaluation, re-design

Depending on the stakeholder group and objectives the following different methods will be used: field observations, focus groups, semi-structured interviews, iterative design thinking workshops, and open multidisciplinary project meetings.

Co-creation activities will be particularly important when:

- re-thinking and re-designing current nursing processes,
- developing a general data strategy with nursing staff, AI experts, and healthcare IT experts, and
- developing of decision support systems (for diabetes and pain management) that are designed, prototyped, and evaluated together with nursing staff and experts.

Experience has shown that it can often be difficult when multidisciplinary groups work together. There may be hierarchical structures, different motivations and aims as well as different languages (e.g. technical language, scientific language, nursing staff language). Barriers for nursing staff is the lack of personnel and the lack of technical skills. Current research reflects that nurses are often not involved in research, development activities, and co-design of Artificial Intelligence Health Technologies (AIHT). The development and implementation of AIHT needs to be consistent, interdisciplinary, and targeted – therefore nurses need to be involved and empowered in the whole development and implementation process. They can contribute nursing skills, knowledge, and expertise, which is necessary to ensure the usability of such technologies (Charalambous and Goldberg 2016; Fachinger and Mähs 2019; McGrow 2019; Pepito and Locsin 2019; Buchanan et al. 2020; Booth et al. 2021; Ronquillo et al. 2021; Cronin 2022; von Gerich et al. 2022; Hübner et al. 2023).

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