

Tim Weiler, Richard Paluch, Dennis Kirschsieper, Rob Procter, Deysi Helen Ortega Roman, Hussain Abid Syed, Hilda Tellioglu, Stefan Hochwarter, Katharina Lichtenegger, Claudia Müller (2025): Negotiating Extra Work: A Reflection on Participatory Research Practices in Healthcare. In: Proc. 23rd EUSSET Conf. on Computer-Supported Cooperative Work - Conference Papers, DOI: 10.48340/ecscw2025_cp02

Negotiating Extra Work: A Reflection on Participatory Research Practices in Healthcare

Tim Weiler^{*1}, Richard Paluch¹, Dennis Kirschsieper¹, Rob Procter², Deysi Helen Ortega Roman³, Hussain Abid Syed¹, Hilda Tellioglu⁴, Stefan Hochwarter⁵, Katharina Lichtenegger⁶, Claudia Müller¹

¹University of Siegen, ²Warwick University & Alan Turing Institute for DataScience and AI, ³Cardiff University, ⁴TU Wien, ⁵HEALTH - Institute for Biomedical Research and Technologies, JOANNEUM RESEARCH Forschungsgesellschaft mbH, ⁶Medical University of Graz

Contact Author: tim.weiler@uni-siegen.de

Abstract. This reflection paper examines the often overlooked extra work required to conduct and sustain participatory research in healthcare. Participatory projects require forward planning, methodological flexibility, and institutional recognition of the additional effort required to enable sustainability. Drawing on three healthcare-related case studies, we analyse tensions between formal project objectives and the realities of researching in complex, situated environments. Extra work manifests at multiple levels: (1) within, (2) at the boundary of, (3) before, (4) after, and (5) outside the project scope. While it can drive innovation and long-term sustainability, extra work also creates tension for researchers balancing emerging demands with project goals, institutional frameworks, and personal capacities. Building on existing CSCW concepts – such as invisible work and articulation work – we systematically apply and extend these perspectives to healthcare technology development. By identifying cross-cutting issues in the case studies, such as participant acquisition and co-benefitting, we refine conceptual understandings of infrastructuring, articulation work and situatedness in participatory research. In doing so, we contribute to



grounded design and Design Case Study approaches and reflect on the methodological and practical implications of navigating the inherent tensions of adaptive long-term engagement in participatory healthcare research.

1 Introduction

Demographic changes are impacting the healthcare sector (Chen et al., 2023; Spitzer and Reiter, 2024), accompanied by a rising number of people in need of care and a shortage of skilled workers (World Health Organization, 2024; Buchan et al., 2015), leading to a number of challenges. Increasing digitalisation (Brönneke and Debatin, 2022; Lapão, 2019) is seen as a solution, but also raises new issues. In response, there has been a growing emphasis on user involvement in healthcare research, as technological innovations tend to lack contextualisation and sustainability without it (Meurer et al., 2018; Ogonowski et al., 2018; Simone et al., 2022). However, participatory research, as an approach to sustained collaboration and mutual shaping of both process and outcome, involves negotiation, workarounds, and challenges that place an additional burden on resources, leading to reluctance to engage in participation (Weiss and Spiel, 2022).

In this reflection paper, we explore additional and often invisible work in participatory health research by analysing cross-cutting issues from three case studies (see Design Case Studies by Wulf et al. (2011)). These were collected and discussed at an international conference workshop on challenges in participatory processes with vulnerable populations. The case studies (Weiler et al., 2024) cover physical factors influencing participation in co-design, care and health in community settings, as well as mobility of democratic societies and skill-sharing for young people with disabilities. They demonstrate that additional and unforeseen work can emerge at different project stages and even outside of the official scope of the project.

This additional work can be conceptualised by concepts such as, invisible work (Star and Strauss, 1999), articulation work (Schmidt and Bannon, 1992; Strauss, 1988; Suchman, 1995), infrastructuring (Pipek and Wulf, 2009), and extra work (Bowers, 1994; Bjørn et al., 2014). In the study by Bjørn et al. (2014), extra work is seen as articulation work, where participants coordinate their activities to harmonise cooperation. We build on these discourses, but understand extra work differently. In this paper, extra work refers to the researchers' perspective and includes all essential tasks that are not formally incorporated into the research plan but are nevertheless essential for the success, sustainability, and impact of participatory research processes. This is often seen as additional on the top, but in fact is fundamental in participatory research (Björgvinsson et al., 2012; Krüger et al., 2021). Our reflection is guided by the following questions:

1. What happens outside formal project boundaries?

2. What forms of adaptive extra work do researchers engage in, and what is meaningful or necessary in participatory research?

We aim to further develop the above theoretical concepts through Design Case Studies and derive methodological and praxeological implications. We argue that extra work is integral to participatory research. Despite being potentially risky due to required extra resources and often uncertain outcomes, it offers opportunities for problem solving and collaboration (see, for example, Björgvinsson et al. (2012)). Finding a balance between extra work and the limitations set by the project's scope and researchers' and organisations' individual situations is important.

2 Related Work

Prior to examining the three case studies, this section outlines key challenges in participatory technology development in healthcare. It discusses the importance of invisible labour, articulation work, and additional work in participatory approaches. Finally, it reflects how retrospective approaches can help understand the practical implications of participatory research as part of participatory design (PD) work.

2.1 Challenges in Participatory Processes in Healthcare

Involving diverse interest groups in healthcare technology development, including patients, relatives, and healthcare professionals, is essential for product quality and added value for the affected groups (Ogonowski et al., 2018; Grönvall and Kyng, 2013). Participatory approaches are instrumental in addressing complex issues in dynamic contexts (Hartley and Benington, 2000; Rittel and Webber, 1974; Jackson and Greenhalgh, 2015), however, are often associated with different challenges (Osterheider et al., 2023). These include resource scarcity (Gulland, 2016; Younger, 2010), social and health vulnerabilities (Lazar et al., 2017; Bittenbinder et al., 2021), recruitment difficulties (Lindsay et al., 2012), potential burden for researchers (Kim et al., 2020; Alexander et al., 2018), hierarchies and power dynamics (Green and Johns, 2019), sustainable relationships (Meurer et al., 2018; Simone et al., 2022), and trust-building (Amann and Sleight, 2021; Jirotko et al., 2005; Müller et al., 2015; Carros et al., 2020), to enable exchange of knowledge between potentially competing parties (Paluch et al., 2024). The increasing complexity of these dynamics is further emphasised by technological advances, such as AI (Delgado et al., 2023; Grönvall and Kyng, 2013), highlighting the necessity for methodological innovation and a heightened awareness of co-creation in sensitive contexts.

These challenges significantly increase researchers' workload, particularly through the implementation of necessary support measures such as digital training for participants (Müller et al., 2015) or the moderation of conflicting interests between academia, industry, and users (Wan et al., 2016).

2.2 Invisible Work, Articulation Work and Infrastructuring

Invisible work is defined as essential but often unseen (Suchman, 1995; Star and Strauss, 1999), as illustrated by care providers (Bossen et al., 2019), health workers (Verdezoto et al., 2021) or technical infrastructures (Star and Bowker, 2006) that only surface during malfunctions and the local resolution of situated accountabilities (i.e., innovation) (Pipek and Wulf, 2009). Schmidt (2016) elaborates on this, highlighting the tendency to underestimate and overlook the competencies required for invisible work, attributable to a lack of documentation and recognition of essential techniques, workarounds, and practices taken for granted. Conversely, articulation involves coordinating unanticipated events to sustain systems (Strauss, 1985; Schmidt and Bannon, 1992), as evidenced in teletherapy (Huber and Pierce, 2023) and ongoing support, ensuring the viability of ambulatory assisted living technologies (Procter et al., 2016, 2018). While much attention has been devoted to healthcare infrastructures, participatory research also anticipates, repairs, reconfigures, adapts, and manages research arrangements to achieve mandated and research milestones beyond data collection and analysis (Pal et al., 2017; Jackson et al., 2012), while supporting healthcare infrastructures. Researchers' everyday efforts within and beyond participatory initiatives are seen as a form of articulation and extra work.

Infrastructuring is defined as the active and conscious working engagement of people in the development and emergent adaptation of infrastructures (Karasti, 2014; Pipek and Wulf, 2009). This emphasises that infrastructures are not static entities, but are shaped by local conventions of practices and continuing design-in-use (Star and Bowker, 2006). They must be understood as relational, as "it becomes infrastructure in relation to organised practices" (Star and Ruhleder, 1996). Researchers' organised practices are often invisible but required to ensure project and infrastructure continuity (Jones et al., 2023; Botero et al., 2020). In the context of PD, infrastructuring with its long-term view has emerged as a methodology for reconfiguring existing systems and elucidating the underlying activities that ensure the functionality of infrastructure (Simonsen et al., 2020). This relational and holistic view of infrastructuring in participatory research establishes a framework to conceptualise invisible and extra work, while considering the timeline of infrastructural projects. The assertion is that infrastructure has been developed through background work and design, leading to opportunities for innovation, tailoring, and reconfiguration. Examining these concepts shows that participatory approaches often require substantial additional work. This aspect is often inadequately addressed by concepts such as invisible work and articulation work. Utilising infrastructuring concepts, we transcend the limitations of articulation work undertaken by researchers in healthcare infrastructural projects. This paper aligns with research on infrastructural inversions, suggesting that infrastructural inversion signifies the vitalisation of discreetly sustained activities, as opposed to those that merely enable the infrastructure to function (Simonsen et al., 2020). We argue that the extra work in

healthcare research, such as participants acquisition, facilitating co-design, and co-benefitting, are critical to the invisible functioning of research (Ribes, 2014).

2.3 Extra Work and Sustainability in Participatory Design

Participatory approaches in the development of healthcare technologies span a wide spectrum. These include PD (Schuler and Namioka, 1993; Sanders, 2002; Simonsen and Robertson, 2013; Smith et al., 2025), co-creation (Sanders and Stappers, 2008), human-centered design (HCD) (Bazzano et al., 2017; Göttgens and Oertelt-Prigione, 2021), and community-based participatory research (CBPR) (Minkler and Wallerstein, 2003), among others. While these approaches share a general commitment to participant involvement, they differ significantly in their epistemologies, goals, and the depth of participation they enable. For instance, PD is rooted in democratic ideals and mutual learning, emphasizing participants' agency and influence on design decisions (Simonsen and Robertson, 2013; Smith et al., 2025). In contrast, HCD and some forms of co-design often remain expert-led, with limited two-way learning and constrained participant influence (Bazzano et al., 2017; Göttgens and Oertelt-Prigione, 2021). This paper acknowledges this spectrum, but broadly refer to participatory approaches to highlight the involvement of diverse interest groups in the development of healthcare technologies. While our cases reflect varying degrees of participation, they all demand additional efforts from researchers to build trust, manage expectations, and navigate institutional and interpersonal challenges — what we describe as extra work (Hartswood et al., 2002). This additional work is even more complex in PD and especially in the context of interdisciplinary technology development projects in healthcare, where mutual learning, shared decision-making, and sustainable collaboration are key principles (Simonsen and Robertson, 2013; Smith et al., 2025).

PD is an approach to technology design that is centred on the needs and involvement of the end-user, addressing long-term appropriation processes of technologies (Stevens and Pipek, 2018). The success of a PD study depends on the outcomes' ability to be interpreted and used in different ways and contexts. This quality is especially useful in healthcare technology design (De Angeli et al., 2016). It is also important to note that technologies need to be integrated into the everyday practices of users, where different processes of meaning shape the technological experience. PD explores how users can participate in the design process and mediate design decisions, and the challenges involved (Björgvinsson et al., 2012). The overarching design objective is to cultivate a socio-technical innovation that fosters openness, trust, reciprocity, and democratic principles (Bergold and Thomas, 2012; Smith et al., 2017). This goal has been a primary motivating factor for researchers, propelling them to undertake additional efforts (Björgvinsson et al., 2010). This frequently necessitates the implementation of supplementary support frameworks, such as the provision of training for less technologically proficient users (Tellioğlu et al., 2014; Paluch et al., 2023) or the

establishment of ‘enabling spaces’ for collaborative reflection (Ehn, 2008; Peschl and Fundneider, 2014).

PD is inextricably associated with additional labour, encompassing both invisible work and articulation work, among other forms. This extra work does not merely constitute additional labour; rather, it is a necessary condition for effective participation. To conceptualise the various types of extra work, it is advantageous to draw on several case studies and distil cross-cutting issues from them. A central aspect of sustainable PD processes is the question of how participants can continue to benefit after the end of the project (Meurer et al., 2018). Our reflection paper builds on the research findings presented in Future Proofing (Simone et al., 2022), where the authors consider what key factors contribute to the sustainability of projects. Analogous retrospective considerations are pertinent to our case studies, as they facilitate the comprehension of the necessary structures to ensure participatory development and the long-term anchoring of technologies, as well as social practices.

However, even in less intensive participatory approaches, involving interest groups often requires researchers to go beyond predefined project boundaries and responsibilities, resulting in comparable forms of invisible or unacknowledged labour.

3 Reflections on Concrete Research Projects: Three Case Studies

In this paper, we build on praxeological approaches such as Grounded Design and Design Case Studies to identify cross-cutting issues, from three different case studies to determine actual practices of participatory projects (as also described by Tenenberg (2024)). Thereby we are further developing existing concepts and reflect on the concept of ‘extra work’. Grounded design is a paradigmatic research approach that follows a praxeological perspective and focuses on the social embedding and contextualisation of IT systems. This approach emphasises that technical artefacts are created in interaction with social structures, usage practices, and organisational framework conditions. It serves to develop conceptual theory on the basis of empirical studies. The generation of knowledge occurs through cyclical interactions between practical implementation and theoretical reflection (Rohde et al., 2017; Stevens et al., 2018).

Design Case Studies, as defined by Wulf et al. (2011), are a methodology employed for the analysis and design of socio-technical systems within their real context of use. The ideal structure for these studies comprises three phases: (1) a pre-study, the objective of which is to understand the experiences, expectations and needs of the participants, (2) a co-design phase, during which the technological artefact is iteratively (further) developed in conjunction with the participants, and (3) an appropriation phase, in which the long-term appropriation of the

technological artefact is examined. Our study is inspired by this methodology, as it provides a conceptual framework for identifying cross-cutting issues.

The cases were selected from a set of studies presented and discussed during a workshop at an international conference and published in a workshop report (Weiler et al., 2024). The workshop focused on the practices of participatory technology development in healthcare. Here it was discussed what practices are needed to conduct participatory research. During the workshop, cross-cutting issues were identified, which were then discussed, selected, and streamlined in five online meetings over a period of four months. A joint selection was also made as to which cases illustrate and represent the topics well and are examined in more detail as representatives. Our selection criteria included (1) relevance to healthcare settings, (2) a strong reflection of participatory approaches, and (3) the presence of concrete examples of unanticipated efforts that emerged throughout the research process. The discussions that took place during the workshop and in the online meetings were documented and subsequently refined over time. The analysis focused on the identification of recurring patterns of extra work across cases, the examination of how researchers navigated unanticipated demands, and the distillation of key insights. The cases provide illustrative examples of broader challenges in participatory healthcare research. Table 3 shows a structured overview over the case studies analyzed.

Table I. Overview of Case Studies and Examples of Extra Work.

Case Study	Context	Healthcare Context	Participants	Extra Work Example
1	Austria, 2018–2022	Equal mobility to all social groups and skill-sharing for young people with disabilities	Road users who are affected by fears, compulsive disorders, or phobias; young people with disabilities	Participant acquisition and preparing for mental burden
2	Germany & Switzerland, 2016–2027	Caring communities and digital literacy of older adults	Older adults, patients, healthcare experts	Developing a physical coffee trolley and supporting public health events
3	Peru, 2019–2023	Understanding complementary feeding practices and promoting nutrition of infants and young children under two years	Healthcare professionals; caregivers of children under two years	Supervising children during the sessions and adapting the physical space

3.1 Case study 1: Challenges in Collaborating with Vulnerable Groups

Case study 1 is based on two research projects conducted in Austria between 2018 and 2022. The first project focused on the mobility of individuals with fears, compulsive disorders, or phobias, while the second project examined how young disabled individuals could share their skills and knowledge (Tellioğlu, 2024). The researchers confronted numerous challenges, particularly in engaging with and

accessing vulnerable populations. Additionally, during the workshop, researchers discussed past projects where participants refused to engage, such as pregnant smokers. This reluctance to participate complicates access to target groups and necessitates alternative approaches to establish trustful, honest, and open communication. Articulating project goals and fostering a shared vision have been shown to reduce the risk of researchers underestimating the abilities and opinions of vulnerable groups and stigmatising them. For instance, people with social anxiety can often only take part through intermediaries and only at specific times, so researchers must be flexible. Another key issue is the risk of paternalism of researchers, who often make decisions in the best interests of the participants without considering their needs and opinions. Collectively, these issues, both emotional and time-intensive, can be draining, as one researcher remarked during the workshop, “I want to quit doing healthcare research.” Engaging with participants’ needs and circumstances requires patience and commitment, which is often perceived as stressful. Researchers emphasise the imperative of this work, saying otherwise, vulnerable groups would remain voiceless and their needs would be overlooked.

3.2 Case study 2: Care and Health in Community Settings – Participation Beyond the Project Boundaries

The second case study (Kirschsieper et al., 2024) reports on a long-term research project (2016-2027) in Germany and Switzerland, which focuses on the development of digitally networked media as cooperative tools, platforms, and infrastructures. As basic research, there is no constraint regarding a strong application orientation. The project is divided into three phases, all with a slightly different focus. The first phase focuses on the fundamental socio-technical aspects of the cooperative design of appropriation infrastructures in conjunction with media practices. The second phase focuses on caring communities and the third phase focuses on telemedicine and telecare. A caring community aims to develop a sense of togetherness and support in a community or neighborhood (Klie, 2015). The premise is that professional caregivers and volunteers share responsibilities, with the objective being the improvement of social support, digital literacy, and health. A group of older adults was recruited as co-researchers. They were trained in qualitative social research and then conducted an independent interview study. The results were analysed with the researchers. Following the analysis, co-researchers proposed the concept of maintaining a physical presence in their neighborhood in the form of a coffee trolley. This was to draw attention to existing care offerings and establish a caring community, and to recruit new supporters. Despite not being a digital artefact, the researchers helped the co-researchers with their trolley. This prompted a reciprocal gesture from the co-researchers, who collaborated on a conceptual level to develop a digital platform, which was desired by the researchers. In the third phase of the long-term project, researchers want to investigate how older individuals use healthcare technology at home. As the

electronic health record was recently introduced in Germany, a local doctor came up with the idea of holding an information event and hoped for support from the researchers. This approach required time and effort, without having direct benefit for the researchers. Nevertheless, researchers needed participants for their study and by supporting the doctor trust and cooperation with the doctor and his team could be built, potentially allowing for ethnographic research in the doctor's office in the future.

3.3 Case study 3: Physical Factors Influencing Participation – Supporting Participants

The third case study was conducted by a multidisciplinary team from the UK, France and Peru, bringing together expertise in public and population health, nutrition, anthropology, and HCI. The project aimed to address malnutrition in children aged 6-23 months in low-income, peri-urban communities in the coastal region of Peru, and the Andean highlands from 2019 to March 2023 (Rousham et al., 2023). It involved multiple phases, including a co-design phase from June to September 2022. The position paper by Ortega et al. (2024) focuses on one of the co-design workshops conducted during this phase, exploring the impact of physical factors on participation in low-resource healthcare settings. The findings showed that using shared spaces within health centres, such as the centre's auditorium, facilitated participant recruitment by providing a convenient location for carers and HCPs. Space constraints meant the workshops had to be moved to a larger room close to the health centre. The study also highlights the role of visual and tangible design materials in increasing engagement and facilitating ideas during the co-design workshops. This case study demonstrates the necessity to adapt participatory approaches to the lives of the participants, and highlights the practical tasks and constraints that researchers must consider in order to enable participants to attend co-design workshops. Consequently, researchers supervised children during the sessions to enable the mothers of young children to fully engage in the study.

4 Extra Work in Participatory Research Projects

In essence, participation refers to the process of bringing together individuals with diverse, complementary expertise to achieve a particular objective, such as the development of technology for the healthcare sector. However, beyond this initial objective, there is often a substantial amount of unseen additional work, as evidenced by the case studies presented here. This extra work is frequently not explicitly defined from the project's outset and is not included in the formal work plan. Consequently, the work plan represents merely a fraction of the total effort expended. These blind spots emerge with high frequency and are identifiable in nearly all projects. Consequently, there is a compelling need for researchers to be aware of these blind spots.

The case studies show that extra work often arises from external requirements or tensions that were not considered in the original project plan. Consequently, there are different levels at which extra work can be located in the project context:

- **Extra work within the project scope:** As in case study 1, this extra work is vital for reaching potential participants and collaborating with them. Unforeseen tasks often arise due to the complexity of accessibility and the preparation needed for researchers to do participatory research in the healthcare sector with vulnerable groups. This extra work is closely related to articulation work.
- **Extra work at the project boundary:** Extra work that intersects with the project boundary is partly within and partly outside its scope. Researchers engaging in the supervision of children to facilitate co-design sessions with mothers is one example (case study 3). While this work may appear superfluous (i.e., someone else could, in theory, supervise the children at that time), it potentially fosters increased willingness to participate in the research project and heightened trust between participants and researchers. This extra work can also be classified as articulation work.
- **Extra work prior to the project:** As in case study 2, efforts are made before the project framework is formulated, like organising an event with a local doctor to encourage future collaborations. This event and its tasks are not part of the current or future research projects, but are to prepare for potential future joint work. This work demands significant resources and extends beyond articulation work.
- **Extra work post-project:** A key issue in participatory research is sustainability, including the fate of outcomes, participants and technological artefacts after the project ends. When these concerns are given due consideration, it can result in the allocation of additional resources post-project, as evidenced in Meurer et al. (2018). In their study on supporting older adults living in their own homes, the authors describe how participants retained the smartphones issued by the researchers even after the project's conclusion. Additionally, the researchers allocated time and resources to continue supporting the former study participants and could still be contacted for support requests, despite the project's termination and the expiration of funding. This commitment is rooted in the long-term relationship with the participants and the belief that gains made in the participants' living environment should not be lost upon project conclusion. In the context of sustainability, extra work can therefore be sustained beyond the official project end.
- **Extra work beyond the project scope:** There are instances of extra work that extends beyond the scope of the project defined by researchers. This was observed in case study 2, where study participants pursued their own project interests related to their neighbourhood trolley, which the researchers assisted with. While this engagement remained aligned with the project

proposal's broader objectives, it diverged from the researchers' CSCW interests in the development and study of technological interventions. The trolley initiative was valuable and conceptually relevant, but did not lead to direct technological development, rendering it less suitable for CSCW dissemination and requiring the researchers to reframe its outcomes. This required a significant investment of resources, beyond the scope of the technological research. However, from the perspective of practice-based research, it was significant for researchers and participants, showing the complex and changing nature of co-design processes.

Figure 1 shows a visualisation of the different extra work levels.

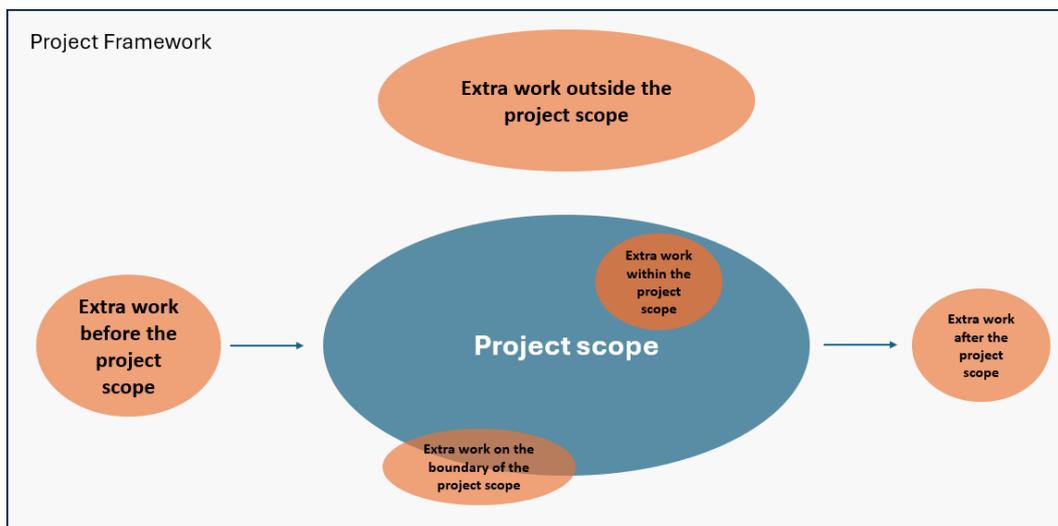


Figure 1. Extra work within a project framework.

4.1 Risks of Extra Work

The concept of extra work has been shown to extend the scope of both articulation (Schmidt and Bannon, 1992) and invisible work (Star and Strauss, 1999), by highlighting not only its necessity for keeping participatory research running but also its explicit location outside core project tasks. While articulation work focuses on coordination and alignment within existing workflows, extra work often requires researchers to engage in activities beyond their formal research scope, which can introduce significant risks in healthcare research settings.

One key risk is the potential misalignment between research objectives and emergent responsibilities. In case study 2, researchers assisted co-researchers in building a coffee trolley – an effort unrelated to their CSCW focus on technical artefacts. Similarly, they supported a local doctor's public health information event, despite it not aligning with their original research agenda. Both instances exemplify how extra work can demand additional time and resources, with uncertain returns. While researchers hoped these efforts would foster goodwill and

lead to reciprocal support in developing their healthcare platform, there was no guarantee of direct benefits. This reflects a core dilemma: Extra work can facilitate trust-building and collaboration (Björgvinsson et al., 2012), but it also risks diverting energy from primary research tasks, potentially compromising the development and implementation of healthcare interventions. Similar concerns have been raised by Büscher et al. (2002), where researchers and co-researchers invest substantial efforts with the inherent risk that the initiative may not yield tangible results.

A second risk is the impact of extra work on resource availability and sustainability. If researchers allocate excessive time to unexpected tasks, they may struggle to fulfill formal project commitments, leading to dissatisfaction among both researchers and participants. This aligns with prior discussions on the ethical responsibility of researchers in participatory projects (Light and Akama, 2014), where unmet expectations can result in frustration, eroded trust, and participant disengagement. Moreover, the sustainability of research interventions becomes a critical concern (Simone et al., 2022). For example, in healthcare research settings, researchers must anticipate long-term consequences, including who will maintain developed tools or proposed caring community programs after a project ends and whether social or clinical interventions in participants' environments should be withdrawn. If extra work is strategically managed, however, it can enhance sustainability by fostering enduring relationships and enabling future collaborations (Meurer et al., 2018).

Thus, while extra work can serve as an investment in long-term engagement, it also presents a precarious balance between opportunity and overextension. Researchers must critically evaluate when extra work is beneficial and when it risks undermining the integrity and feasibility of their projects, tools or programs for healthcare. It also requires a balance to ensure that it does not lead to professional burnout or inefficiencies (Mhaidli and Roemmich, 2024).

4.2 Co-Benefitting

There are different categories of cooperation: investments, where only the recipient benefits; mutual cooperation, where both sides benefit (Melis and Semmann, 2010), cooperation in which the parties involved have opposing interests and those in which they have the same interests (Easterbrook, 2012). The forms of cooperation in these healthcare-related case studies impact the motivations of participants and researchers. In the long term, both parties often aim to benefit equally, improving patient outcomes and service efficiency (Bødker and Iversen, 2002). Melis and Semmann (2010) state that this reciprocal dynamic typically requires an initial contribution from one party, known as an 'investment'. On the one hand participants invest their time to support researchers for altruistic reasons (Estcourt et al., 2016; Gysels et al., 2008; Soule et al., 2016) and anticipated personal benefit, such as access to novel treatment options, information, and improvements in health and medical care (Estcourt et al., 2016;

Moorcraft et al., 2016; Soule et al., 2016). In participatory research, participants are often expected to invest, though access and motivation are not always guaranteed (Montesanti et al., 2017; Pradhan et al., 2020). On the other hand, researchers need to invest time and resources, often in the form of extra work that they themselves and participants benefit equally from.

The concept of co-benefitting emerges as a central theme in the case studies analysed. In case study 2 for example, researchers allocated time to support various interest groups with the anticipation of reciprocity or to facilitate collaboration in subsequent stages. In case study 1 parents of young adults were very interested in enhancing the possibilities for further support for their children. They delivered additional information between the workshops to the researchers to include in their design and development work. Case study 3 employs a similar approach, where mothers of young children wanted to be involved and have a say in the research, but participation was limited because of childcare. By offering to supervise children during the sessions, researchers obtained valuable insights from mothers during their co-design workshops, and the mothers themselves were able to be more focused during the sessions. This model is based on the principle of reciprocity (Dreessen et al., 2020), where all parties are expected to contribute to and benefit from the research process. In the literature, this mutual benefit is covered in particular by mutual learning (Bossen et al., 2016; Teli et al., 2019), but concepts such as “design for equivalence” also aim to achieve this (Geppert and Forlano, 2022; Geppert, 2023). The concept of co-benefitting is inextricably linked to sustainability, particularly in the context of post-project considerations. For instance, it enables participants to retain and utilise the prototype or the technical device provided, even after the conclusion of the project (Meurer et al., 2018).

Addressing the belief that doctors are under pressure and unable to accommodate external requests (Akoglu and Dankl, 2021; Farrington, 2016; Gulland, 2016; Younger, 2010), it is important to consider how both parties can benefit from such interactions. Rather than a passive approach of merely receiving benefits, a more proactive strategy should be adopted, where doctors are encouraged to reciprocate the efforts made by researchers. The concept of co-benefitting can be beneficial over the conventional paradigm of participatory research as it is more dynamic and collaborative, but also necessitates extra work. In certain instances, the framework extends beyond the limitations of the research project itself, by engaging in activities not related to it. Case study 2 shows how researchers invested effort and resources to support a local physician before a potential project collaboration. The physician had a clear vision of his needs, and the researchers were clear about their expectations for future collaborations. In such circumstances, it can be rational to assume a risk by allocating resources without certainty of a favourable outcome. However, the circumstances of the researchers and the projects’ context are significant, since not all individuals and projects can allocate additional resources and derive mutual benefits. Co-benefitting allows both university researchers and participants to share

knowledge and use it to design practical health technologies (see also (Hult et al., 2020)).

4.3 Differing Research Contexts

Extra work is often pivotal to research projects' success, but necessitates researchers to be able to allocate resources. This is often limited by funding and graduate programmes, e.g. for doctoral students. In the USA, doctoral programmes typically include coursework, exams and a dissertation (Powell and Green, 2007), while in Europe, research is prioritised from the outset, with fewer formal courses, so different resources are available. In the UK, doctoral programmes usually last 3 to 4 years and students must complete their research and submit dissertations within this timeframe (Andres et al., 2015). In other countries, the duration is more flexible if there is third-party funding (Nori et al., 2020). In Germany for example, doctoral students often have a lot of autonomy, with few time constraints and enough resources to support each other and do extra work (see case study 2). This affects the different positions researchers have and the impact they can have on their fields and projects.

A comparison of the researchers' circumstances in the case studies reveals significant disparities. Case study 1, conducted in Austria, involved researchers with a background more closely related to computer science, indicating a specialisation in healthcare technologies and their development and design rather than direct patient interactions. Consequently, research strands such as those in case study 2, involving the neighbourhood trolley, appear less relevant, as it is not a digital healthcare artefact. The development of prototypes, despite extensive user involvement, is frequently constrained by technical, organisational, and social barriers (Bødker and Kyng, 2018; Vines et al., 2013). These prototypes are often not implemented because they do not fit the context (see case study 2). This can make researchers question their role in healthcare research, as shown by the statement that people no longer want to pursue a career in healthcare research (see case study 1). At the same time, this shows that the way people see these challenges is based on their backgrounds and positionalities. Researchers from different fields may approach the engagement with vulnerable populations in different ways — some might see it primarily as a methodological or ethical consideration, while others might view it as an opportunity for deeper collaboration and mutual learning. However, perceptions of responsiveness and ethical obligations vary among individuals (Block, 2024). As shown by case studies 1 and 2, potential frustration due to a non-technological approach is related to researchers' backgrounds, aligning with the 'Third Space' in PD (Muller and Druin, 2012), where technological and social perspectives are actively negotiated. Grounded Design (Stevens et al., 2018) shows technology design is embedded in complex social processes. Interventions are shaped by these processes, settings and target groups, and also influenced by researchers' backgrounds, as they navigate challenges of introducing technology into evolving socio-material settings. Case

study 2 took place in Germany and Switzerland and was carried out by doctoral students. Here, researchers could pursue various lines of action and also invest resources beyond their research projects. The researchers' aim is to position and anchor the university well in the region. This enables researchers to adopt a more unique perspective, beyond the confines of individual research projects, which may not be accessible to other universities and research institutions. This distinctive university provides substantial time and space for extra work.

Case study 3 is set in a very different environment from the first two. It is situated in low-resource communities in Peru and is conducted by an interdisciplinary and intercultural team of researchers from three countries (Peru, France and the UK). A notable aspect of this case study is that the intercultural context and local conditions have increased the complexity of the project, requiring researchers to work within the local health system, resulting in extra work. Trust between researchers and study participants is vital in participatory projects (Carmel, 1999; Cheng and Macaulay, 2008; Hardwick et al., 2013; Kanawattanachai and Yoo, 2002; McAllister, 1995; Paluch et al., 2024), but its establishment is highly challenging, when researchers are from a distant continent and culture (Bailey et al., 2021; Kajubi, 1999; Krüger et al., 2021). Therefore, a young researcher new to the context of case study 3 studied the regional context before travelling there for the first time and working with local actors. Furthermore, designing contextual visual materials facilitated familiarity with the context and helped to challenge and reduce stereotypes. The cultural differences necessitates a lot of care to both build trust and provide a secure framework for the participants in the long term, as also described by Krüger et al. (2021). They advocate for a flexible approach to method selection and an open structure for project management, enabling such a balancing act, aspects that also seem crucial for extra work. Additionally in case study 3 it was also necessary to conduct interviews with the local participants via WhatsApp. The asynchronous nature of WhatsApp communication meant the researcher's availability was outside working hours, particularly due to differing time zones. Some caregivers responded to questions after working hours, typically around midnight European time. This highlights the need for increased communication and organisation, resulting in extra work due to differences in time, location and culture. The situated nature of research projects impacts the amount and kind of extra work researchers can do. Limited resources in these environments mean less extra work and fewer opportunities for activities beyond the project. This phenomenon is influenced by various factors, including research funding conditions, project conditions, and contextual factors.

We advocate a more open-ended and exploratory approach in interdisciplinary technology development research projects because of the potential for multiple research strands (case study 2). It is emphasised that context-sensitive inquiry is important, rather than prioritising the rapid replication and deployment of existing technologies across diverse contexts (Suchman, 2002; Bannon and Ehn, 2012). Not all domains or problems are suited to technological intervention. A rigid focus

on technology-driven solutions may overlook social practices and user needs (Dourish, 2006). Negative or inconclusive research outcomes should not be dismissed as failures, but recognised as valuable contributions to the research community, despite potential dissatisfaction of research sponsors (ibid). These insights inform future research directions, highlight systemic barriers and reveal unexpected opportunities for innovation (Rogers, 2012; Le Dantec and Fox, 2015). Adopting these perspectives fosters a more reflexive and iterative research culture, leading to sustainable and meaningful technological interventions. Extra work can play a crucial role in this process, as it enables researchers to engage deeply with the social realities of their study contexts, build trust with participants, and adapt research approaches dynamically. Without these additional efforts, many participatory projects risk remaining superficial, missing critical contextual nuances, or failing to create sustainable impact. Recognising extra work as an integral part of co-design processes acknowledges the reality that participatory research cannot be fully planned in advance but must remain open to ongoing negotiation, adaptation, and responsiveness to emergent challenges.

Thus, interdisciplinary technology development research projects in healthcare should be characterised by openness, a willingness to explore and participation in order to adapt technical artefacts to clinical and social realities. It is important to recognise that technology alone is not enough; rather, participation and long-term collaboration with affected interest groups in a shared learning space are required (Fitzpatrick and Ellingsen, 2013).

5 Conclusion

In this paper, we utilised three case studies to explore the concept of extra work and its relationship to aspects of co-benefitting and situatedness of the studies. The nature of extra work can be understood through a reflection on its various levels, namely (1) extra work within the project scope, (2) extra work at its boundary, (3) extra work prior to the project, (4) extra work post-project, and (5) extra work beyond its scope. Often, extra work is unseen and unforeseeable at the outset of project planning, bearing similarities to articulation work in that it fosters and facilitates the successful implementation of participatory approaches, while also preparing for potential future collaborations and providing long-term sustainable support for study participants. To the greatest extent feasible, all parties should directly or indirectly benefit from extra work, even when the additional resources required entail a degree of risk.

The potential for extra work and its significance are closely associated with the context-specific nature of research projects and the researchers themselves. It is therefore crucial to find a balance between embracing extra work as a driver of innovation and sustainability, while also acknowledging the limits set by project goals, institutional frameworks and individual capacities in terms of overwork. A greater recognition of extra work and situatedness in academic discourse could enhance the comparability and reproducibility of studies.

Although extra work is frequently unseen and unforeseeable, it plays a pivotal role in facilitating meaningful engagement, fostering trust, and ensuring the long-term sustainability of participatory research endeavours. It facilitates the requisite flexibility to navigate complex socio-technical settings, adapt to unforeseen challenges, and bridge the gaps between different interest groups' needs. The recognition of extra work as an integral component of research signifies an acknowledgement of the reality that participatory approaches do not function within isolated, predictable environments; rather, they necessitate ongoing negotiation, adaptation, and care. Instead of being perceived as an optional add-on, extra work should be recognised as a fundamental component of responsible and ethical research practice in CSCW and related domains.

As with all qualitative research, the generalisability of our findings is limited. Our analysis is based on three case studies, which, while offering rich insights, cannot claim to represent the full diversity of participatory healthcare projects. However, by abstracting extra work into five levels, we provide a conceptual framework that can be applied and further explored in different settings. The case studies serve as illustrative examples of these dimensions, rather than exhaustive representations of all possible manifestations of extra work. Future research could build on these insights by examining a broader range of cases across diverse cultural, institutional, and disciplinary contexts and thus continue to explore the practice of extra work in greater depth.

Acknowledgments

We thank all participants and collaborators across the different research projects for their valuable contributions, as well as the respective research teams for their support.

This work was supported by several funding bodies:

- The German Federal Ministry of Education and Research (Bundesministerium für Bildung und Forschung, BMBF), as part of the CoCre-HIT project (Grant no. 16SV8795) and the TeleDiag@smart project (Grant no.16SV9158).
- The Austrian Research Promotion Agency (Österreichische Forschungsförderungsgesellschaft mbH, FFG)
- German Research Foundation (Deutsche Forschungsgemeinschaft, DFG). Project-ID 262513311 – SFB 1187.
- The Medical Research Council, part of United Kingdom Research and Innovation (UKRI), under grant reference MR/S024921/1
- The Peruvian National Council for Science, Technology and Technological Innovation (CONCYTEC/PROCIENCIA), under grant 032-2019-FONDECYT

We would also like to thank all community participants in the PERUSANO project and the different interest groups from the participating health centres for their engagement and collaboration.

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