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Whom do we include and when? participatory design with vulnerable groups

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ABSTRACT

This article makes three contributions to participatory design (PD) research and practice with vulnerable groups: 1) a framework for understanding stakeholder engagement over the course of a PD project; 2) approaches to making user engagement and PD activities more inclusive; and 3) an analysis of how the design and power dynamics of PD projects affect vulnerable groups' participation. A map of engagement is developed to evaluate stakeholder involvement from initial problem definition to design outcome. The map is applied to three projects aimed at increasing inclusion of vulnerable groups in the planning of public sector services. The first looks at codesign activities to support decision-making in the context of intellectual disabilities; the second looks at culturally diverse youth navigating crisis without adequate assistance from public services; and the third examines nursing students adapting to work in the health sector without accommodations for learning disabilities. Comparing the projects reveals patterns in project planning and execution, and in stakeholder relationships. The article analyses how users are defined, engaged and supported in PD; how proxies shape vulnerable groups' involvement and PD projects as a whole; and opportunities for greater inclusion when the entire PD project is taken into account.

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1. Introduction

Participatory design (PD) is increasingly employed in the public sector to involve communities in decision-making and planning (Holmlid 2012). In tandem with this push for more democratic citizen engagement is the growing recognition that public services need to be more reflective of and responsive to their diverse users. Governments and public service providers, as well as designers and their clients working with vulnerable groups, have a vested interest in more effective social services and a responsibility to prioritise inclusion (Margolin and Margolin 2002; United Nations 1948). The importance of service availability to a wide range of users calls for more inclusive design. We take inclusive design to mean moving beyond a one-size-fits-all approach towards

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meeting the needs of specific target audiences (Spencer González et al. 2020) and ‘consider[ing] the full range of human diversity with respect to ability, language, culture, gender, age and other forms of human difference’ (Inclusive Design Research Centre n.d.). Below, we apply this thinking to the design of PD processes to consider who is included, when and how.

Values of democracy, equality, representation, openness and exchange underline PD, with the idea that participants are not only research subjects but also contributors to the design of a service or other outcome that will affect them (Holmlid 2012; Sanders and Stappers 2008). A defining characteristic of PD is ‘genuine inclusion’, meaning that participants shift from ‘being merely informants to being legitimate and acknowledged participants in the design process’ (Luck 2018, 5). However, the extent to which ‘genuine inclusion’ can be achieved in PD varies based on context and approach. It can be challenging to involve users with complex needs or stakeholders operating within complex systems of public service provision. PD aims to be democratic, yet barriers to participation remain, especially for so-called ‘vulnerable’ groups, which we define as those who are differently abled or empowered and who are at risk of being marginalised, even temporarily, in the context of public services. These groups may be overlooked in PD because they may not have (or are assumed not to have) the capacity to participate fully in collaborative design as it is currently practised. This may be for any number of reasons related to ability, access or sociocultural factors that might limit participation. We note that when disability is understood as relative or context dependent – when the design does not match the user’s ability (Inclusive Design Research Centre n.d.) – anyone could be ‘disabled’ in PD.

This article examines the processes and power dynamics of PD with vulnerable groups. The objective is to explore how PD projects can be made more inclusive. Three projects conducted by the authors are compared: the first explored codesign activities to support decision-making for those with intellectual disabilities living in supported housing; the second focused on culturally diverse youth navigating crisis without adequate assistance from public services; and the third dealt with nursing students adapting to work in the health sector without accommodations for learning disabilities. Our involvement in these projects gives us unique perspectives on how they were planned and executed. While they represented different PD approaches and outcomes, they all strived to increase access to public services and collaborative design processes for vulnerable groups. As we analyse the projects from problem definition to final outcomes (including a prototype toolkit, a beta version of a mobile application, a research tool and recommendations), it becomes clear that the extent of participation varied throughout.

We begin with an overview of the challenges and power dynamics faced by designers working with vulnerable groups in PD. We then explain our method and approach to analysis, a ‘map of engagement’ that we developed to assess stakeholder involvement at each stage of a project. After introducing the three projects, we use the map of engagement to visualise and compare them. First, we describe how vulnerable groups were defined, recruited and engaged, and look at how initial assumptions of users influenced the projects and participation. We also describe tactics employed to increase access and support for vulnerable participants. Second, we examine how two categories of proxies represented vulnerable groups and shaped user involvement: institutional partners and professionals; and individuals with personal relationships to the vulnerable users. In our discussion, we look at the overall design of the PD projects and the roles of different

actors to reflect on power dynamics and user engagement throughout. We evaluate how much space was given for user input and collaborative design, and what conditions informed the planning and relationships behind these projects. We question whether our approaches improved or limited participation and how inclusivity could be further addressed.

1.1. Challenges guiding PD with vulnerable groups

In PD with vulnerable groups, there is a reluctance to generalise best practices because of participants' diverse and often unique requirements. Designers and researchers aim to create responsive methods that build on participants' interests, strengths, lived experiences and contexts rather than expecting them to conform to design processes (a number of examples are found in a special issue of this journal edited by Slegers, Duysburgh, and Hendriks 2015). They also seek to empower participants by building 'capacity to participate' through PD (Hussain, Sanders, and Steinert 2012; Smith and Iversen 2018; Drain and Sanders 2019), and by giving them responsibility and designerly roles (e.g. Burnett and Coulton 2017; Winton and Rodgers 2019). In a study of designers working with people with cognitive impairments, Hendriks, Slegers, and Duysburgh (2015, 73) conclude that designers face six types of challenges, applicable to PD with any target group: '(1) positioning the impairment in a codesign project; (2) equivalence in participation; (3) balancing viewpoints of the stakeholders; (4) ethical challenges and impact; (5) adapting existing codesign techniques; (6) data collection and analysis'. Our findings make connections between many of these issues and different phases of the three PD projects compared below.

1.2. Power dynamics in PD with vulnerable groups

PD confronts the power dynamics typical of much design practice, however efforts to build more democratic design processes cannot guarantee equality between professional designers and participants. More work is required to balance power relations in PD with vulnerable groups (Hussain, Sanders, and Steinert 2012), in part because 'the differences between the worlds of the researcher and the designer and those of the persons with an impairment are potentially greater' (Hendriks, Slegers, and Duysburgh 2015, 79). Proxies help to bridge this gap by acting as representatives or mediators for end-users in the design process (e.g. caregivers speaking for or assisting patients with Alzheimer's in PD). They provide valuable insights into participant behaviours and needs, and proxies often stand to be impacted themselves by the outcomes of PD. At the same time, they present limited, biased perspectives which cannot replace the voice of the vulnerable user. In their recent reflection on genuine participation, Raman and French (2022) discuss the balance between caring for vulnerable participants' well-being and risking a 'paternalistic mindset' that prevents rather than supports capacity to participate (753). Instead of limiting participation or relying on others' perspectives, the PD process should adapt to participants' needs and prioritise their expertise based on lived experience (Raman and French 2022).

A number of frameworks exist to evaluate level of participation and power sharing in PD. For example, Arnstein's Ladder of Participation (1969, 2019), grounded in planning and community engagement, shows eight steps moving from non-participation to tokenism to citizen power. Hussain's Design Participation Ladder (2010), based on PD with children with disabilities, defines three levels: included, consulted and empowered. In the PD Collaboration System Model, based on work in Cambodia with people with disabilities, Drain and Sanders (2019) emphasise capacity to participate and the influence of design, cultural and societal contexts. These frameworks are useful for assessing extent or conditions of participation, but they do not directly address how PD projects develop over time, or how stakeholders other than designers influence participant engagement.

One of the challenges facing inclusive PD processes is when to engage with participants. PD case studies tend to focus on a 'single design activity and rarely on long-term or full-scale projects' (Andersen et al. 2015, 253), and on what happens during a project rather than before or after (Smith and Iversen 2018). Smith and Iversen take a wider view, looking at scalability and long-term relationships with communities. They describe 'stage 0', when participation is 'configured' and 'users, and even researchers and designers, are invented through acts of creating and defining the project itself' (2018, 18). Similarly, Pedersen explores 'design before design' (2016), the work of planning a codesign project with stakeholders and participants. Costanza-Chock (2020, chapter 2, 19) outlines a model where degree of participation, from 'weak (consultative/extractive)' to 'strong (governing)', is plotted across phases of design. These temporal perspectives align with our analysis of participation over the duration of a project and the influential role of designers and institutional stakeholders early in PD initiatives.

In relation to the literature discussed above, this article contributes to the call by Hendriks, Slegers, and Duysburgh (2015) for 'method stories', in which designers learn from others' PD practices, while recognising that there is no single approach to adapting codesign techniques. The map of engagement adds to tools for evaluating PD processes by making patterns visible in planning, execution and stakeholder relationships over time. These patterns raise essential questions about equality and power dynamics in PD with vulnerable groups.

2. Methodology

To examine the three projects and facilitate understanding of their inclusivity, a series of meetings was held by the authors, each of whom had closely worked on one or more of the projects. We explored each project in terms of processes, partnerships, data collection strategies, analysis and outcomes. We reflected on the challenges and opportunities of engaging with vulnerable populations and creating more inclusive environments for different stakeholders.

In comparing the projects, we realised that mapping them over time was useful for communicating how they were planned and carried out. This process of visualisation led us to create the 'map of engagement' (Figure 1), showing different stages of interaction with stakeholders and their alignment with design processes. We applied the maps retroactively to the three projects, documenting the main activities using the categories we decided upon together.

MAP OF ENGAGEMENT IN THE DESIGN PROCESS								
		Project Phases						
		1 Problem and user definition	2 Pre- engagement	3 Problem redefinition	4 Design	5 Development	6 User testing	7 Final outcome
Stakeholder Involvement	Design team and primary users							
	Design team, proxies and secondary users							
	Design team only							

Figure 1. Map of engagement template.

The maps include seven phases (from left to right):

- (1) Problem and user definition: conceptualisation of the project and user groups, background research, funding and ethics proposals
- (2) Pre-engagement: first contact and recruitment of users
- (3) Problem redefinition: user engagement to focus project aims based on user needs and contexts
- (4) Design: ideation with users to develop design concepts in response to needs identified in phase 3
- (5) Development: design development based on concepts generated in phase 4
- (6) User testing: evaluation of prototypes by users leading to further refinement
- (7) Final outcomes: presentation of project deliverables (prototype toolkit, beta version of a mobile application, a research tool and recommendations) to partners/ service providers

In the map, each phase is represented by a column of activities, which may have taken place at different times within that phase. Three rows divide these activities by stakeholder (from top to bottom):

- (1) Design teams with primary users: design researchers working with vulnerable groups who are the targeted service users
- (2) Design teams with proxies and secondary users: design teams working with people who know the primary users through personal or professional relationships (e.g. as family members, counsellors or representatives of stakeholder institutions that serve those populations), and who might be secondary users of the service (e.g., counsellors who might use the service to assist the vulnerable groups)
- (3) Design teams alone: design researchers (students and faculty).

The design teams were involved in all activities on the maps. The top two rows show activities where the designers worked with stakeholders, while the bottom row shows activities where the design teams worked independently of proxies and users.

Each case study is briefly described below, along with its individual map of engagement (Section 3, Figures 2–4). We then combine the three maps in order to identify where they overlap and diverge (Section 4, Figure 5).

3. Three projects

The three design research projects were selected based on a number of similarities and the authors' familiarity with them. Each project involved multiple stakeholders and aimed to increase access to services for vulnerable groups. The projects led to different types of design outcomes: a toolkit prototype to facilitate discussion of service provision, a beta version of a mobile application for crisis planning, a research tool in the form of a diary and recommendations for accommodation services. The projects were driven by design researchers and students from within academic institutions in partnership with government and non-profit organisations dealing directly with vulnerable populations. All projects were completed one year before we began writing this article. Table 1 shows how the projects differ in scope and setting.

3.1. Project 1: toolkit: testing codesign with people with intellectual disabilities

This project started by questioning whether an intellectual disability would be a hindrance to conducting codesign activities. The WHO (2018) defines intellectual

Table 1. Case study overview (number of participants in parentheses).

Project	Duration	Design researchers	Collaborating institutions	Research participants (primary users)	Research participants (proxies and secondary users)
1. Toolkit: Testing codesign with people with intellectual disabilities (Finland)	2019 (4 months)	Design student (1)	Local service provider (1) University (1)	People with disabilities living in supported housing (12)	Service managers (3) Housing unit workers (4)
2. Mobile application: Designing a mobile application with and for youth in crisis (Canada)	2015–2019	Faculty (5) Consultant (1) Design students (15) Additional design students at workshop (18)	College (1) Province-wide government institution for addiction and mental health (1) Local service providers (60) including organising group (15)	Youth ages 13 to 24 who had experienced crisis (40)	Parents (6) Counsellors/Service providers (6)
3. Diary study: understanding the landscape of professional placements for nursing students with learning disabilities (Canada)	2017–2019	Faculty (2) Design students (3)	University (1) College (1)	Students who have identified with disability (12)	Faculty (5) Student access service providers (3) Clinical instructors (14)

disabilities as those that affect intellectual and adaptive functioning, and thus affect communication skills. This inspired an interest in stretching the boundaries of codesign to test how someone with an intellectual disability, who has difficulties in speaking and expressing opinions, might participate in workshops and how to adjust codesign methods to match their needs. The project was conducted in Helsinki, Finland, in collaboration with a municipal service provider of supported housing for people with an intellectual disability, as outlined in Finnish national legislation (Laki kehitysvammaisten erityishuollosta [Act on Disability Services and Assistance] 2016).

Following a period of exploratory research to understand the context and to further project planning, the PD process was designed with the social workers of the housing unit (phase 1 – problem and user definition). The first engagement with users occurred during phase 2 (pre-engagement) when a plain-language letter invited the inhabitants to participate in a research project to develop decision-making tools. Phase 3 (problem redefinition) activities included meeting participants to explain the process and address possible barriers. Phase 4 (design) involved two workshops where participants tested sharing opinions and comments through codesign methods chosen by the researcher such as personal reflections in writing, post-it notes ideated together and group discussions. At the end of the project, a toolkit prototype was created from the best functioning methods used in the workshops in order to facilitate discussions between social workers and residents with disabilities about decisions related to their personalised service plans (phase 5 – development). Phase 6 (user testing) concluded the project with meetings to discuss findings and the potential usefulness of the toolkit with the users, proxies and later with service managers. As a final outcome, a revised version of the toolkit was proposed for the organisation to further test (phase 7 – final outcomes).

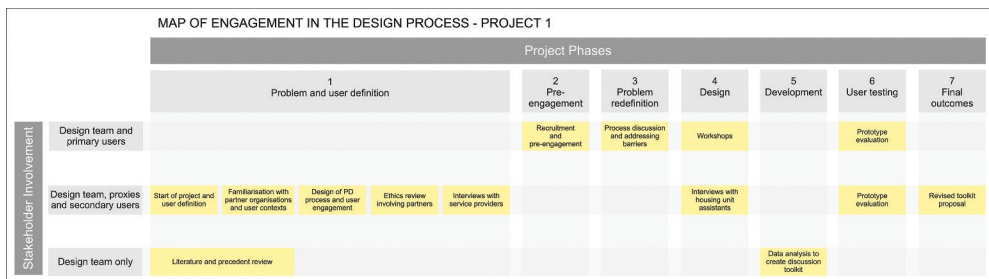


Figure 2. Map of engagement for Project 1. Toolkit: Testing codesign with people with intellectual disabilities.

3.2. Project 2: mobile application: designing with and for youth in crisis

This multi-year project developed out of a need to improve service delivery for youth coping with crisis who were not adequately supported by mainstream health and community services in the Regional Municipality of Peel, Canada (Hodson et al. 2019). Service providers identified the user group as culturally diverse youth ages 13–24 who enter ‘the system’ through interaction with crisis response teams, hospital emergency rooms and the justice system. The project brief emerged when these organisations

recognised the need for a digital alternative to paper crisis plans. Perceived barriers to youth participation in PD included stigma about mental health and vulnerability when sharing personal experiences in group settings.

The project involved research, design and testing of a mobile application for crisis planning. In phase 1 (problem and user definition), the PD process was conceptualised by the design faculty leading the project in consultation with two ethics review boards, project partners and service providers with expertise in mental health, addiction and crisis counselling in the target community. The student researchers and faculty further refined the PD process as the project progressed. In phase 2 (pre-engagement), youth and their families were recruited to join focus groups and complete surveys (phase 3 – problem redefinition). These led to a better understanding of user groups, experiences of crisis, needed supports and the potential role of technology. Results were distilled into three challenges addressed in a workshop in phase 4 (design) where students and youth collaborated to generate potential app functions and user scenarios. The students then analysed these to create a design brief which guided phase 5 (development). Iterations of the app were presented to youth and counsellors in phase 6 (user testing). The beta version was later transferred to a service provider for further evaluation (phase 7 – final outcomes).

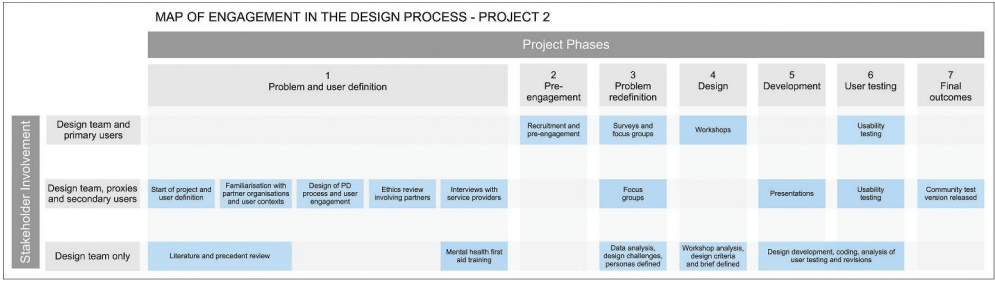


Figure 3. Map of engagement for Project 2. Mobile application: designing a mobile application with and for youth in crisis.

3.3. Project 3: diary study: understanding the landscape of professional placements for nursing students with learning disabilities

The aim of this project was to develop a fundamental understanding of challenges faced by vulnerable nursing students and relevant stakeholders (e.g. faculty, clinical employers) in Toronto, Canada. Accommodation processes for students who identify with disabilities (visible and invisible) tend to focus on classroom learning. Nursing students, like many in healthcare and other fields, are required to complete a certain number of training sessions within a practicum (clinical environment). Strict professional practices in healthcare settings do not align with the academic accommodations students receive and challenge them to meet their clinical placement requirements. The students did not feel comfortable sharing their experiences, particularly as it might jeopardise their success in professional contexts, and hence few opportunities were available to uncover issues and explore possible interventions.

PD was used to generate a user-centred research tool (diaries) to collect data and engage stakeholders in a more inclusive way. User engagement occurred during phase 2

(pre-engagement) when researchers connected with interested partners and potential stakeholders at higher education institutions' access centres and clinical placements. User engagement during phase 3 (problem redefinition) consisted of interviews with stakeholders (i.e. clinical instructors) used to inform the design of the diaries, and again in phase 4 (design) to collect data from users (i.e. students with disabilities) through diary studies. This was followed by refining and testing the diary (phases 5 – development and 6 – user testing). Insights were then generated regarding potential obstacles for accessible field placement experiences, as well as recommendations for the redesign of the accommodation services offered by accessibility departments within the higher education institutes and clinical settings (phase 7 – final outcomes).

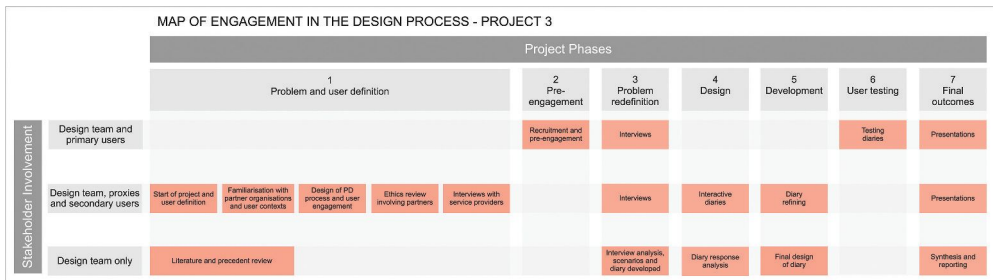


Figure 4. Map of engagement for Project 3. Diary study: understanding the landscape of professional placements for nursing students with learning disabilities.

4. Findings

Combining the three maps of engagement revealed patterns in how the projects were conceived and executed. As seen in [Figure 5](#), the projects began in a similar fashion (phase 1) with literature reviews, planning sessions with partners and service providers, and ethics reviews. These reflect common research practices and requirements from universities and funders. Similar issues emerged during recruitment and pre-engagement (phase 2), but the projects diverged once they involved users in research and collaborative design ([Figure 5](#), starting with phase 3) in response to the unique contexts and needs of the vulnerable groups. Below, we discuss the inclusion and participation of primary and secondary users and proxies. We question how vulnerable groups were defined, engaged and supported, and what roles the other stakeholders played in shaping these projects. We build on those findings in the discussion ([section 5](#)) to reflect on how power dynamics and inclusivity vary across the project phases.

4.1. Defining primary users (phases 1–2)

In phase 1, each project started with pre-existing categories and characteristics of the vulnerable groups. These were often based on ability, such as intellectual disability (project 1), mental health (project 2) or disability impacting learning experiences (project 3). These categories were largely defined by the organisational stakeholders and the complex systems within which those institutions and user groups co-exist. This impacted who was selected to participate and how PD activities were planned to meet their needs.

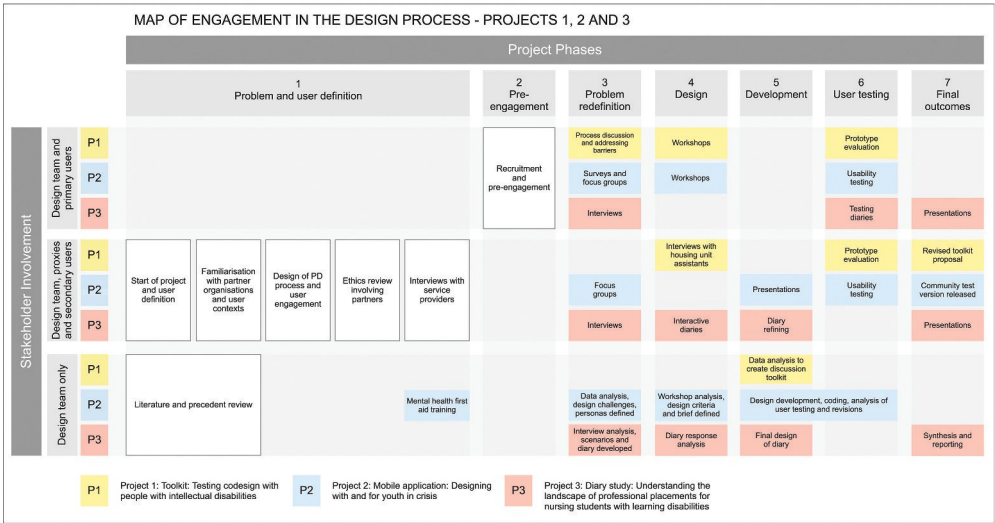


Figure 5. Map of engagement. Comparison of the three projects.

With project 1, the social workers guided the designer to work with those who had the strongest verbal communication skills. This could lead to the conclusion that PD activities reliant on verbal communication exclude certain audiences and consequently are less adaptive to different needs and preferences. In project 2, when the design team formulated recruitment materials and came face-to-face with counsellors and prospective users, it became clear that the concept of crisis needed to be expanded beyond mental health and substance misuse to reflect the fact that crisis can affect anyone. This resulted in a user group with a greater variety and complexity of challenges. In project 3, inconsistent user definitions and lack of communication among schools and clinical placement sites led to confusion about what support students were entitled to receive. Students given in-class accommodations did not necessarily obtain additional support in their clinical placement, meaning that those with disabilities (especially invisible disabilities) were assumed able to complete their field placements without accommodations. This negatively impacted the recruitment activities as students were less likely to come forward.

4.2. Engaging and supporting primary users (phases 2–6)

Early introduction through pre-engagement sessions (phase 2) helped both the participants and researchers in terms of building relationships and managing expectations, what Raman and French (2021) refer to as ‘contextual preparation’. In project 1, the social workers asked the designer to visit the social housing unit before any PD activities, explaining that people with intellectual disabilities often require more time to build their confidence with new people. This also increased participants’ sense of belonging to the project. In project 3, nursing students with disabilities were not pre-identified and pre-engagement events helped to give them the confidence to come forward. Subsequent

engagement activities were necessary to communicate goals and objectives to the nursing students and this encouraged them to fill out the diaries.

Balancing power relations and building trust between designers and participants were emphasised. In projects 2 and 3, this meant having design teams that reflected the demographics of the user group and giving more agency to the students and participants. The students acted as front-line researchers and designers (phases 1–7), and the participants acted as experts, designers and users (phases 3–6/7). In project 2, the value of the youth's contributions was intentionally reinforced by assigning participants leadership roles, using empowering language and financially compensating them for their time.

Using personas helped participants to feel more at ease. For example, in project 3, personas were embedded within stories (scenarios), which made it possible to highlight a range of limitations without focusing on type of disability. For example, instead of discussing a particular form of neurodiversity, the story discussed time management issues, which apply to both visible and invisible disabilities. While the usefulness of personas in design has been questioned, and they risk misrepresenting diverse users based on assumptions and stereotypes (Costanza-Chock 2020), in projects 2 and 3 we found that both the student designers and users could empathise with them. Participants felt more comfortable designing for the personas than putting their own experiences at the centre of design activities. This aligns with Neate et al.'s finding that personas can 'enable [users with diverse needs] to more actively become a designer' by, for example, critiquing design through the eyes of the persona (2019).

Finally, measures were put in place to promote the wellbeing of participants (phases 2–6), especially when their needs exceeded what the design team was qualified to provide. In project 2, participants were required to review a 'screener' to identify any reservations (e.g. readiness to share their story, listen respectfully and identify signs of discomfort) and to ensure they had crisis numbers on hand. Importantly, there was at least one local counsellor present for anyone who might need help. Attention was also paid to emotional and physical accessibility and safety with events organised in locations familiar to participants.

4.3. Role of secondary users and proxies

While vulnerable groups were the focus of the three projects, the maps of engagement illustrate that proxies had equal or more presence. Below, we describe the proxies' roles in shaping the projects.

4.3.1. Institutional partners and professionals in the field (phases 1–7)

The first group consists of organisations considered partners or facilitators (e.g. schools, hospitals, housing and counselling organisations) as well as professionals who work directly with the vulnerable groups (e.g. social workers, counsellors). These proxies played considerable roles throughout, first by defining the user groups and the research projects with the design teams, in itself a form of PD, though not acknowledged as such at the time (phase 1). They helped to make apparent the support networks that are crucial in delivering services for vulnerable populations and they became valuable allies for the design teams. They provided training (project 2, phase 1), reviewed engagement plans and design work, gave guidance

on communication and language, answered questions about the users and warned of potential issues (phases 1–7). At the end, project outcomes were transferred to several of the partner organisations to carry forward if they chose to (phase 7). Each of these contributions had a significant impact on how projects unfolded.

4.3.2. Individuals with personal relationships to the vulnerable groups (phases 2–6)

The impact on project development and outcomes was less obvious when it came to proxies who were personally related to the vulnerable groups, but their roles were nonetheless important in representing the primary users and facilitating their participation. In project 2, parent focus groups (phase 3) revealed new perspectives on how support systems work, what crisis looks like within a family and the disconnect between service providers and communities. During ethics review (phase 1), questions arose about legal guardians and the need for parental consent. Self-determination was an important issue for project 1 participants, whereas safety and confidentiality were concerns in project 2, especially for youth under 18. In both cases, consent forms suggested participants share the information with families. In project 2, several parents accompanied their children to the workshops but waited outside (phase 4), which appeared to increase comfort for the whole family. Involving family members required balancing the vulnerable users' privacy and independence with the need for safety and additional information.

5. Discussion

Comparing the maps of engagement allowed us to see the balance between primary and secondary users and the design teams. Overall, we found that PD became more challenging when there were more pronounced differences in power dynamics. Additional resources were needed for ethics reviews, recruitment, pre-engagement activities, measures to ensure wellbeing and PD activities that elicited and emphasised the vulnerable groups' contributions. Despite these efforts, the maps of engagement helped us to see that institutional actors and proxies often played more significant roles than the vulnerable users in defining project parameters and needs. Below, we examine the extent of collaborative design, limitations to 'genuine' participation and opportunities to increase inclusion.

5.1. Extent of engagement and ownership

The combined map of engagement (Figure 5) emphasised at what stages we gave room for user voices and made it more visible when that input affected design decisions. This led us to classify activities based on the extent of vulnerable groups' participation. In Table 2, participation grows from the bottom up, as users are increasingly included from representation in secondary sources to active participation in design activities. As a whole, the three projects are examples of PD in that they were collaborative and involved stakeholders in a variety of ways. However, there were only a few instances of 'codesign' (top row) where designers and non-designers created new design outcomes together, such as design concepts, product names, app features and user journeys (Figure 5, phases 4 to 6).

Table 2. Extent of participation.

Extent of participation (inclusion of vulnerable group in the process)	Typical activities
1. Users are actively involved in designing a product or service	Collaborative design workshops, user testing
2. Information is solicited from users and proxies	Research workshops, interviews, surveys
3. Stakeholders with knowledge of users are informed and given opportunities to provide some feedback	Meetings, presentations
4. Secondary sources reporting on users are consulted	Literature review, experts training the design team, personas developed by design teams and later used in design process

The projects cannot be uniformly labelled as PD. Rather, there were moments of PD and varying degrees of inclusion throughout. Arnstein's and Hussain's ladders of participation allow a critical perspective of Table 2. Our projects reached rung seven of Arnstein's framework (1969, 2019) when power was delegated to users in codesign workshops (eight is highest with citizen control over a project); and they reached the highest level of participation, 'empowered', in Hussain's framework (2010), when participants influenced the design of services. However, decision-making always reverted to the design teams or proxies. Even though designers prioritised users' ideas, it was the designers who determined project outcomes.

As a result of varying levels of participation, the projects risked creating unrealistic outcomes with little stakeholder ownership. The design researchers, secondary users and proxies identified problems (phase 1) and the primary users were then involved to focus those problems and codesign solutions (phases 3–6). Participants were assumed to be invested in the issues and their opinions were emphasised, but they were not in a position to advocate for the delivery of the services they helped to design (phase 7 and beyond). Furthermore, by attempting to address power imbalances, the design teams focused PD activities on primary users, intentionally leaving institutional stakeholders out of 'codesign' roles. Had those stakeholders also been prioritised as users, project outcomes would likely have taken another form and may have been adopted more fully. Instead, institutional partners required more human, technical and budgetary assistance for implementation. This suggests that to ensure the longer-term success of a service developed with vulnerable groups through PD, an alternative approach is necessary. Future research could explore how to involve secondary users in codesign without overshadowing the needs of primary users.

Moving across the map of engagement (Figure 5) reveals gaps in user involvement, particularly at the start of the projects and after their completion. Each project began with the designers or partner organisations identifying a 'design problem'. The organisations and social workers, along with the literature reviews, were instrumental in defining the profiles and needs of the vulnerable groups but they could not provide a full picture of the users and their lived experiences. Nevertheless, these early understandings of the users became entrenched through project planning, funding and ethics applications (phase 1). Interaction with the vulnerable groups could not begin until after ethics approval when the contours of the projects had already been established (phase 2). Thus, while the projects demonstrate a range of levels of engagement, the primary users' agency was constrained by how the projects were organised and the roles of other stakeholders.

Analysing the projects over time also raised questions about prior and ongoing relationships with communities. Each project had its own history involving networks of design researchers and participating organisations. This represents an unofficial phase blurring with ‘pre-design’ or the ‘fuzzy front-end’ of codesign (Sanders and Stappers 2008). It could even be considered ‘stage –1’ if we extend Smith and Iversen’s (2018) framework for codesign project development. While these professional relationships are sustained over longer periods and may lead to future projects, the relationship between the design researchers and the vulnerable user groups started and stopped with the three projects.

We observe that the design teams were more prepared to address inclusivity and to customise approaches when planning specific PD activities and moments of direct engagement with primary users (phases 2–6). The design teams were less equipped to consider how entire PD projects could be made more inclusive and how power might be shared with vulnerable participants throughout. Instead, the designers followed the research procedures and timelines required by academic institutions and funding bodies (phase 1 in particular). This added rigour to project planning and thorough consideration of ethics, but it also limited primary user involvement, especially at the start of the project.

5.2. Opportunities to increase inclusion of vulnerable groups

5.2.1. Genuine inclusion

Based on this analysis, we returned to the idea of ‘genuine participation’, in which participants move from ‘being merely informants to being *legitimate* and *acknowledged* participants in the design process’ (emphasis added, Luck 2018, 5). We asked what ‘genuine’ inclusion means over the duration of a project: who was included, when, how, in relation to whom and to what extent; and what makes the different forms of inclusion we observed ‘genuine’ or not. The maps of engagement capture when vulnerable groups were ‘*acknowledged*’ by being invited into the design process, painting a picture of the *amount of involvement* in comparison to other stakeholders. If the involvement of vulnerable users appears to be balanced or even weighted more heavily in their favour, this could be interpreted as a ‘genuine’ attempt at inclusion by project planners. However, we note that the absence of vulnerable groups at important moments (e.g. when user groups and the initial design problem are defined) can limit what appears to be significant presence in codesign activities later. Across the maps, we analysed the *extent of engagement* (Table 2) in each activity, in essence questioning whether the primary users became ‘*legitimate*’ participants by actively contributing to design processes and influencing design outcomes. We observe that codesign is limited to specific activities that respond to predefined problems and processes and that ‘legitimate’ participation could have been extended throughout.

5.2.2. Project structure

We see several directions for changing how projects and relationships are initiated and structured. The first is making space for primary users early in the process. User acceptance and ownership should be promoted but not limit opportunities for researchers to explore the complexity of the system with as little stakeholder bias as possible. As others have noted, rather than starting with institutional stakeholders and proxies, an

exploratory research phase with primary users would give designers more perspective and the vulnerable groups more agency in defining the design problem (Smith and Iversen 2018; Hendriks, Slegers, and Duysburgh 2015). A more formal and transparent ‘getting-to-know-you’ period for all stakeholders could help to manage expectations, understand roles, build trust and produce more realistic outcomes, while a working group that represents all stakeholders could oversee the project and contribute to more balanced decision-making. Beyond the duration of the project, other models of partnership, including longer-term collaboration with vulnerable communities, could lead to greater accountability for design researchers and partner organisations (Smith and Iversen 2018). It could also help to sustain participant empowerment outside of the project (Hussain, Sanders, and Steinert 2012; Lundmark 2018) and encourage new project development beginning with vulnerable groups instead of institutions.

5.2.3. Academic and funding processes

Changing how PD work is done in academic settings requires a different approach before project plans are established. This could include funding for exploratory research prior to phase 1, in which vulnerable community members would help to define PD projects before grant applications and lengthy ethics approvals are initiated. New consideration could be given to how primary users are considered relative to other stakeholders, such as alternative roles (e.g. project planner instead of research participant), representation in planning meetings and financial compensation in the same way that academic researchers and institutional partners are recognised for their time. Funders and schools could also consider how to support longer-term relationships between design researchers and vulnerable communities beyond funding and academic timelines.

5.2.4. Evaluation

Lastly, formative and summative evaluation of inclusivity throughout PD projects could lead to more responsive processes and better understanding of their short- and long-term impacts. Here, the map of engagement could be used to plan and assess projects in a variety of ways. Beyond our own observations and anecdotal evidence, we do not know how the vulnerable groups we worked with perceived inclusion. To some degree, each of the three projects involved reflection and adaptation as conditions evolved and new challenges appeared, but there was no formal evaluation of the process with participants. Interviewing users, partners and design team members before, during and after projects, then mapping their expectations and experiences of PD across project phases, would build understanding of inclusion.

6. Conclusion

This article contributes to PD research with a preliminary framework, the map of engagement, for designers and others to evaluate the balance of stakeholder involvement over the course of a project. Understanding how a PD project unfolds over time in relation to the design lifecycle can be valuable for investigating the notion of relevant and sufficient (i.e. optimised) user engagement. By taking a holistic view of PD projects, design researchers can examine whether inclusion can be designed into every step. By mapping project phases against stakeholder participation, the amount of involvement (time) and extent of

engagement (contribution to design processes and outcomes) can be made visible for different groups. This visualisation supports planning and evaluating 'genuine' inclusion through understanding who is included, when, how, in relation to whom and to what extent. Comparing stakeholder participation helps to reveal power dynamics by showing who is present or absent at different points and who is making decisions that impact primary users and the overall project. This allows for critical reflection on how design problems and processes are established, and how users are defined and assumptions made about their capacity to participate. Ideally, vulnerable users could contribute to direction setting, project planning and oversight in the same way as institutional stakeholders.

The version of the map presented here needs to be further tested to establish its usefulness in PD. For example, the maps show the stages of a project but not the amount of time or resources dedicated to each step or the extent of participation (Table 2). We propose that the map be applied to professional and community contexts where resources and priorities differ from the academic institutions that led the three projects discussed. This would generate knowledge and support evaluation about typical processes, roles and approaches to inclusion in PD.

We applied the map of engagement to three PD projects that aimed to increase inclusion of vulnerable groups in the development of services in the public sector. By taking a high-level view of the projects, we observed patterns in planning and execution. The maps of engagement allowed us to visualise and compare the roles of multiple stakeholders over seven phases, from problem definition to final outcomes. This made it easier to identify when the primary users were involved, and how different power dynamics influenced their engagement. We found that definitions of the vulnerable users, established before and early in the project with institutional partners and service providers, informed the PD process and may have limited participation. Nevertheless, these definitions became starting points to create more inclusive and supportive engagement strategies. We also found that the proxies shaped project parameters, often playing more significant roles than the vulnerable groups the projects sought to prioritise. The proxies' contributions to the design process were invaluable, but in some ways, reduced the agency of the primary users. The vulnerable groups entered projects when their roles and the design problems were already pre-defined. The map of engagement highlighted moments when primary users were actively involved in design as well as absences of primary users at the start and end of projects. This raised questions about the extent to which the projects achieved inclusive and collaborative design, and led us to propose ways in which vulnerable users could be foregrounded across projects without losing the perspectives of other stakeholders. Our analysis demonstrates that questions of equality and 'genuine' inclusion in PD can be asked not only of design activities and relationships between researchers and participants, but also of how entire PD projects are planned.

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