



Co-Designing with Extreme Users: A Framework for User Participation in Design Processes

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RESEARCH



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ABSTRACT

The demand for user participation in design processes is increasing, and there is a need to formulate guidance on how to involve disabled users and their representative organisations. Their participation contributes an extreme user perspective to the design process. The aim of this study was to develop an empirically grounded framework for user participation in co-design processes, involving the users with wide range of characteristics. The study was theoretically grounded in ‘participatory design’ and ‘value sensitive design’ and used an exploratory study design with online workshops to iteratively collect and analyse data. All participants collaborated on an online Miro-board to identify themes and formulate guiding principles for the framework. We propose a framework consisting of three themes: participation fundamentals, participation ethics and participation practicalities, entailing 11 guiding principles. By applying this framework, the premises, methods and activities in the design process will be accessible to all participants, and user participation in design projects will become more transparent, equitable and easier to implement. It will enable all users, people with disabilities and others, to participate and contribute to a design that can be used by the widest range of people.

KEYWORDS:

accessibility; universal design; participation; disability; impairment; qualitative thematic analysis

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Participation of users in a design process is considered as one of the most important factor for a successful outcome of the design (Kushniruk & Nøhr 2016; Steen, Manschot & Koning 2011). Participation in design projects can, like in any collaborative process, range from mere tokenism (i.e., symbolic representation), to a source of information, to partnership and to full citizen control (Arnstein 1969). Even when full citizen control is not the goal, a number of values can be found when professionals and lay people collaborate, for example, stronger justification, bringing a diversity of voices to the process and framing problems (Tritter & McCallum 2006). From the groundbreaking work on principles for universal design (Story, Mueller & Mace 1998), the important relation between design and disability has been discussed (Joost & Bieling 2012; Pullin 2009) and the importance of participation in design by people with disabilities are presented both as an important principle (Lid 2014; Tanabe, Pearce & Krause 2018) and in practical experiences of co-design, participatory design and participatory action research (Bourke et al. 2018; Brereton et al. 2015; Hendriks, Slegers & Duysburgh 2015; Lazar et al. 2018). Although people with disabilities are still often excluded from participating in design processes (Henni et al. 2022).

In this work, we distinguish between impairment, defined as ‘problems in body function or structure such as a significant deviation or loss’ (World Health Organization 2002), and disability, which is viewed as a social construction as described by the social model of disability (Oliver 1996) and as a form of oppression imposed by society (Abberley 1987). But we also acknowledge that the dichotomy between impairment and disability is complex (Anastasiou & Kauffman 2013). Our position is that people with impairments are often disabled by inaccessible design. Hence it is important to focus on the design process and how people with disabilities can have a voice in the design process. The overall aim is to enable people with disabilities to have an impact or influence over the design result and make a desired outcome for the participation (Davis & Andrew 2017).

Concepts like user-centred design (Norman & Draper 1986), service design (Steen, Manschot & Koning 2011) and universal design (Steinfeld & Maisel 2012) argue that users should be collaborating partners throughout the design process, rather than merely being informants or test objects.

There is a risk that both design and design processes contribute to the exclusion of users with impairments and thereby disable people or induce stigma, not by purpose but as a result of ignorance or misguided actions (Garland-Thomson 2011; Laitano 2017). To mitigate this risk, it is important to facilitate people with impairments to participate in design processes and avoid their needs from being overlooked or neglected (Easton 2013). This situation raises questions about how to ensure fairness and facilitate influence from users in the design process. It also requires attention to power relations among all stakeholders in a design process (Friedman & Hendry 2019). How should this participation be organised and executed to be appropriate for all persons involved? Participatory design (Halskov & Hansen 2015; Robertson & Simonen 2012) offers methods to arrange collaboration that contributes to the quality of the designed artefact, at the same time addressing how to enable users to take part and be partners in the design process. Fairness in participation needs to be both ethically and practically grounded (Friedman & Hendry 2019; Jacobs & Hultgren 2018; Johansson 2019; Tanabe, Pearce & Krause 2018) and it is also a part of shaping a democratic society (Frauenberger 2015; Björgvinsson, Ehn & Hillgren 2010).

The participation of people with disabilities in the design process is justified by two arguments: (1) the extreme user perspective represented by people with impairments provides high quality in the design and (2) a human rights perspective provides equality, equity and fairness for all people, where equality gives everyone the same opportunity to participate and equity acknowledges that some might need special arrangements to reach the same level of participation. Collaboration with users who have impairments, representing an extreme user perspective (Brown 2009; Hildebrandt & Hindi 2020), will set the norm for a design that is usable for everyone.

Participation in all aspects of society is a fundamental principle of the United Nations Convention on the Rights of Persons with Disabilities (CRPD; United Nations 2006). CRPD targets accessibility as a core principle and a precondition to participation. The CRPD establishes accessibility (ISO

2019, 2020) as a quality that needs to be addressed in any design process. There is a large body of literature presenting examples of how people with disabilities have been included in specific design or research processes (see e.g., Bourke et al. 2018; Lazar et al. 2018). How participation works in practice and problems related to participation are also described in many examples (see e.g., Liabo, Ingold & Roberts 2018; Lindblom et al. 2021; Sproson et al. 2022; Wilson et al. 2020). There is also work done on defining the roles of the participants (Dada et al. 2022; Smits et al. 2020). Despite all this literature, there are only a few frameworks presenting the general conditions under which such collaboration should be organised. An attempt to establish principles for user participation that include people with disabilities and with accessibility in mind was the European FORTUNE project (Bühler 2001). Similar principles, but without a specific focus on accessibility, have been suggested by the International Association for Public Participation (2021). In both the frameworks, the idea of partnership is central, and there is an emphasis on user participation in the design process should be fair and provide real influence for all collaborators. But still there is a need to formulate more details on how participation should be organised to promote the full participation of people with disabilities and their representative organisations. The justification of this representation needs to be recognised as an important step towards the realisation of a society that caters for all.

The aim of this study was to develop an empirically grounded framework for user participation in co-design processes, enabling the participation of users with the widest range of user characteristics. The intention is to present guidance on general principles for collaboration that should be agreed upon before the practical collaboration starts.

METHOD

STUDY DESIGN

This study has an exploratory design (Stebbins 2001) drawn from participatory action research methods (Macdonald 2012). The study is theoretically grounded in participatory design and value sensitive design (Friedman & Hendry 2019). Participatory action research brings collaboration and partnership perspectives. Participatory design brings democracy and equity perspectives. Value sensitive design brings an ethical perspective emphasising participation from both direct and indirect stakeholders. All three perspectives draw on dignity and respect for human diversity.

STUDY SETTING AND PARTICIPANTS

The framework was developed along with the co-design workshops conducted in the CoDeAc (2021) and DigiKog (Begripsam 2022) projects, involving people with disabilities. CoDeAc is a research project using co-design methods to develop eHealth services together with people experiencing cognitive impairments. The DigiKog project was for developing requirements for cognitive accessibility through collaboration between designers and people with cognitive impairments. In both projects, participants with cognitive impairments from Begripsam and Funktionsrätt Skåne provided examples of situations in earlier design processes that they considered unfair. These discussions served as the starting point of this study and also to design the study.

Participants in the CoDeAc and DigiKog projects were recruited from the Begripsam Group, whose members have experience of cognitive impairments, developmental impairments and neuropsychological impairments. Also the disability rights organisation 'Funktionsrätt Skåne' sourced members from the 37 disability groups, the Swedish Dyslexia Organisation, the Autism and Asperger Organisation, the Swedish Aphasia Organisation, Neuro and the FUB. The Begripsam Group is an action research community developing methods for co-design to promote participation in the digital society for people with disabilities. Funktionsrätt Skåne serves as an umbrella organisation for all the 37 disability rights organisations. FUB organises people with intellectual impairments and their relatives. The participants with disabilities represented a very broad range of impairments, including people with mild and moderate intellectual impairments, autism, ADHD, dyslexia, stroke, aphasia, acquired brain damage, depression and low vision. They also varied widely in terms of age, gender, educational background and occupation. They all had experiences of being disabled by how the society is organised and

poor design when using the internet. The participating researchers represent the research fields Human-Computer Interaction, Accessibility, Disability Studies and Health Science. The authors brought both insider and outsider perspective (Wilson, Janes & Williams 2022) to the study. Some of the authors have lived experiences of disability, some working within the disability rights movement and with activist methods to change society, while others are working within the academia. In total, 66 people participated in the development of this framework.

PROCEDURES FOR DATA COLLECTION AND ANALYSIS

As part of the CoDeAc and DigiKog projects, participants in workshops discussed factors that facilitated or impeded user participation in co-design, with the purpose of elaborating a framework for user participation.

Six online workshops were conducted between March 2020 and June 2021. The workshop discussions initially followed a semi-structured scheme covering the discussion of prerequisites for a good collaboration in the co-design process as well as about issues concerning accessibility, fairness and practical issues to optimise the co-design process. During the workshops, an iterative process of data collection and data analysis was applied. All participants were engaged in the data analysis, which was conducted using a qualitative thematic analysis (Braun & Clarke 2006). The European FORTUNE project (Bühler 2001) principles on empowered participation in design were used as a starting point for the discussions with an introductory question about if people agreed with the principles and if they wanted to change, add or delete anything. The principles were further elaborated by discussions and suggestions made on digital sticky notes on a Miro board (MIRO 2021). These notes, consisted of direct quotes from participants or suggested wordings of a principle or guideline, were organised into provisional themes in a collaborative process with all participants. After each workshop, the discussions and data analysis were summarized on the Miro board by one of the researchers (the first author). The Miro board was used as an online shared collaborative space, allowing all participants to revisit the board to add quotes or comments and edit and comment on the analysis at any time in between workshops. The finalisation of the themes and guiding principles was made as an iterative process by all authors. Following the principles of participatory action research validation of data was a continuous process between all participants and was made in iterative cycles (Macdonald 2012). In the last workshop, consensus was reached among all participants on the final wording of the participation framework.

ETHICAL APPROVAL

This work received ethical approval from The Swedish Ethical Review Authority (D-no: 2019-04419, decision date: 11 September, 2019). Prior to participation, all participants gave their consent to participate. Information about the study was given in both written and oral forms and easy to comprehend with pictogram support when necessary.

RESULT

The analysis resulted in a framework for user participation consisting of three themes: participation fundamentals, participation ethics and participation practicalities. These themes entailed a total of 11 guiding principles (Table 1).

PARTICIPATION FUNDAMENTALS

The participants with impairments emphasised the importance of creating circumstances of equality in power relations between all stakeholders in the design process. They often experience being in a subordinate, and only reactive, position when invited to participate late in a design process. Furthermore, their representative organisations are often not invited or even denied participation. The explanation given to the representative organisations was that the inviting party only wanted individuals who represent themselves not organisations. In some cases, it was expressed that the organisation had a political agenda that would risk posing a bias to the design process.

| PARTICIPATION FUNDAMENTALS | PARTICIPATION ETHICS | PARTICIPATION PRACTICALITIES |
|--|---|---|
| Collaboration is based on the idea of active partnership. | Project decisions are guided by the CRPD. | Project premises, methods, activities, material and communication are made accessible to all participants. |
| Users with impairments and their representative organisations are acknowledged for contributing with expertise relating to the 'extreme user perspective'. | Collaboration is based on the ideas of fairness, equity and human diversity. | The project plan contains work packages and tasks that are appropriate for user participation and allow for reflection in between activities. |
| Users are represented throughout all the appropriate parts of the design process. | Design solutions are sought to fit the widest range of users. Known potential limitations in the end result of the design are documented and explained. | Project activities are evaluated continuously throughout the process and adjusted, if necessary. |
| Users receive reimbursement on the same basis as all other project partners. | | |
| The project collaboration is outlined in a written mutual agreement. | | |

Table 1 The framework for user participation in the design process.

CRPD, Convention on the Rights of Persons with Disabilities.

The participants with impairments wanted to be treated as subjects rather than objects, and the knowledge that derived from lived experience should be acknowledged and appreciated as representing an extreme user perspective. To have a genuine and proactive impact on the design process, it is important that the participants to be part of the process from its early stage and throughout the whole process.

Several participants emphasized the important of receiving reimbursement as a primary principle. Receiving reimbursement for participating in design project activities was viewed as an important acknowledgement that everyone was on board on equal terms. One participant described the subordinate position that comes with working for free or receiving a small gift, while all the others in the design team get a salary as: 'They say that my experience is important and that they appreciate that I am willing to contribute, but they want me to work for free'. Another participant mentioned as: 'I cannot leave my ordinary work to participate if I am not compensated for the loss of income'. From an overall standpoint, it was considered important to acknowledge that collaboration should be built on an active partnership.

Given that every design project has different conditions, it was considered important to discuss and agree on the terms for the collaboration at the beginning of the process. To clarify terms and conditions in advance would cater for a well-executed collaboration. This should be documented in a written agreement.

PARTICIPATION ETHICS

CRPD was considered, by the participants, as a good guide to inform project decisions whenever there was a doubt about which alternatives would be the most beneficial for maximizing inclusion in design projects. All user participants in co-design processes, including people with disabilities and their representative organisations, should be treated with fairness and as equals. Representation of a diverse set of users would allow people with a wide range of characteristics to participate.

The outcome of the design process should be something that could be used by the widest range of users and with respect for human diversity. One participant described this as: 'The project should be fair, but also the result needs to be fair', emphasizing that accessibility and usability are important qualities both in the design as a process and in the design as a final quality of the artefact. Some participants expressed concerns based on negative experiences of participation: 'There is a risk of being co-opted, to be taken as a hostage in the process', or 'They wanted me to be there, but I can't see they took any notice of what I said'. They shared previous experiences of being invited to participate in project collaboration but then not being listened to their inputs. They perceived it as the project management felt it was enough to merely 'tick a box' claiming that they had involved people with disabilities in the project.

It was considered important to be fair and transparent about potential limitations in a design. If trade-offs had to be made, they should be communicated to all members of the design team. Several participants had experienced that a common metaphor to hide decisions that will result in the exclusion of people with impairments is when designers express that the project needs to focus on 'low hanging fruits' or to reduce the scope and produce a minimum viable product (MVP). One participant aptly remarked: 'People with impairments are never low-hanging fruits'.

PARTICIPATION PRACTICALITIES

Accessibility was considered as a key to user participation. Every step in the design process, including activities, material and communication, should be planned and prepared with accessibility in mind. The participants expressed that by having a focus on accessibility, potential barriers to user participation could be handled. It was also considered important that the project management made efforts to remember and accommodate the accessibility needs expressed by the participants. 'It is a bit embarrassing to have to say to everyone that it is difficult for me to read. It is better when the project manager remembers this and reads texts out loud without pointing out that it is done especially for me', as described by one of the participant.

Any design method can be used as long as it respects human diversity and applies measures to make it accessible. Participants emphasized the importance of using methods, activities and materials adapted to be accessible for them. Also it is important to provide accessible communication by reading text out loud, having sign language interpreters in workshops or slowing the pace of discussions.

Participants also argued that the time allocated for different phases of a design process could be distributed differently, with less time spent on activities relating to initial user research and more time on activities relating to collaboration with the users during the whole design process. One participant expressed: 'If we are involved all along, the designers do not need to spend so much time in the beginning, doing "user research" about us that have impairments... just because they are not familiar with people like us'. Another participant expressed: 'I prefer if they talk with me rather than read about me'.

A very practical premise is to be given enough time to prepare the participation beforehand and for organisations to find representatives. A representative for a disability rights organisation expressed: 'We are not magicians that can draw participants out of a hat on short notice'.

The plan for the design process should contain work packages with the prerequisite that people with disabilities will take part. This might impact the length of each work package, the number of tasks in each package, the length of each activity and the time between activities.

It was considered important for people with impairments and their representative organisations to have time to reflect in between activities. One participant expressed it like this: '*They want me to answer straight away on issues that they have discussed for months! I need time to think and reflect... to form my opinion*'. Participants stated that there must be time for reflection and sometimes time for external conversations with peers outside the design process and to return to issues in iterative loops.

The participants considered it important to have recurring and easy ways to evaluate the quality of user participation. Retrospective reflections are often part of an agile process and could be useful for this purpose. Other evaluating activities discussed were short questionnaires.

Even the best of plans can hardly predict everything, it is important to have flexibility and readiness to adapt the design process and practicalities in response to feedback from participants. From previous experiences of participation in design processes, the participants provided the following feedback on accessibility issues to project management: the room used for a design workshop had no microphones or loudspeakers, the materials used were not accessible to all, the speed of presentation was too fast, etc. The representatives for disability rights organisations expressed that it is important to aggregate information about experiences from several individuals participating in design processes to get an overview of how well the processes worked. The participants suggested that disability rights organisations could create a survey to collect aggregated experiences of user participation at a broader level.

The growing demands for user participation in design processes need to be framed in a way that enables all users to be represented. It is unrealistic to expect that project managers of a design project have the knowledge and experience to organise this work without guidance. Hence, there is a need for a framework that takes all users into account. An early attempt to establish such a framework was the EU-funded FORTUNE-project (Bühler 2001). Our suggested framework draws on this earlier work and presents a contemporary proposal for user participation. It is intended to be used to reach an agreement on the general terms upon which the collaboration should be based. This framework then needs to be complemented with more detailed planning on how collaboration in a specific case should be carried out. As outlined in the introduction, there is a lot of guidance and cases available for how to manage the more practical aspects of collaboration.

The findings presented in this study are in agreement with Jacobs and Hultgren (2018), who argue that design sensitive to values, such as value sensitive design, must align with a particular ethical theory to distinguish genuine moral values from mere stakeholder preferences. In this context, we propose that the CRPD can be used as a specific ethical framework for the overall direction of a co-design process. We also suggest that universal design can be used as the ethical stance in design processes.

THE DEVIL OF INACCESSIBILITY IS IN THE DETAILS

It was a common experience among the participating representative organisations that user participation in design processes often fails or people with impairments are frustrated over collaboration being hampered. The reason behind disabling collaboration is often the activities within the design process are partly inaccessible. Johansson describes the development of accessible co-design activities as ‘scaffolding’ (Johansson 2019). Effective scaffolding needs detailed attention to the prerequisites for participation. Only then people with impairments can take part as equals in the practical work undertaken in a design process.

Universal design means that collaborative design activities should be framed by keeping accessibility and diversity in mind for all citizens in the society (Steinfeld & Maisel 2012). People possess differences, but these differences can be surmounted with a focus on details.

POWER OR IMPACT?

An influential model for citizen participation, introduced by Arnstein, is the citizen participation ladder (Arnstein 1969). At the bottom of this ladder, there is no interest from power holders to give the participants any influence. In the middle, there are some consultations, and participants are being listened to, but they have no power to ensure what they say will lead to any change. Only the top three steps in Arnstein’s ladder give the participant actual power: partnership, delegated power and citizen control. Arnstein’s hierarchical model has been criticised because citizen control is not always the most sought-after form of participation. The quality of user participation can have other measures than power. In design, sharing knowledge, lived experience and perspectives, does not necessarily need to be explained by power relations. Davis and Andrew (2017) propose critical pragmatism as an approach focusing on outcomes and processes rather than power relations. We agree on this, and the framework presented in this paper aims for impact rather than control. This aligns with Tritter and McCullum, who argue that user involvement is about the impact and real change, both on an organisational as well as a practical level, and the users will not remain engaged in the process if they cannot see those changes (Tritter & McCullum 2006). In their model, users become co-producers in a system of involvement, allowing for both individuals and their representative organisations to take part in a production process. According to Tritter and McCullum, it is possible to create a ‘user involvement system’ by inviting interested individuals and groups as a self-determined engagement, where participants bring their personal experience and organisations can contribute with a more holistic perspective. This approach, when applied in a healthcare setting, has been framed as patient and public involvement (O’Shea, Boaz & Chambers 2019).

Even if there are some differences in approaches, participation is central in all collaborations where users are involved, and the origin behind many models can be found in the tradition of participatory design. Participatory design has a long tradition of democratizing the design

process, aiming for users to have a strong influence on what should be designed and how it should be designed. Participatory design has been an inspirational concept for many later participatory approaches. In commercial settings, the collaborative approaches have been framed as user-centred design. Participatory design and user-centred design often share the same practical methods as well as processes for co-design. Our framework combines the democratic and emancipative perspectives from participatory design with the ambition in user-centred design of designing effective and usable solutions for the market.

EQUAL OPPORTUNITIES TO TAKE PART

One study observed that there is a hierarchy of power when professionals and lay persons are supposed to collaborate, where professionals are at the top and lay persons are at the bottom, establishing a relationship between knowledge and power (O'Shea, Boaz & Chambers 2019). Professionals often question the legitimacy of public knowledge. They also found that lay persons often have been restricted from resources which professionals could access.

An important role of a framework for user participation is to ensure equal opportunities in taking part in the design process. In our framework, we see the dual participation from both individuals and their representative organisations as a means to handle those issues. Single individuals or small numbers of individuals are at risk of being co-opted or being subjected to what Arnstein describes as tokenism – a symbolic representation with no real intention to influence. It is important to acknowledge that equal opportunities for some participants mean that they need to be supported by carers or family members to be able to take part. Participants might also need easy-to-read material or augmentative alternative communication.

The participation of organisation representatives in the design process can create a balance and overview which cannot be expected from a single person. Engaging different actors on an equal footing might also mitigate 'adaptism', that is, the tendency to base design processes on an imagined typical user of the end product, and handling people with impairment as separate cases, in need of adapted design or as being out of the scope (Hedvall et al. 2022).

We have noticed that some designers argue against user participants being paid for their work when taking part in a design project. They argue that payment produces a risk of undue influence and user bias or that users might be coerced to be more positive if paid. We argue that this is an obsolete standpoint, an echo of views on participation where users/people with impairments are regarded as test objects under study. In contrast, our standpoint is that user participants are subjects engaged in a partnership to contribute with expertise in user experience, to deliver well-designed artefacts. This aligns with other findings on the matter (Singer & Couper 2008). When seen as a subject and collaborating partner, there is nothing undue with payments. If other people involved in the design process get paid for their work, the same should be applicable for the user participants too.

COLLABORATION – BRIDGING A DUAL WEAKNESS

Bühler noticed a dual weakness in the enterprises, while developing technology, often have weak contacts with end users with disabilities and their representative organisations and lack the knowledge of what technology can do (Bühler 2001). He also stated that users and their representative organisations are not trained well enough to participate in development processes. Consistent with Bühler's earlier work, we have found that it is important for project management to come to an agreement with users and representative organisations on the premises for user participation; for example, how the work should be organised, what kind of tasks should be performed and terms for payment. We have found that the allocated time in a project plan is often not sufficiently adjusted to enable user participation of people with impairments and their representative organisations. The result is that the project either skips the user participation entirely or squeezes in some low-quality participation just to tick the box, saying that user participation is mandated. The fact that some project managers do not fully understand why representative organisations should play a role in the design process, beyond recruiting users, indicates a need for further attention to the accumulated experiences that such organisations can bring into the design process.

Parts of the dual weakness can be bridged over by more educated representatives from the disability rights organisations. One representative from a disability rights organisation expressed that to make a high-quality contribution, there is a need for training and education on how to contribute to the design process even better.

QUALITY IN THE DESIGN AND EMPOWERMENT

There are strong arguments for collaboration with users with disabilities and their representative organisations in design processes. The quality of the end result is supposed to be better if users are involved (Steen, Manschot & Koning 2011), especially users with diverse needs (Himmelsbach et al. 2019). It is fair that people who will use the end result not only can benefit from, but also influence on, what is being designed and how it is designed (Andersen et al. 2015). Empowerment is a goal in its own right (Barnes 2004) and an important step to avoiding oppression and disablement of people (Abberley 1987). Empowerment and emancipation are parts of the process of liberating oppressed people and populations. People with impairments can be described as being oppressed and disabled by an inaccessible society (Abberley 1987), and the society is being shaped in and through design processes. Those design processes could either result in a fit or a misfit as fit could be described as 'a generally positive way of being and positioning based on an absence of conflict and a state of correct synchronization with one's circumstances' (Garland-Thomson 2011). Thus, by providing a framework for participation in design processes, we also suggest that there are ways to move beyond the current established design practices that keep reiterating harmful, oppressive and disabling norms.

REPRESENTATIVENESS – MOVING BEYOND STRAW MAN LOGIC

CRPD clearly states that disability rights organisations should be represented and actively involved in the shaping of the society. This is a matter of justice. But there are as well practical and pragmatic reasons why they should take an active part. The organisations have accumulated and integrated knowledge and a holistic perspective which cannot be expected from a single individual. The organisations might also have useful ongoing cooperation with researchers and skilled experts in the field that can provide important input to a specific design process. Working only with a small group of individuals could potentially lead the designers to propose design solutions that are biased or too narrow, for example, solving problems for a few individuals rather than for a population with experience of diverse impairments and diagnoses. Here, the representative organisations can bring a wider picture and knowledge and experiences accumulated over a long period of time.

Beresford and Campbell (1994) discuss that power holders often raise arguments about representativeness and question whether a specific person is the best one to represent people with impairments. They mean that people in charge of a design project express concern about getting an incomplete or biased picture from individuals with impairments or other marginalised groups. At the same time, people with disabilities report being devalued, undermined and excluded by having their involvement regularly challenged on the grounds of being unrepresentative. They also note that design project management often struggles with the concept of 'typical users' and fails to acknowledge the broad diversity in the general user; that insight from one single atypical user can be very important. Our experience is that such mistrust between stakeholders in a design process can be bridged by a partnership approach and collaboration built on a long-term relationship. This includes the need for people with disabilities and their representative organisations to also be allowed to sometimes work on their own to penetrate a problem or discuss alternatives and then bring the result into the current project. There are many examples of successful collaboration, and there is a growing body of publications presenting particular cases where non-verbal participants collaborated to design a prototype (Wilson et al. 2020) or ICT application for people with intellectual disabilities (Bourke et al. 2018).

When proposing a framework for inclusive autism research, Chown et al. (2017) argued that it is important that autistic people either define or validate the problem that needs to be researched and that project ethos should be guided by the social model of disability (Barnes 2019). The same argument could be used for design processes and the inclusion of people with any kind of impairments, highlighting the importance of early collaboration with all stakeholders. This collaboration can also prevent straw man fallacies (Talissee & Aikin 2006),

for example, the presentation of selective arguments claiming that people with different impairments have conflicting needs that cannot be solved and preconceptions about how people with impairments think or behave.

TRANSFERABILITY OF THE FRAMEWORK

The presented framework for user participation targets design processes, but the framework could potentially be applied to user participation in any research and development process. The need for specific accessibility measures might shift depending on the people participating in the process, but the framework's guiding principles for accessible, collaborative processes are applicable to all users.

CONCLUSION

This paper presents a framework for user participation in design processes consisting of three themes: participation fundamentals, participation ethics and participation practicalities, entailing 11 guiding principles. By applying this framework, participation will become more transparent, equitable and easier to implement in specific design projects. A thoughtful application of this framework will benefit any design process. It will allow all types of users, with or without impairments, to participate and contribute to the design of products and services that can be used by the widest range of users.

We argue that every enterprise or organisation doing design should acknowledge the importance of user participation and co-design. Then, each specific design project should identify how such user participation could be carried out in the specific case. A beforehand negotiated agreement on the terms and conditions for the project at hand will cater for a successful collaboration with all stakeholders. Potential barriers to user participation can be handled in advance, making it possible to focus on factors that enable high-quality end results.

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COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

CG and SJ set up the study design. SJ, CG and TL had the principal responsibility for data collection. All authors have contributed substantially to data analyses, interpretation of data and results. SJ had the principal responsibility for drafting the manuscript and all other authors (CG, POH, ML and TL) contributed to the drafting of the text. All authors have read and approved the final manuscript and are accountable for all aspects of the work.

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