

2022

Towards an inclusive co-design toolkit: perceptions and experiences of co-design stakeholders

Eamon Aswad

St John of God Community Services, eamon.aswad@sjog.ie

Emma Murphy

Technological University Dublin, emma.x.murphy@tudublin.ie

Claudia Fernandez-Rivera

Technological University Dublin, Claudia.Rivera@TUDublin.ie

See next page for additional authors

Follow this and additional works at: <https://arrow.tudublin.ie/scschcomart>



Part of the [Computer Sciences Commons](#)

Recommended Citation

Eamon Aswad, *Emma Murphy, Claudia Fernandez-Rivera, and Sarah Boland. 2022. Towards an Inclusive Co-design Toolkit: Perceptions and Experiences of Co-design Stakeholders. In *Computers Helping People with Special Needs: 18th International Conference, ICCHP-AAATE 2022, Lecco, Italy, July 11–15, 2022, Proceedings, Part II*. Springer-Verlag, Berlin, Heidelberg, 284–292. DOI: 10.1007/978-3-031-08645-8_33

This Conference Paper is brought to you for free and open access by the School of Computer Sciences at ARROW@TU Dublin. It has been accepted for inclusion in Articles by an authorized administrator of ARROW@TU Dublin. For more information, please contact arrow.admin@tudublin.ie, aisling.coyne@tudublin.ie, gerard.connolly@tudublin.ie, vera.kilshaw@tudublin.ie.



This work is licensed under a [Creative Commons Attribution-NonCommercial-Share Alike 4.0 International License](#).
Funder: Irish Research Council

Authors

Eamon Aswad, Emma Murphy, Claudia Fernandez-Rivera, and Sarah Boland

Towards an inclusive co-design toolkit: perceptions and experiences of co-design stakeholders

Eamon Aswad^{1&2}[0000-0001-7692-7820], Emma Murphy²[0000-0001-6738-3067], Claudia Fernandez-Rivera²[0000-0003-4226-9262], and Sarah Boland¹[0000-0002-9857-6977]

¹ Saint John of God Liffey Services, Ireland

² School of Computer Science, Technological University Dublin, Dublin 7, Ireland
{*eamon.aswad, sarah.boland*}@sjog.ie {*emma.x.murphy, claudia.rivera*}@tudublin.ie,

Abstract. Participatory design holds great potential for the creation of inclusive technology but existing toolkits and resources to support co-design are not always accessible to designers and co-designers with disabilities. In this paper we present two studies to assist in facilitating the creation of a sustainable, accessible, inclusive co-design toolkit for individuals with intellectual disabilities i) exploration of the perceptions and experiences of lecturers (n=5) and students (n=5) involved in co-design activities via individual interviews and ii) a protocol and initial findings from focus groups with men and women with intellectual disabilities to inform on best co-design practices (n=15). Positive reflections were reported on the co-design experience by all participants. Communication was highlighted as a theme that requires further attention and specific support during co-design processes with third level designers and co-designers with intellectual disabilities.

Keywords: Co-design, Inclusive Design, People with intellectual disabilities.

1 Introduction

The current project is based on an exploration of a “Co-Design Programme” which has been a collaboration project between two organizations in Dublin, Ireland: Technological University Dublin (TU Dublin) and St. John of God (SJOG) Liffey Services. Co-design refers to “collective creativity as it is applied across the whole span of a design process” [1], and it is an approach used in a variety of domains [2,3] to provide beneficial outcomes for all parties involved. TU Dublin and SJOG have run an innovative co-design programme since 2016, where third year computer science students collaboratively design with SJOG service users to create accessible digital applications. These service users, further referred to in this paper as “co-designers”, are men and women with intellectual disabilities, who have been involved in co-design activities with TU Dublin during their attendance at SJOG Liffey day centre services. The procedure of which has been published elsewhere [4]. This collaboration has generated a rich source of tacit knowledge on specific design tasks, methods and approaches that has potential benefits for both students and co-designers. The aim of this present study is to record and integrate the knowledge of stakeholders involved in a co-design programme to

inform the generation of a sustainable co-design toolkit resource. The resulting toolkit is intended to strengthen engagement and better facilitate the co-design process and open other opportunities to engage in co-design for adults with intellectual disabilities. This project will also provide a practical solution to overcome some barriers to inclusive co-design for designers with disabilities.

2 Co-Design: Benefits and Challenges

Understanding how a toolkit may assist the co-design process, requires an apprehension of codesign methodological advantages and disadvantages. Turner, Merle and Dichon [5] provide a review of co-design literature and suggest that assessment and value of co-design lies within four domains for the consumer or “co-designer”: enjoyment, perceived control, pride of ownership and complexity. Leveraging these domains is suggested to enhance, not only the co-design process, but the resulting outcomes, such as toolkits. However, some common challenges in evaluating experience-based co-design are; power dynamics, methods for gathering experiences, design of improvements and ensuing implementation and impact [6]. Power dynamics are primarily cited in healthcare research, where status and identity come into play[7], this is less likely to occur when the process is centred around the co-designers, *for* the co-designers. Furthermore, specific processes can be implemented to increase this equity and engagement in co-designing with individuals with disabilities, such as a co-development opportunity, digital prototypes, non-finito features and inclusion of a proxy [8]. Focus groups have been used as a methodology for reporting and validating the experience of co-designers with disabilities [9]. The production of a tangible, practical co-designed toolkit that places the co-designers’ opinions at the heart of the design, ensures subsequent follow up and impact. We aspire to address these complexities in experience-based co-design by assessing the collaborative process directly, engaging with stakeholders around their opinions of benefits, challenges and possible improvements. Thereby contributing to the literature on an archetype of “successful” co-designing, via the production of a comprehensive toolkit. This encompasses investigating an authentic collaborative approach that encourages equality and inclusivity.

Men and women with intellectual disabilities do not frequently take part in research [10]. Despite positive attitudes towards participation in research [11] and the necessity for greater representation. One barrier to recruiting individuals with intellectual disabilities is the complexity of the consent process. The requirement to protect vulnerable populations is evident, particularly in decision making, however, this may be at the cost of exclusion. Various modes of communication may be required so as inclusion and consent do not threaten exclusion of those unable to give an “autonomous or ideal consent” [12]. Therefore, we highlight the importance of an accessible protocol to engage individuals with intellectual disabilities to focus groups, and the proposed protocol focuses on co-designing accessible technologies.

This paper focuses on i) individual interviews with lecturers and students in TU Dublin who were involved in the co-design programme and ii) a protocol and initial

findings from focus groups with the men and women who have been involved in the co-design collaboration with SJOG Services and TU Dublin. The data gathered will assist in developing an accessible co-design toolkit with SJOG services users with intellectual disabilities. We aspire to give a voice to a demographic of people, who historically, we're not invited to participate in software design and to leverage their lived experience, to support more universally designed technology.

3 Student and lecturers perceptions and experiences of co-design

Data was gathered qualitatively for this study via individual semi-structured interviews with lecturers and students in TU Dublin who were previously/currently involved in a Co-Design Project with SJOG co-designers. These co-design activities involved meeting together once per week over a semester-long module. While there was no formal co-design toolkit used, students and co-designers were introduced to design thinking tools such as Empathy maps [13] and "*I like, I wish, What if?*" [14] techniques to aid collaboration. These tools were modified to make them more visual, with icons and photos included to enhance accessibility for the co-designers.

3.1 Participants

The lecturers (n= 5) and students (n =5) in the research were self-recruited after an invitation to participate was circulated via email by the principal investigator. All the lecturers had previously either been supervisors, module leaders or lecturers of the co-design programme based in TU Dublin. They had extensive experience with universal design and inclusive ICT. All the students were computer science undergraduate students, who had taken part in the co-design project during their third year in their undergraduate degree in TU Dublin (in 2020-2022). All the students had taken part in the online co-design programme due to COVID-19 but the lecturers had been involved in both online and previous in-person co-design activities. Three researchers individually interviewed each of the ten participants, with interviews ranging between 15-55 minutes.

3.2 Methods

A semi-structured interview script was created with open ended questions to elicit participants' perceptions and experiences of the co-design projects on the following themes: i) what worked well ii) what were the challenges iii) how the process could be improved. At the end of the individual interviews with the lecturers and students, they were invited to take part in an interactive focus group session with the SJOG co-designers. All participants agreed to be contacted to be involved in subsequent focus group sessions.

The interview data was analysed by the research team using the practical steps for thematic analysis as outlined by Clarke and Braun [15]. NVivo version 12 software was

used to facilitate the coding and sorting process. Themes were highlighted via patterns emerging from the data set within each category. All themes were identified on a semantic level and were verified across both groups. Analysis was completed by two of the researchers, the third researcher facilitated any disagreements amongst the process of data analyses.

3.3 Results

The information provided by the lecturers and students assisted in the iteration process of the co-design focus groups. The primary aim was to evaluate the following themes: i) what worked well ii) what were the challenges and iii) how could the process be improved. Given the structure of the interviews, specific data directly related to the designer and co-designer's benefits (skills, novelty, perspective taking, empathy, inclusion) challenges (expectation management, conceptual difficulty, technical jargon), and impact (personal, professional, field) were identified. Further themes were also discovered, most notably, the themes of Communication, Accessibility and Collaboration.

Co-Design Benefits Both students and lecturers were forthcoming in describing the proposed benefits of their involvement in the co-design programme for both parties; the co-designers and the designers. Whilst a grade was the intention of the module for the students, this was not the only positive attained outcome as described in detail by Lecturer 3 *"Definitely it improved the potential of getting a job, 100% at a gruesome metric, that it was a real success in that way, improved their communication skills, their presentation skills, their interaction skills, and not least for their communications."* The students reflected on the value of their learning within the module of; accessible design thinking, perspective taking, empathising, understanding the lived experience of others and interacting with a novel population *"it's the first time we're ever actually building something for someone and it was quite gratifying to see every Friday that the co-design team were happy to see us and to see that we were, implementing their ideas and we're actually listening to them, taking things on board."* – Student 3. Furthermore, all participants reported a reciprocal relationship of fun, enjoyment, and friendship *"I'd like to think they really enjoyed it, because I really enjoyed it as well. You know, it really did seem like they enjoyed seeing us every Friday."* -Student 4.

Co-Design Challenges From the lecturers viewpoint, the challenges students faced the most revolved around being co-designers, leaving their technological comfort zone and "technical jargon" to engage in communication with a novel diverse population that requires a significant amount of *"soft skills"* and handling the honest criticism and redesigning that may be associated with it. All whilst balancing the group dynamics of the team project. *"So, for them was really to develop this empathy and the ability to understand what users were trying to say and analyse those data because they were, you know, students trained to make things. You know to create these circuits devices. So, for them I think was really a great opportunity to learn how to deal with people rather, than how to deal with technology."* – Lecturer 2. The students also endorsed the demands of the group dynamics and limiting the use of technological jargon.

Communication was considered a central component by all participants, particularly within facilitating or hindering the co-design process, on both sides. *“Definitely with the communication. Sometimes at the start it was challenging. Definitely to encourage the co-designers to talk, but then to wait, say wait for three seconds after they finished speaking, to make sure, there's nothing else to say.”* – Lecturer 2. All students completed the co-design programme remotely. This was suggested to be less interactive for both students and co-designers and a preference was stated for face-to-face by all students. This was hypothesised to enhance the co-designing by process by providing more information for the students and being more tangible for the co-designers (prototyping, attention, senses).

Co-Design Tools In response to these challenges the students solicited their developed strategies to compensate, such as games *“I really think for this process the aspect of games really opened people up”*, online whiteboards, or prototyping tools *“for the bridge between us and the service users, we ended up using a website called Figma”*. However, in terms of co-design information sharing and communication, it was the tools developed at SJOG that were reported as most effective by the students.

All students remembered using some form of the tools *“we did use the “What IF” quite a lot because that was how we kept track of their needs and what they wanted to see. Because some of their requests just weren't feasible in the time that we had and that's something that we had to explain to them as well. But the “What IF” was very helpful because if we would send something on a Monday. They would update the “What if” during the week and then we'd have that information before coming into the meeting. So that was that was very helpful.”* - Student 1. They also provided insight into how those tools were helpful. *“Yeah, absolutely because it just outlined in a very clear way, what they wanted to see from the app. Because verbal communication for them could have been tough at times. It outlined their thoughts and feelings and then we can react to that”*. – Student 2. *“So, they [the design thinking tools] effectively help shape their ideas and feedback. So like whatever they said like that was technically possible, like as far as our skills were like, we could do that and put it in for them.”* – Student 3.

Accessibility and Collaboration Accessibility and collaboration were two recurrent themes throughout the lecturer and student interviews. Accessibility was associated with a change in thinking about design for the students, how it impacts others, and the limitations others may possess. Students reinforced ideas of familiarity, functionality, universal and accessible design, ease of use and were determined to include these concepts in their own future designs, with some citing their final year project's revolving around accessibly designed projects. *“Nowadays it's not just good enough to make it work for you, you have to make it work for others as well”* – Student 5.

Accessibility of the interfaces being co-designed for the end user co-designers was a priority for all stakeholders and as highlighted above students appreciated that the design thinking tools were accessible to the SJOG co-designers. Interestingly, according to Lecturer 5, some computer science students struggled to understand some of the highly visual design thinking tools such as empathy maps as they require a different approach to processing and understanding information. *“In my experience some students find this type of visual information very easy...others would be more like a*

“computer science”...type of person” – Lecturer 5. This is an important observation and highlights the need to acknowledge diverse capabilities and learning styles from both the perspective of students and co-designers in the creation and choice of accessible tools and supports.

The idea that the co-design project was a collaborative process was vehemently expressed by the students and lecturers, including items such as design collaboration, co-designer’s needs, equality, listening and feedback, building rapport, information imparting, idea sharing and feelings. For the students, they suggested if they focused on understanding the needs and wants of the co-designers, their technical skills could fill the gap – *we really tried to focus on their input in our meetings, so we made it a very big part of our project to focus on what they wanted”* - Student 3. Although, it was understanding these needs and wants where the co-design tools were suggested to be necessary.

4 Iterative focus groups with co-designers with intellectual disabilities

In total, five one-hour focus groups will be organised; one for every phase of design thinking (Empathise, Design, Ideate, Prototype, Test) as proposed in Hasso Plattner Institute of Design [16]. All the focus group sessions will have the same format, with some slight variations taking place between the sessions in terms of design process content. The first and last session place a higher emphasis on introductions and reflection, respectively.

4.1 Participants

Participants for the first two focus groups (n= 15) were recruited from St. John of God Liffey Services, and (n=5) students and lecturers who previously participated in co-design activities. Participants self-recruited, through a gatekeeper, after reading the modified (highly visual), easy to read (included images, colour formatted) information leaflet and consent form that the gatekeeper will send to them.

4.2 Methods

During each focus group participants work together on a design challenge using some co-design tools to brainstorm ideas or to sketch a graphical user interface or give feedback on an existing design. The purpose of the focus group format is to recreate the context of the co-design process that the participants have already been involved in, this is to reduce the (possible negative) effect of introducing a new context to the participants. These series of focus group sessions mirror the codesign process. The intention of holding the focus group sessions within the same context of the codesign process, is twofold; to help minimise any discomfort to the participants as the context will be familiar and to allow participants to naturally provide and describe information about their experience while going through the same process.

The intended format of a single focus group session is welcome and introductions, ice breaker/ warm up design task, content section, team discussions and reflections. At the end of the focus group session, participants will be asked some questions for feedback. Some sample questions are: “How did you find this co-design session?”, “How did you find communicating with the students in this co-design session?”, “What could have made this co-design session better for you?”.

4.3 Initial Findings from focus groups with men and women

At the time of writing this paper, two focus group sessions of the design phases have taken place and we would like provide some observations to better assist others within in this space. Preliminary focus group findings from the co-designers themselves, reinforced some of the previous theme outlined in study 1, most notably; “It makes me feel important”, “we want our own designs”, “Teamwork”, “helping”, “fun”, “new people”, “friends”. Similar to the student’s experience – it is quite difficult for the co-designers to name or label what they don’t like, perhaps not wanting to be wrong or to offend someone. Focus group co-designer participants preferred more visualisations or tools to assist in this form of comprehension. A commonly occurring issue in within research is biasing individuals or influencing their answers whether knowingly or not, this can be even more pronounced in more vulnerable populations. In order to make sure that support staff or facilitators do not bias the co-designers, great care and attention needs to be paid to language, prompts and turn-taking in the sessions.

5 Discussion

While the primary outcome of the co-design project was a co-designed app that was developed, it is evident that more benefits were attained and challenges/barriers are present – for both the co-designers and designers, albeit, in different forms. The fundamental similarities underpinning this programme as cited by the students and lecturers was the challenge of communication, for SJOG co-designers to advocate for themselves and most importantly, what they don’t like (response bias), while the students were challenged to speak colloquially removing their technological jargon, enjoyment and engagement in a novel experience, with novel individuals and the resulting outcomes of learning, inclusion and a physical project to represent the collaborative work.

The themes revealed, are quite similar to the benefits proposed by Turner, Merle and Dichon [5] for the co-designers, particularly in terms of “enjoyment” and “sense of ownership”. Of the barriers described by Colin Gibson et al., [17], we subscribe that “overly complex concepts” is an evident challenge to those with intellectual disabilities within co-design and that it is essential that tools are developed to reduce these challenges, for example by providing a template to break down difficult concepts. This particular barrier was also reported by the students and lecturers in terms of “abstracting”.

6 Limitations

It is acknowledged that the students who agreed to provide information on their experience in the co-design project, may have been more likely to be the students who had a positive experience.

7 Conclusion

In qualitative interviews student and lecturer participants who engaged in the co-design process reported their experience of the benefits and challenges of this interactive process, within the computer science domain. Communication was highlighted as a central theme within this process, particularly in supporting and engaging individuals with intellectual disabilities in co-design via tools made for co-design. Actively involving individuals with disabilities in co-design research is essential but can be an elaborate process that may place an impetus on researchers. We have provided a detailed description of a co-design focus group protocol and research consent procedure, potentially providing valuable insight for other researchers, particularly around involving individuals with intellectual disabilities in informed research practices of co-design. These exploratory studies are an important part of facilitating the creation of a sustainable, accessible, inclusive co-design toolkit.

Acknowledgments

This research is supported by the Irish Research Council (www.research.ie). We would also like to thank all participants for their time, enthusiasm and valuable input.

References

1. Sanders, E. B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, 4(1), 5–18. doi:10.1080/15710880701875068
2. Bolger, P., Brereton, P., Grant, O., & Torney, D. (2021). Better together: knowledge co-production for a sustainable society. In *Better together: knowledge co-production for a sustainable society*. White Paper (pp. 1-104). Royal Irish Academy.
3. Boyd, H., McKernon, S., Mullin, B., & Old, A. (2012). Improving healthcare through the use of co-design. *NZ Med J*, 125(1357), 76-87.
4. Boland, S., Mooney, E., Gilligan, J., Bourke, P., & Bourke, D. (2018). A Co-Design Partnership to Develop Universally Designed ICT Applications for People with Intellectual Disability.
5. Turner, F., Merle, A., & Diochon, P. F. (2011, December). How to assess and increase the value of a co-design experience: a synthesis of the extant literature. In *Mass Customization, Personalization, and Co-Creation: Bridging Mass Customization and Open Innovation*.
6. Dimopoulos-Bick, T., Dawda, P., Maher, L., Verma, R., & Palmer, V. (2018). Experience-Based Co-Design: Tackling common challenges. *The Journal of Health Design*, 3(1), 86–93. doi:10.21853/jhd.2018.46

7. Donetto, S., Pierri, P., Tsianakas, V., & Robert, G. (2015). Experience-based Co-design and Healthcare Improvement: Realizing Participatory Design in the Public Sector. *The Design Journal*, 18(2), 227–248. doi:10.2752/175630615x14212498964312
8. Sitbon, L., & Farhin, S. (2017). Co-designing interactive applications with adults with intellectual disability. *Proceedings of the 29th Australian Conference on Computer-Human Interaction*. doi:10.1145/3152771.3156163
9. Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, 29(7), 1013–1030. doi:10.1080/09687599.2014.902357
10. Cook, T., & Inglis, P. (2012). Participatory research with men with learning disability: informed consent. *Tizard Learning Disability Review*, 17(2), 92–101. doi:10.1108/13595471211218875
11. Conroy, N. E., McDonald, K. E., & Olick, R. S. (2021). A survey study of the attitudes and experiences of adults with intellectual disability regarding participation in research. *Journal of Intellectual Disability Research*, 65(10), 941–948. doi:10.1111/jir.12877
12. Doody, O. (2018). Ethical challenges in intellectual disability research. *Mathews Journal of Nursing and Health Care*, 1(1), 1-11.
13. d.school (n.d.) Empathy Map. Available: <http://dschool-old.stanford.edu/wp-content/themes/dschool/method-cards/empathy-map.pdf>
14. d.school (n.d.) I Like, I wish, What if. Available: <http://dschool-old.stanford.edu/wp-content/themes/dschool/method-cards/i-like-i-wish-what-if.pdf>
15. Clarke, V., & Braun, V. (2014). Thematic Analysis. *Encyclopedia of Critical Psychology*, 1947–1952. doi:10.1007/978-1-4614-5583-7_311
16. Hasso Plattner Institute of Design (2010) An Introduction to Design Thinking: PROCESS GUIDE. Available: <https://web.stanford.edu/~mshanks/MichaelShanks/files/509554.pdf>
17. Colin Gibson, R., D. Dunlop, M., & Bouamrane, M.-M. (2020). Lessons from Expert Focus Groups on how to Better Support Adults with Mild Intellectual Disabilities to Engage in Co-Design. *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*. doi:10.1145/3373625.3417008