

Facilitating inclusion in co-design through online communication

Our experience and recommendations

This document was drawn up following a participatory study to develop evidence-based recommendations in the field of technology for autism. This study included participants from the autistic and autism communities (parents, professionals, researchers).

1. Community spirit

The participants needed to feel part of a group working towards a common goal. This sense of belonging can be tricky to establish on an online platform and we were wary of making the study feel like an impersonal series of questionnaires. To avoid that, we adopted the following methods:

a) Role elucidation

We explained the role of each subgroup in different parts of the study. For instance, in our third round, where researchers were invited to join in, we explained how we needed their expertise and scientific judgement in order to guarantee the quality of the guidelines emerging from the rest of the panel. We were inviting them as equal participants, though, and not as research partners, for example.

b) Investigator-participants communication

We established direct email communication between the participants and the investigator. We wanted the participants to feel the project management team was easy to reach and interact with. We replied to the emails (varying from tech questions to complaints) as promptly as possible and required as much information as possible to ensure the suitability of our answers.

c) Simultaneity

Each of the four rounds had a precise start point and deadline and participants could not join at random time points. Beyond the practical reason of better organising the investigator's workload, that choice aimed at reinforcing the feeling of interdependence among participants. Contrary to an online survey, where data are collected for a relatively long period of time and analysed in the very end, we emphasised the fact that participants' responses defined the design of the next round, the rest of the panel's responses and ultimately the route the study would take. That is why it was essential for everyone to adhere to the deadlines.

2. Consensus

As a diverse group, people often expressed different or even contradictory opinions. We opted for a voting system. After grouping similar statements to a summary statement, we presented them to the panel and asked them to rank them in order of importance. The outliers were also taken into consideration by adding comments and words of caution to the final set of statements.

3. Anonymity

Based on the *Delphi* methodology, anonymity was of paramount importance for our study. In contrast to methodologies with similar goals like focus groups, an anonymous online study allows all voices to be heard without stronger personalities or well-known people dominating the discourse. For example, when we used quotes from a previous round, we anonymised them and asked all participants to compare their personal experience to those reflected in

the quotes.

4. Accessible information

A detailed information sheet was given to all participants prior to their consent to participate. Complementary information about the study was also available on the project's website which participants could optionally consult. In case participants needed clarifications, the investigator remained at their disposal throughout the study.

5. Equal weight

For the quantitative part of our analysis, the panel was treated as a homogenous group without differentiating the source of each rating. The statements were then presented to the panel in the order of their mean ranking.

6. User interface

To host and facilitate our participants' online communication, we used a bespoke experience management platform. In case of software limitations e.g. some features not displaying properly on mobile devices, we warned participants about those in each round of our study to ensure ease of access.

7. Language

Given the diversity of our participants' panel, several language-related considerations had to be taken into account while designing our study:

- a) We worked with participants from different countries to ensure the study was as inclusive as possible. As a result, the language of the study was English. We reassured potential participants that we were forming an international panel whose first language was not necessarily English and although fluency was required, a few difficulties in language production should not deter them from participation.
- b) Our study was conducted in English and for that reason we had to make a choice between identity-first ("autistic person") and person-first language ("person with autism") when talking about autism. The questions were written in identity-first language, but we invited participants to describe themselves or the people they care/work for in the words deemed most suitable to them always in a respectful manner.
- c) Given the fact that part of our panel had an autism diagnosis, we tried to avoid figurative language whenever possible to help them concentrate on the message rather than the means of conveying it.

8. Precision and predictability

As predictability helps create a more stable and engaging environment for autistic people, we established a very precise schedule for the 3 months of our study to which all participants had to adhere. Additionally, every round of the online study contained information specific to it reminding participants of the previous activities, presenting them a summary of the results and preparing them for the upcoming activities.

9. Translate participant ideas in design possibilities

The study was co-ordinated by a moderator at all stages, who analysed participant input and designed the subsequent rounds according to that. In parallel with the quantitative analysis, we followed a qualitative method, namely thematic analysis to cluster similar ideas into overarching themes, so as to avoid repetition and provide the panel with well-organised material.

10. Eligible participants

Expertise in the field of technology for autism was the main requirement for participation in our study. For the researchers subgroup the expertise was easy to determine. For the

community part of the panel, we relied upon our team's networks and for those participants that volunteered to participate, we conducted a simple screening to determine their relationship with digital technology and autism.

11. Handling complaints

Complaints are almost unavoidable when co-operating with a group with diverse ages, backgrounds and priorities. We reminded them the rules of the study they had consent to as well as their right to withdraw at any time and provided tech tips whenever possible.

12. Maintain participant engagement

We knew from the start that participation to our study was a long commitment and a resource-intensive task.

a) Financial compensation

We felt it was appropriate to financially compensate the participants and opted for a gift voucher for a popular e-commerce platform.

b) Personal emails

As mentioned above, the researcher was in direct communication with the participants who were addressed with their names and were invited to bring forward any questions or concerns they might had.

c) Reminders

We were aware that our participants were often busy professionals and/or parents that had plenty other priorities in their lives. We therefore sent them reminders twice, as the deadline of each round was approaching. In case of unforeseen circumstances, we gave a couple of days' extension to some participants, as we wanted to keep as many as possible on board.