# Involving People Affected by a Rare Condition in Shaping Future Genomic Research

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# Abstract

Background There is evidence that involving potential participants and the public in co-designing research can improve the quality of the study design, recruitment and acceptability of the research, but appropriate methodologies for doing this are not always clear. In this study we co-designed a way of involving people affected by a rare genomic disease in shaping future genomic research about the condition. The aim was to report the process, experiences and outcomes of involving people in genomic research in a standardised way, in order to inform future methods of involvement in research co-production.

Method Participants were recruited from an online community hosted by an Australian-based rare disease charity and were over the age 18 years. Once people gave consent, we shared learning resources with participants and invited them to complete an online survey before joining a two-week facilitated online discussion, followed by a second online survey. We used 'Standardised Data on Initiatives (STARDIT)' to map preferences, plan involvement and report any outcomes from the process, with quantitative data analysed descriptively and qualitative data thematically analysed.

Results Of the 26 people who gave consent and completed the initial survey, 15 participated in the online discussion and 12 completed the follow-up survey. STARDIT was used to report six outcomes from the process, including 60% of participants' responses showing a change towards 'widening' their view of who should be involved in research to include more people. Outcomes also included an improved understanding of research and how to be involved. Participants enjoyed online discussions, found learning resources useful and asked to stay involved in the research process. The partner organisation reported that a similar online discussion will be used in future research prioritisation processes.

Conclusion Involving people in co-designing the process improved the study design, ensuring it met the needs of participants. Whilst the study includes participants from only one disease group, using STARDIT allowed us to map people's preferences and report the methods and outcomes from involving people, providing a way for learning from this case study to inform future research studies beyond the discipline of public health genomics.


# Full Text

Due to technical limitations, full-text HTML conversion of this manuscript could not be completed. However, the manuscript can be downloaded and accessed as a PDF.

# Figures

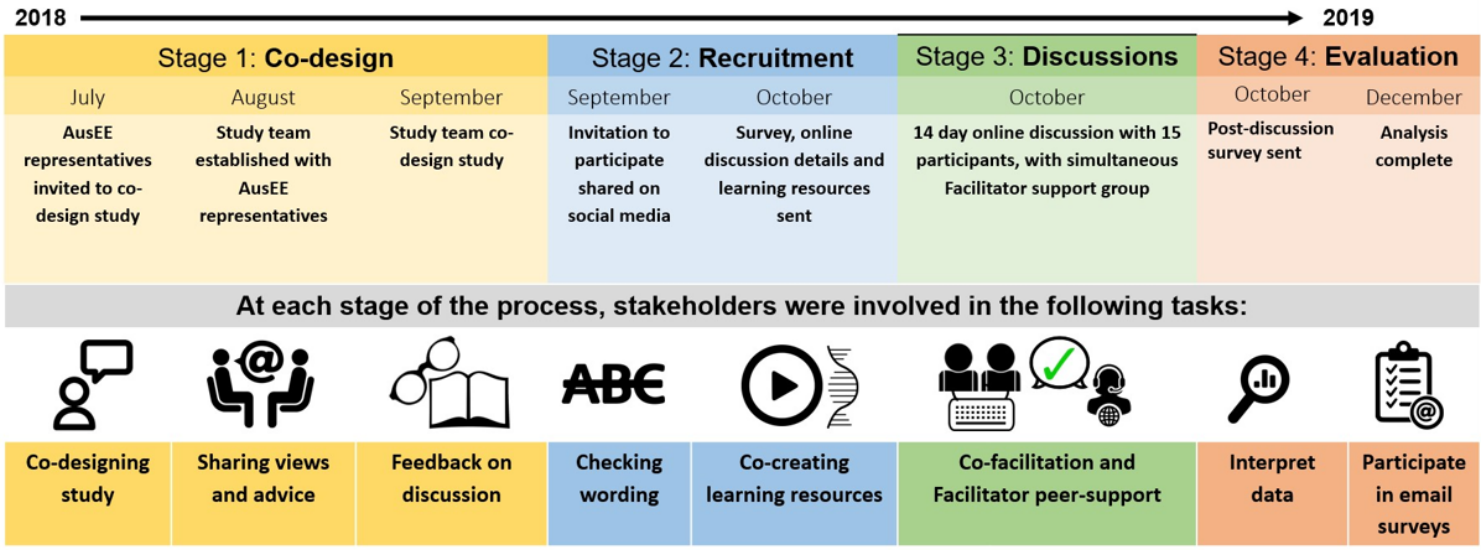


**Figure 1**

Timeline

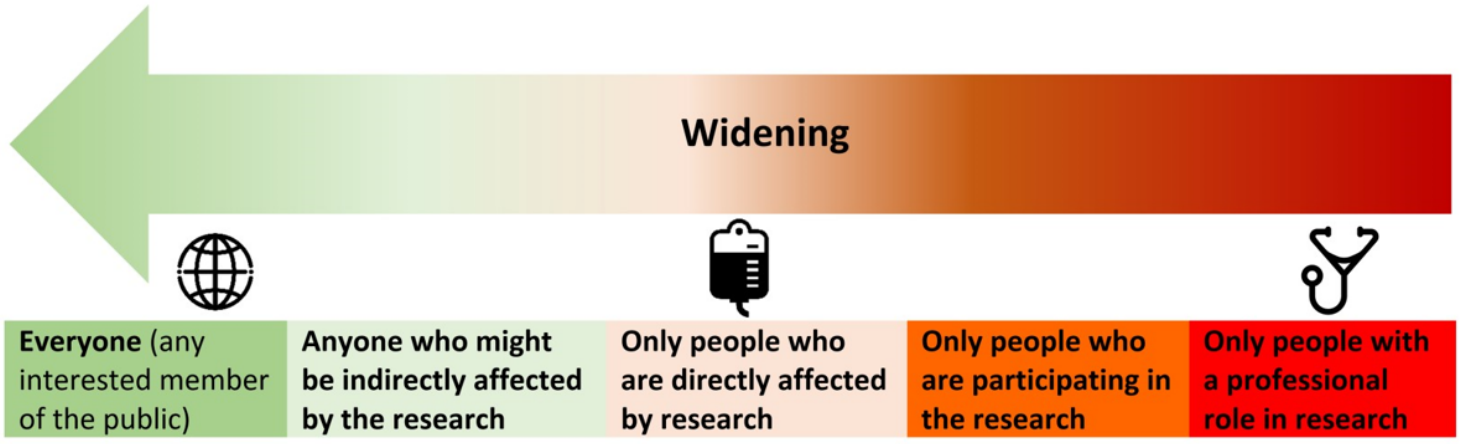


**Figure 2**

Who should be involved in research

**Figure 3**

Process summary


**Figure 4**

Online discussion visualisation

# Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- AdditionalFile3GRIPP2reportAusEEV25.pdf
- AdditionalFile2STARDITreportAusEEV25.pdf
- AdditionalFile1DataandAnalysisAusEEV25.pdf