

HOW TO RUN AN ADVISORY GROUP FOR SMARTPHONE RESEARCH WITH YOUNG ADULTS WITH RARE GENETIC CONDITIONS

Introduction

Young adults with genetic conditions are underrepresented in Patient and Public Involvement (PPI). To support our research in smartphone apps with young adults with a rare genetic disease called Tuberous Sclerosis Complex (TSC), we ran a small advisory group. In this document we provide an overview of our experiences from both the advisory group members and the researcher.



For Members

Being an advisor helped me meet two wonderful people with whom I coordinated and helped in the whole research. This group helped me know more about the research study and helped me gain more insights on how a research is conducted. I gained a unique, holistic perspective on the study.

I also got to learn about the rare genetic condition more and more closely on how it affects people who are suffering with TSC. I experienced talking to two people whom I didn't know before and who came from different cultural backgrounds. This group has changed the way I look at research. *Navida*



I've really enjoyed being an advisor as this study has really helped me reflect on things such as my mood and sleep patterns as I never really gave it much thought before through this study.

I've also had the pleasure of meeting 2 very lovely people who have made the experience fun and insightful. *Poppy*

For Researchers

Running an advisory group can be really exciting but it can be a bit nerve racking if you have never run one before.

I really enjoyed running the group and it was really useful to have the advisors help design the research. They gave me lots of great ideas and things to think about.

The most important thing is to be open and put the advisors at ease whilst organising and running the groups.

Kate



How We Ran the Advisory Group

The three of us met online once a month via video call. The meetings lasted between 45 minutes and 1.5 hours. After each meeting, we completed a reflection form, and these were discussed at the following meetings. At the beginning of stage 4, the advisors also took part in an individual reflection with a representative from the Tuberous Sclerosis Association (TSA). This feedback and the reflection forms were used to inform these guidelines.



For Members

What Went Well

We liked being part of a smaller group rather than a larger one - It allowed us to speak up in meetings easier.



We thought the length of the meetings were good, as they gave enough time to discuss things properly and in detail.



We liked that we had the opportunity to test out the app and enjoyed piloting it.



We felt that we could contact the researcher at any time with our concerns or questions.



We felt that our suggestions were listened to and taken on board.



What Didn't Go Well

We felt that we didn't know the other advisor well enough in the beginning to have differing opinions.



Sometimes the meetings went a bit too fast.



We would have liked to design the recruitment documents ourselves rather than just commenting on them.



We had some anxiety about sharing our results or opinions in the group.



We sometimes didn't have enough time to complete the work outside of the meetings.

What Should Be Done in The Future

Provide a 'getting to know you' session for the advisors.



Make sure to plan for extra time and to check advisors understanding of research terms and what they are being asked to do.



Start the advisory group early enough to involve them in all stages of the research process, including conception and ethics submission.



Add a 'Guidance Slide' at the beginning of each session highlighting all advisors are equal and are experts in their own areas, either research or lived experience.



Send 'out of meeting' work as far in advance as possible and highlight reasons if there is a short deadline.

For Researchers

What Went Well

It was nice to see the advisors ask each other about their opinions



I felt the advisors were proud of the work they had done and liked that they were contributing to the research.



Providing summaries for each meeting was helpful to the advisors



We had enough time to give breaks for the advisors which was important, especially when the meetings would go on longer than normal.



The advisors gave really useful information in the meeting reflections of how to improve the group as it went along.

What Didn't Go Well

In the first one or two meetings, the advisors would only talk to me and not to each other.



I forgot to show the final versions of the recruitment documents.



Each advisor preferred a different format of communication (pictures/words) which I did not account for.



I forgot to record a couple of the meetings which made it difficult to write the meeting summaries.



I did not share my own reflections with the advisors until the end. The advisors discussed they wanted to hear my reflections as the group went along.

What Should Be Done in The Future

You should facilitate connection between the advisors, e.g., letting them chat at the end of each meeting without the researcher there.



Make sure to show all research documents and keep the advisors updated with how the research is going.



Personalise meeting summaries to fit the needs of each advisor



Make to sure to auto record all meetings (with advisors consent) and make notes of all decision made in the group



Share and discuss advisors and researchers reflections as the group progresses.

Please tell us what you think about these guidelines [CLICK HERE](#)

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