Participatory Research Ethics Surgery discussion summary

12 December 2024

Overview

We had the first official session of the Inspiring Ethics Support Group on 12 December! Our session's central quandary was an ongoing project to develop a digital therapy platform for individuals with swallowing difficulties. The platform's design involves both clinicians and service users (PPI), and the next phase focuses on evaluating its acceptability and usability rather than clinical effectiveness. The project researcher asked about the type of ethical approval needed, especially considering potential recruitment from social media or charity groups rather than directly from NHS services.

Main discussion

Ethics for the Digital Platform Evaluation

1. **NHS REC approval likely not required:**

- Since the project is not a clinical trial and focuses on evaluating an existing or extended intervention rather than establishing clinical efficacy, attendees generally believed it would not require full NHS REC approval.

2. **Alternative routes to approval and guidance:**

- **HRA decision tool:** The Health Research Authority's online decision tool was recommended to confirm whether NHS REC approval is necessary.
- **Institutional or community-based options:** Researchers could seek review from their institution's internal governance structures, such as R&D boards, or engage with community-based networks (e.g., Lambeth Community Research Network) to ensure appropriate oversight.
- **Social Research Association or Similar Bodies:** External ethical review bodies exist, but can be expensive (in some cases over £3,000). Exploring community-driven processes might be more cost-effective and context-sensitive.

Additional discussion

Autoethnography and researcher wellbeing

A separate query was on ethics applications around autoethnography in marginalised communities. The group noted that ethics committees may emphasise researcher vulnerability and well-being which can be disempowering. Since some committees are not familiar with such methods, researchers may need to carefully explain the methodology and potential safeguards to avoid unnecessary ethical hurdles. This was a big topic area and we agreed to address it at the next meeting.

MOUs, governance & documentation

Participants also discussed challenges related to Memorandums of Understanding (MOUs) and data-sharing agreements. They suggested engaging with umbrella organisations, publishers, or entities like the NCCPE could help navigate complex agreements. They may already have relevant documentation to draw on. People also emphasised the need to simplifying agreements and documentation. Overly detailed or lengthy contracts and data-sharing agreements can overwhelm community partners. Streamlining and simplifying these documents is essential to foster equitable, authentic community participation.

Next session

Our next session is on **13 February, 2-3pm**. If you're interested in attending, you can sign up using this form.

Additionally, if you have experience in participatory research and would like to be one of our "experienced researchers" offering guidance at this or other future sessions (paid £50!), please use our experienced research sign-up form.

Questions currently on the agenda for next session:

- Autoethnography researcher wellbeing (mentioned above)
- Recruitment of participants with acute mental ill-health for research