Participatory Research Ethics Surgery discussion summary

13 February 2025

Overview

We had the second session of the Inspiring Ethics Support Group on 12 December! Our session discussed three quandaries: 1) The best approaches for recruiting and supporting patients with mental health needs in acute hospital settings; 2) Whether obtaining consent is required from peer researchers from ethnic minority backgrounds who are co-designing and delivering a research project on maternal health; 3) Suitable approaches for engaging with children and young people with diverse needs accessing services in an advisory group to inform strategy development and research in Child and Adolescent Mental Health Services.

Main discussion

Recruiting and supporting patients with mental health needs in acute hospital settings

1. **Assessing capacity**

- The primary consideration is how researchers can assess capacity and enable on-going renegotiation of informed consent through the research process.
- **Develop a clear protocol to assess capacity:** This should be done with a clinician and in line with the Mental Health Act.
- **Identify who can conduct this assessment:** For example, a nurse who professionally can gauge and understand whether the participant is too distressed to take part that day.
- **Understand that informed consent and engagement requires on-going renegotiation:** If someone else is unable to participate in the research, if will require you to go back at another time. This can be a long process. Equally, if you have built relationships over-time on the ward, some people who previously weren't interested in taking part may change their mind and those who originally said yes may decide to no longer participate.

Co-producing research about improving maternal health with peer researchers

1. Is consent required?

- Although a truly participatory and co-productive research model may not require obtaining consent from peer researchers who are co-producing research, there was some discussion about what kind of consent may be required and when. It was highlighted that it is important to not see consent as simply signing a 'piece of paper' but an opportunity to discuss and reflect on power dynamics with peer researchers throughout the process and at different stages of the project. Several suggestions were made.
- **Creating a consent form and information sheet specifically for peer researchers:** This would reflect their role as peer researchers (not as traditional participants). For example, how the research they produce will be used, as well as supporting them to define how they want their contributions to be attributed and recognized (e.g. using their name, a pseudonym, remuneration), as well as what outputs they may want to be involved in or opt-out of.
- **GDPR:** From a data collection/processing perspective, researchers must follow GDPR regulations particularly for medical-related or sensitive data. This requires in the least a clear information sheet about what data is collected/stored, how it will be used to aid transparency.
- **Publishing in academic journals:** It was noted that some reviewers and journals will not accept or public peer research without obtaining consent from peer researchers. Some researchers may want to consider whether they want to publish in journals that do not align with co-productive principles altogether.

Engaging children and young people with diverse needs in an advisory group for CAHMS

1. **When do you need consent from parents/carers?**

- In the UK, consent is required from parents/carers for children and young people under the age of 16. Over the age of 16, young people can consent to participate themselves.

2. **Is ethical approval required?**

- Whether ethical approval is required and from whom depends on several factors. For example, whether they are existing patients recruited through the NHS/services

or using another approach (e.g. charities or community organisations). If you're not directly recording lots of new data, the level of participation is consultation or considered PPI, it's not usually required.
However, it can vary from trust to trust. NHS ethics can take months, so this is important to factor in if it is required.

- **Speak to your RD team:** There is usually an ethics flow chart available or alternatively use the HRA decision tool. You can also liaise with your research ethics committee (if you are based in a university) to confirm they are aligned to the NHS process.
- **Contact the HRA for guidance on PPI:** The HRA website has guidance on PPI. They also have a helpline and email address for queries.

3. **How to best engage children and young people**

- Several suggestions were made about what to consider when planning activities with children and young people.
- **Consider their age and level of understanding:** Younger children tend to work better if they are given a task and processing time. Older age groups tend to be more comfortable just giving feedback. If you are working with a broad age range, it might be worth considering splitting the group into age-based subgroups to improve engagement.
- **Context and setting matter:** Where you hold sessions and whether parents are around (even if you don't need consent) can impact how young people engage with activities. For example, they may be more comfortable in a youth or community setting compared to a board or meeting room at the hospital.
- **Working with SEND students:** It is important to have facilitators with expertise in working with young people with diverse needs. This includes considerations about making the meeting environment safe, inclusive and accessible for them to participate fully, types of activities you use, adapting materials and resources etc. Local charities or SEND teams in the NHS may be able to provide training around specific levels of need by age group.

Useful resources

- Dickens, L. and Butcher, M. (2016), Going public? Re-thinking visibility, ethics and recognition through participatory research praxis. Trans Inst Br Geogr, 41: 528-540. https://doi.org/10.1111/tran.12136
- 10 for 10: McPin Co-production toolkit
- NIHR Guidance on co-producing a research project

- HRA PPI guidance
- NIHR Ethical practice guidelines on Public Involvement and Community Engagement
- HRA decision tool for determining whether NHS ethics is required

Next session

Our next session is on **14 March, 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.