**Inclusive practices and approaches in Patient and Public Involvement (PPI) and some challenges that are encountered.**

Alice Wreford gave a presentation reflecting on the lessons learnt from her PhD research. The study looks at the design of interventions aimed at increasing social connections.

The discussion groups – an inclusive approach:

* The library was seen as a pragmatic venue, as it was a safe, non-religious, accessible known place, with access to toilet facilities. Libraries also offer low to no-cost bookable spaces facilitating small group/private conversations where required. This was particularly valuable in the study which had limited funds available to support research costs.
* Two researchers sat in the library next to some flyers and posters which introduced the research. They acted as friendly faces ready to engage with any potential interested individuals about taking part in the discussion groups.
* Having researchers present in the library was seen as positive. It enabled more apprehensive individuals to build a level of comfort to then feel safe to tell their story.

 *“we'd been there for several days. It takes them days to build up the courage to speak to us, but because we had been there again and again, they then felt comfortable after a few, perhaps days of smiles, to engage with us”.*

The survey:

Stakeholder, public involvement and academic collaborations were used throughout survey development to make sure the results were meaningful. To obtains results from the survey, three recruitment methods were used.

1. Use of a third-party recruitment panel.

A recruitment company was paid to use their networks to access individuals in certain communities. The recruitment company sent out the survey on the researcher’s behalf to individuals in their networks, and if the survey was completed a small payment to individuals was made. This is the standard way of collecting this type of survey data. It was noted that despite these recruitment panels representing the general public on the basis of demographics (e.g. ethnicity, age and gender), it is not known if they capture the true views of the general public. This was of particular concern in this research context because, instinctively, those more likely to be socially disengaged, are less likely to work with recruitment panel services. Benefits of this method include the large number of responses that could be obtained, relatively quickly - 400 respondents in three weeks.

1. Online link sharing.

The survey link was disseminated through academic networks, and various organizational partners with a QR Code and a flyer to complete etc.

1. In-person stalls (Researchers at the library with their laptops, the same method used to recruit to the group discussion.)

The researchers were able to answer any questions about either the study or the survey itself. Researchers were able to offer support if needed to complete the survey (particularly useful for those with visual impairment or those unable to comfortably use a computer mouse). This recruitment method, although labour intensive (only 19 respondents recruited in 5 days) was felt to be valuable as individuals said they would not have taken part without researcher support. Preliminary results also suggest that these results differ from the more traditional methods of the survey recruitment panel. With this being said, these respondents were verbally sharing rich insights into their views and experiences as they answered the questions. These conversations were not captured within the survey, thus may have been more meaningfully evidenced through a qualitative data collection method: “*with each question they were giving us such insights into their experiences, their day-to-day antidotes around the question, that isn't information we were able to collect because we didn't have ethics approval, but it was very interesting to see’*. It was also good way of building trust and engaging with people. The researchers were of the belief that this experience of completing the survey, whilst being able to share wider experiences verbally with a researcher was very much enjoyed by respondents.

Overall Challenges and Learnings

* The purpose and need of the research was challenged - A member of the public felt it was already known what is wanted/needed in the community by the community, though this individual did not give examples of what it was. Another queried why this type of research, and the wider NIHR was being funded when the NHS is in such a dire state.
* The researcher got the support of key organizations who had a lot of on the ground experience with community groups and this helped reach individuals, as well as access to community spaces where these individuals were (this is known as an ‘asset based approach’).
* Asset based approaches worked well. The venues were able to be utilised at no cost – with thanks to the support of the organisations. With limited funds/budget in the research this was helpful.
* Using known venues, e.g. library, supported respondents to believe that the research was genuine and not a scam to be worried about. This was very important when engaging some individuals in the survey.
* Issues around safety for researchers going to a range of community venues (particularly those with limited or no supporting staff) with expensive digital equipment, and participant payment vouchers should be considered - good practice would ensure multiple researchers on site.
* In person stalls facilitated conversations. By researchers being on site for a few days trust and familiarity was built, allowing people to connect with the researchers and discuss issues/concerns without the pressure of completing the survey. This method also overcame issues of digital exclusion and supported people with disabilities to take part. As mentioned, feedback on how the survey was experienced and what meanings participants may be attaching to questions was also obtained. However, researcher time in relation to recruitment numbers needs consideration in comparison to responses received through a third-party recruitment service.
* A suggestion would be for researchers to also include service users to help people fill in surveys which can help break down some of the hierarchies.
* Transportation of researchers was an issue, as some community groups are located quite far away with limited access to public transport.
* The survey was predominately recruited in a library setting via in-person stalls. The results may therefore represent, a certain group, as a certain type of person may access libraries and that may shape their preferences for experience and engagement with community. Likewise, some people will not go into a library and would not have been captured. A variety of different assets (venues) may improve the results of the study.
* The impact of remuneration rate should be considered in the range of recruitment context (including areas of varied socioeconomic demographics). There was also scepticism over the financial incentive which was seen as being “high”: “*All you want me to do is complete a 15 minute survey and give a 10 minute discussion”.* In some instances, the value of the voucher was off-putting to potential candidates.
* Demonstrate respect for communities. As researchers we need to be mindful how we present ourselves, and show a genuine respect for people's time and expertise.
* In discussion groups food and refreshments can help foster connections and engagement - particularly the cultural conversations about food. It can also be an
important way of showing respect and appreciation without monetary exchange.
* Hesitancy around surveys and filling in consent forms and handing over personal details can be a barrier to participating in research for various people.