Patient and Public Involvement (PPI) Group: Reflections

Friday 9th February 2024

Working with a PPI group involves consulting people with lived experience for their advice and guidance on designed, planning and conducting a research project.

My research project will involve interviewing hospital ancillary workers (cleaning staff, catering staff, and porters) about their experiences at work during the pandemic. The experiences of this group of people during COVID-19 have not yet been heard. I want to find out about their experiences and perceptions of working during COVID-19, with the aim to provide them with a much-needed voice within the research domain. The aim is that this will generate crucial insights into issues such as infection control, communication, professional boundaries, and the extension of job roles in response to COVID-19.

To enable me to do this – to equip me with the foundations and knowledge to capture their voices authentically - it was imperative to seek guidance from people who worked in these roles during the pandemic. I have never worked in any of these roles and lack any experiential insight into what they involve. It could have compromised the project's aim if I had made assumptions about them: how to approach them, what matters to them, what their own wishes are. Their guidance on these key aspects of the research informed an appropriate study design. Their input shaped effective recruitment methods and prevented poor and irrelevant research questions from being asked. Therefore, having the opportunity to speak to some hospital ancillary workers about their experiences and being able to seek their guidance to inform the planning of the project was invaluable.

The first challenge was recruiting participants. Taking time to share unpleasant experiences with a stranger is not an appealing prospect for many people. By sheer luck, I was, however, fortunate to know a personal contact working as a hospital cleaner. After locating some willing staff members via this personal contact, I met with 5 members of staff from catering, cleaning, and laundry services at Hull Royal Infirmary. It was an informal discussion and we chatted over a coffee. I was initially apprehensive: would they want to share their personal experiences with a stranger? An 'outsider'? I did not expect the meeting to generate the rich, raw, and incredibly valuable discussions that flowed.

I had some set questions which I thought it would be helpful to explore:

What do you think would encourage people to take part?

Where do you think staff would prefer to take part – e.g. home, hospital, or online?

What topics/questions do you think I need to ask staff about their experiences of COVID-19?

What might put people off taking part?

Where do you think I should advertise my project?

I left with these questions answered and with various insights to help guide my project. The group were very keen to share their experiences. This supports the current, albeit, limited evidence which suggests that: hospital ancillary staff have felt overlooked, undervalued, and have had little voice throughout the pandemic. The group echoed these findings and indicated that they thought staff would be keen to share their experiences: this opportunity alone – to be heard - could encourage

them to take part. It was also suggested that I should directly ask ancillary staff: 'Did they feel listened to?' and 'Did they feel valued by other staff members?'. Issues with Personal Protective Equipment (PPE) were also highlighted, which also aligns with existing research findings: hospital ancillary staff may not have had access to enhanced PPE and were not always included in PPE training. Thus, 'What was their access to PPE'? was a recommended question.

The group stressed that interested potential participants may be discouraged from participating due to fears of employer retribution. There was a sense of fear around speaking out and whistleblowing. This emphasised the importance of explaining to participants that their participation and contributions will be anonymised. This was also considered when discussing where the research should take place. A coffee shop at, or nearby, to the hospital will be permissible, providing the seating is as private as possible. It was suggested that participating online should also be given as an option, which could encourage participation due to the anonymity this offered: away from the hospital and out of earshot of managers and other staff.

It was suggested that a stall could be set up in the foyer area of the hospital, to advertise the project to staff around their shifts. A poster which could be handed out to staff was also suggested, to provide them with the opportunity to read this in their own time. It was proposed that the posters could contain a QR code linking to a webpage about the research project, which would again safeguard the anonymity of staff by providing a further opportunity to read the information in their own time. Whilst it was decided that a stall in the foyer would not be practical, physical copies of the posters will be printed out so that staff will be free to take a copy to read in their own time. A QR code linking to a webpage about the study will also be included on all posters, to also facilitate private reading.

Overall, the PPI group meeting was invaluable to my research. It provided some significant preliminary insights into the experiences of hospital ancillary staff and guided key decisions in terms of designing the project, as described above. The group's enthusiasm to share their experiences and perceptions reinforced the need to provide this opportunity for hospital ancillary staff to be heard. They are an overlooked but crucial group of people.

Blog post written by Sarah Kearsley, BA (hons), MA, CertEd. University of Hull Doctoral candidate for PhD Health Studies – Living with Death, Learning from COVID - *Identifying and understanding the impact, and responses of, health and social care workers dealing with death under social distancing.*