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Nurses in care homes as advisors in research: benefits for all?

Introduction

Patient and public involvement (PPI) is held as best practice in health and social care research. This is based on the premise that public insights will enable researchers to understand more diverse experiences and so help ensure the research is appropriate for practice (Dudley et al., 2015). In this perspective piece we explore inherent tensions that may arise when nurses take part in public involvement activities which relate to their professional roles. The accounts described here are drawn from the experiences of two care-home nurses who took part in a public involvement advisory group within a research study exploring the mental wellbeing and resilience of care-home nurses during the COVID-19 pandemic (the 'THRIVE' Study[1]). Nurses' reflective accounts are supported by the researchers' theoretical reasoning for involving care-home nurses in PPI activity. First, we explain the nature of PPI in the THRIVE study, then the nurses provide first-person accounts of their experiences before we draw general conclusions that may be applicable to all nurses considering PPI roles in research.

Context of the PPI involvement

In August 2020, we began to develop a funding application which would enable us to research the distinct experiences of Nursing and Midwifery Council (NMC)-registered nurses working in older people's care homes during COVID-19. We were keen to learn about the impact of the pandemic on the resilience, mental health, and wellbeing of these nurses. The THRIVE study aimed to understand how nurses coped with the impact of working during the pandemic and what types of support were available in care homes, which are distinct from National Health Service (NHS) settings. It was a 12-month study funded by The Burdett Trust for Nursing, finishing February 2022. There were two main phases of the study: Phase

[1]The THRIVE Study: Understanding the distinct challenges for nurses in care homes: learning from COVID-19 to support Resilience and mental wellbeing (https://www.uea.ac.uk/about/school-of-health-sciences/research/projects/understanding-the-distinct-challenges-for-nurses-in-care-homes-learning-from-covid-19-to-support-resilience-and-mental-wellbeing).

1, where we interviewed 18 care-home nurses working in England and Scotland about their lived experiences of nursing during the pandemic and how it affected wellbeing; and Phase 2, where we held workshops with a new group of nurses to identify strategies and support for nurses' wellbeing in care homes. Further details can be found on our website.

To ensure the research had relevance and applicability to practice, we were eager to include the views of care-home nurses throughout the study to guide us on the appropriateness of the research questions, the ways in which we could recruit and collect data from this often-invisible nursing workforce, their insights into the meaning of the data, and possible dissemination routes. Therefore, we sought expressions of interest through local care-home networks and newsletters routinely sent to care-homes asking NMC-registered nurses to join the study's Advisory Group. The Advisory Group met once when planning the study, then four times throughout the study's duration. In addition, a nurse-manager of a nursing home joined the research team as a co-applicant, having managerial responsibility alongside the research team for the study's management and progress.

What is distinct about their involvement is that the nurses, each of whom works in an older people's care home that provides nursing care, were going through equivalent experiences as the nurses who consented to participate in the THRIVE interviews and workshops.

The purpose of this *Perspectives* contribution is to share the views and experiences of these Advisory Group members here, in their capacity as co-authors, thereby conveying to other nurses what it is like to become involved as PPI members in research. We also want to highlight how, reflecting on their own involvement in the THRIVE study, nurses contribute meaningfully to research, bringing significant insights that are otherwise unavailable to research teams, so extending the relevance and value of research to nursing practice in care homes. The following section reflects the nurses' own voices.

Nurses' thoughts on their PPI involvement in THRIVE study

The advert to join the THRIVE advisory group piqued our interest, especially as we had some awareness of research through collecting data for other studies and collaborating with hospitals, psychiatrists, and students. However, our previous experience was not extensive, and we felt some trepidation in getting involved in research activity at such a busy time with the pandemic.

After discussion with the research team about what being involved would mean, we agreed. As advisors in research, we would be contributing our own perspectives, helping to shape interview topic guides and giving opinions on how the research was progressing. Predominantly we decided to be on the Advisory Group for a few reasons: on the one hand, it provided opportunities to do something different; on the other, the COVID-19 situation was such a horrendous time that this would be a chance to get something positive out of

COVID. However, one of us initially thought we would be part of an interview-like scenario, but after further chats with the research team decided to continue in the PPI role as it was interesting and always enjoyable. We noted it is a privileged position to be in because not only was THRIVE giving us the chance to help analyse data, but it also took on board our own experiences as a care-home nurse. As time on the Advisory group continued the opportunity to look at research data and talk about our experiences, was also part of clearing the head and putting some sense to everything.

A specific challenge of taking part in this PPI activity was how close it was to our own experiences. For example, hearing the heart-breaking experiences of THRIVE interview and workshop participants both validated our experiences but also brought them into heightened focus. When care-home nurses who were participants in THRIVE spoke of their struggles to get support, this resonated very closely with our own experiences and we recognised the need to reflect and to support each other but that with one or two nurses on shift you don't get to support each other in a way that probably exists on a hospital ward, where there are more people present.

When reviewing the anonymous interview data with the researchers, we discussed and compared our own experiences to that of the interviewees, and what became apparent was that nurses in care-homes feel that they are forgotten. We were able to explain to the researchers that there's almost snobbery that you're a second-class nurse because of being based in a care-home, but it's important for us nurses to be recognised. This helped them understand that the comments from a small sample of nurses in the research were similar to our own and those of the colleagues we worked with. Personally, it was pleasing to see how informal comments amongst our colleagues could now be seen in research data. As would be expected in any public involvement in research, even when you have the same professional role as the participants, there was some variation between their experiences and our experiences. Important for the researchers was the knowledge that our experiences broadly resonated with the themes they found in the interview data.

A benefit of being in the Advisory group during this turbulent work time was the opportunity it provided for us to look at things in a calmer, more structured environment. We noted the need to acknowledge the Advisory group and the research data as separate from our work which mirrored it: it was the same but different from work and being separate was important because we were all in the thick of it, bubbling away coping with COVID, you needed to be separate from it and look from the outside back on it. This mirroring of experiences was positive in that by listening to other nurses' experience and acknowledging them we felt less isolated.

An important professional point was that reflecting on how others worked heightened awareness of how our own working practices might be quite insular, not knowing what was happening anywhere else. From being involved in the THRIVE Advisory group we gained

insight that we, as care-home nurses, are not alone and it is important to look beyond the daily work especially during COVID when you are scared and so focused on keeping people safe within these walls.

Being in the Advisory group linked with our professional development and increased our understanding of research. We found that through being involved in reading and commenting on the interview data we reflected on our practice, and the activity was as beneficial to us as to the research team: it was a kind of CPD (continuing professional development) and could be put in our revalidation portfolio. There was also a sense that looking at experiences through the lens of research, shifted some of the emotional impact. It forced us to think in a certain way, not emotionally but very matter-of-fact. Thinking beyond emotion and getting some action and developments out of it means you identify needs or gaps in your learning as you see things in a more holistic way.

We strongly felt that, as nurses practising in care-homes, being involved in research made us feel a bit more empowered taking ownership of how you're feeling and being the voice of care-home nurses.

As senior care-home nurses we were able to make time and re-arrange work to do this. That said, there were work emergencies which meant we had to miss meetings at the last moment. We were fortunate in that the research team recognised this and valued whatever input could be made. However, nurses considering this public involvement role might need to be explicit with the research team and their managers about how much time is expected, what happens if someone can't make scheduled meetings. It is also important to consider and discuss if there is individual or organisation compensation for taking part.

In summary we would encourage other nurses to become involved in research either as participants or for a more involved role as public involvement advisor within PPI activity. Taking part in THRIVE Study Advisory group enabled us to share opinions and thoughts and to be part of the narrative of care-home nursing. A particular bonus was that research enables you to connect with people outside your own organisation from which further connections can be built.

Conclusions

The Advisory group nurses' personal accounts reveal that becoming engaged with research was a positive experience personally and professionally. Although they encountered data that spoke of emotional trauma and distressing situations experienced by the nurse interview participants, they acknowledged they gained new insights into their own experience. However, had the THRIVE Study taken place earlier in the pandemic it may have been more difficult to talk and share opinions on the research because their own experiences of COVID-19 would have been still too raw. This highlighted the need for

researchers to ensure that appropriate support is in place for public involvement partners as much as that which is ethically expected for those taking part in research as consented participants. Particularly novel in the THRIVE study was that nurses involved in PPI were still living the experience in similar ways to the participants. More usually, patient and public involvement members draw on previous lived experience taking a more retrospective view, and this experience may not always directly align with the research area they are supporting. We suggest that professional self-reflective skills mean that there can be two-way benefits in engaging with nurses as public involvement members who are living the same experience as participants. Reflecting on participants' experiences and their own is a way of processing and making sense of experiences, while recognising that others are experiencing the same things supports professional development and reflective practice. This is especially important for nurses who often work in isolation from colleagues such as care-home nurses.

However, there is a debate as to whether health professionals such as nurses should be public involvement members in research about nursing. A major funder of health and social care research in the United Kingdom is the National Institute for Health Research (NIHR), which defines public involvement as 'an active partnership between patients, carers and members of the public with researchers that influence and shape research' (NIHR, 2021). In effect, this means that people who work in health and social care are not seen as eligible members of a PPI group within research that aligns closely to their experiences, as they are not seen to be 'the public'. We argue that observing a definition too rigidly in effect compartmentalises each PPI role. The consequence of such tight definition is that at each research exchange we draw narrowly on knowledge and ideas from only one role at any one time. This would be to the detriment of research as we are all the sum of our lived and historical experiences (Van Manen, 1997). Differentiating who is 'the public' and who is not is counterintuitive and closes off a dynamic that enhances and strengthens research. In the THRIVE Study the experience of involving nurses who had direct experience of working in the area of research interest as 'public' partners was seen to be positive to both the research and the nurse.

References

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