

Why you should read this article:

- To gain insight into patient and public involvement in research
- To understand how PhD students can involve patients and the public in the planning and conduct of their research
- To find out about the benefits of involving patients and the public in PhD research projects

Involving patients and the public in nursing PhD projects: practical guidance, potential benefits and points to consider

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Abstract

Background Funders, academic publishers and governance bodies increasingly require research to involve patients and the public. This also enables nurse researchers to increase the visibility of scholarly nursing roles, which are poorly understood by the public. There are different approaches to involvement, and a wealth of guidance about how it can and should be implemented. Less is known about how it should be done in the context of a nursing PhD.

Aim To discuss the experiences of the authors' nursing research group in involving patients and the public in PhD research, reflect on the benefits to be gained from doing so, and highlight considerations for those planning to involve patients and the public in their doctoral research projects.

Discussion It is essential to decide in advance of a study who you will involve, how to reach them and why you are involving patients and the public. Some potential benefits of involvement are: more accessible documentation, refined methods and better research outputs created in collaboration with patients and the public.

Conclusion Patients and the public should be involved in nursing PhD projects. Not only does this improve the quality of the research and raise the profile of nursing research, but it provides the opportunity for students to learn skills that they can develop further throughout their academic careers.

Implications for practice Obtaining high-quality patient and public involvement is an important skill for nurse researchers. The first steps in acquiring this skill should be taken during research training.

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Keywords

research, study participation

Introduction

Involving patients and the public in the design and conduct of health research is increasingly considered good practice (Greenhalgh et al 2019, Biddle et al 2021). Involving people with experience of the research topic can improve measurable outcomes such as recruitment (Crocker et al 2018) and generate qualitative improvements such as making a project more relevant to patients (Crocker et al 2017). Patients who are involved in the development of research report feeling more valued, confident and knowledgeable about their health (Brett et al 2014).

We aim in this article to discuss our nursing research group's experience of involving patients and the public in PhD research, reflect on some of the benefits gained, and highlight some important considerations for those planning to involve patients and the public in their doctoral research projects.

Background

Nurses are well-placed to engage patients and the public in research (Fletcher et al 2021); this can be of value to the nursing profession. Public perceptions of nurses put them in the incongruous position of being well-trusted and poorly understood (Girvin et al 2016). The onus is on the profession itself to improve how nursing is understood, and nurses – particularly those in scholarly or strategic positions – are expected to make themselves and their roles more visible (ten Hoeve et al 2014). It seems prudent to raise the profession's profile by using approaches that capitalise on nursing's trustworthiness. We can do this as nurse researchers by consulting and collaborating with patients and the public in the design, development and conduct of research.

Guidance for researchers

Patient and public involvement in research can take many forms, and the National Institute for Health Research (NIHR) (2021) provides comprehensive guidance

for researchers on how to do this. NIHR (2021) classifies involvement using three definitions of relevance to this article:

- » Consultation: asking members of the public about specific issues related to the research, often during one-off meetings.
- » Collaboration: an ongoing relationship and shared ownership over most decisions.
- » Co-production: sharing equally between researchers and contributors the responsibility for decisions and the generation of new knowledge, from the beginning to the end of the project.

The UK Standards for Public Involvement (UK Public Involvement Standards Development Partnership (UKPISDP) 2019) is a further resource, structured around six domains: inclusive opportunities, working together, support and learning, governance, communications, and impact. UKPISDP (2020) provides examples of how researchers across the UK have integrated the standards into their studies.

However, many different frameworks exist to support involvement, and researchers will need to tailor guidance to suit their own circumstances (Greenhalgh et al 2019).

Benefits to researchers

A researcher's approach to patient and public involvement will depend on several factors, including funding, time available and experience. The influence of these factors will be felt keenly for nurses undertaking a PhD, but we believe it is important for this skill to be acquired at a formative stage in a researcher's career. Patient and public involvement comes with unique challenges, but it can also be an enriching experience for researchers and contributors (Dawson et al 2020).

Furthermore, we would emphasise that the focus placed on avoiding 'tokenism' (Ocloo and Matthews 2016) means involving patients and the public in nursing PhD projects is an important part of training and can aid students in learning how to avoid it (Troya et al 2019).

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Key points

- Involving patients and the public in the design and conduct of research is increasingly expected by funders, publishers and governance bodies
- PhD students should gain experience of involving patients and the public in research
- There are different ways to involve patients and the public. Choosing the right approach will depend on your experience, the aims of your research and the resources you have available
- If done well, patient and public involvement can be an enriching experience for everyone involved

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Setting such standards at the outset of a research career should be a statement of intent, signalling a commitment to meaningful engagement, which will grow with experience.

The research group

The palliative, end of life and bereavement care studies group at the University of Glasgow's School of Medicine, Dentistry and Nursing comprises a team of nurses from a wide range of clinical backgrounds and several countries. Table 1 provides an overview of each researcher's PhD thesis topic, and the way patients and the public were involved in the design and conduct of the research.

Each researcher worked independently, with the support of their academic supervisors. Some projects were independently instigated by the researcher, others were undertaken as part of a funded studentship or scholarship. All projects aligned with the group's goal of improving the way nurses care for people with life-limiting and palliative conditions and the bereaved friends and relatives of such people.

Questions to consider

There are some important questions that should be asked before involving patients and the public in doctoral research.

Who should you involve?

PhD programmes may comprise several phases, with people with different characteristics recruited to each stage. It is therefore important that contributors can provide relevant insight for each phase. CM, MD and MS involved contributors with experience of their research topics for the duration of their PhDs; they supplemented this with short-term input from larger groups assembled to support specific phases.

CM's research focuses on people with multimorbidity – more than two chronic conditions – and includes a study in which it was important to gain insight from

people with a wide range of conditions. An 11-person group with a wide variety of chronic conditions was therefore convened by the researcher to ensure his study's documentation and processes were accessible.

MS collected data in Turkey but she required ethical approval from institutions in Scotland and Turkey to do so. This meant that all her study documentation had to be produced in both English and Turkish, so that the committees could review them. She therefore recruited contributors in both nations to ensure the study's English and Turkish documentation was clear and that the translated documents retained the same meaning in both languages.

How will you identify and recruit contributors?

Identifying suitable potential contributors for a study requires students to go out to the physical and online locations where potential contributors meet (NIHR 2021). This can require ad hoc as well as targeted methods. For example, a chance encounter at a digital health conference led to the involvement of a patient advocate in AF's PhD. In contrast, MD and ST recruited contributors at a structured patient and public involvement event at their university. Both approaches yielded contributors who were enthusiastic about the research topic and patient and public involvement.

BA's research focuses on the relationship between culture and heart failure, so he needed to recruit contributors from diverse cultural and ethnic backgrounds. Accessing tight-knit relational networks organised by ethnicity, religion or immigration status requires a physical presence to build trust. BA attended social events and spaces where people from his targeted cultural groups met. He was then able to recruit contributors by establishing rapport and integrating with these groups.

Table 1. Project summaries

Researcher's initials	PhD topic	Contributors	Eligibility criteria	Recruitment methods	Contact methods	Influence of contributors on research
CM	Development of a nurse-led intervention for people with multimorbidity	12	» Living with two or more chronic conditions or caring for someone with two or more chronic conditions	Social media Online Newsletter	» Email » Video calls » Messaging apps » Phone » Post	» Manuscript proofed and redrafted with comments from a contributor » Ethnography documentation developed and reviewed with input from contributors » Methods adapted including more use of technology, better support for people with impaired communication and addition to the participant information sheets of pictures of the researcher
BA	To explore the impact of culture on palliative care for people with advanced heart failure from diverse backgrounds	4	» Living with heart failure or caring for someone with heart failure » Belonging to one of the targeted cultural groups	Face-to-face through cultural and social events and meeting places	» Mostly face-to-face » Email, video calls and messaging apps during COVID-19 lockdowns	» Guidance on suitability of methods » Disseminating findings through cultural networks » Analysis of qualitative data
MD	To develop an intervention for caregivers of people with life-limiting conditions	3	» Caregivers of people living with life-limiting conditions	Structured patient and public involvement event at host university Social media	» Face-to-face meetings with the primary contributor » Phone calls with secondary consultants » Video calls and email during COVID-19 lockdowns	» The experiences of the primary contributor assisted in directing enquiry towards differences between male and female caregivers » The method of collecting data for the focus groups was refined » It contributed to the validation and identification of themes in qualitative data
AF	To explore the effects of patient online self-diagnosis and health information-seeking on the patient-healthcare professional relationship and medical authority	2	» People who have used the internet to self-diagnose or look up health information, particularly for heart failure and cardiac conditions	Social media Networking at a digital health conference	» Face-to-face » Video calls during COVID-19 lockdowns	» Informed research questions and data collection tools » Reviewed ethics submissions, manuscripts and participant-facing documents. Recommended inclusion of researcher photo on information sheets
CP	To evaluate an existing palliative care service and develop a nurse-led intervention for people with cancer and their families in Indonesia	3	» One person with cancer » One person caring for someone with cancer » One nurse working with people with cancer	Social media	» Video calls » Email » Occasionally face-to-face	Provided contextual information on their experiences of cancer, which influenced the questions asked in the qualitative study
MS	To explore the symptoms associated with heart failure and the influence of personal and clinical factors on these symptoms	5	» Living with heart failure or caring for someone with heart failure » Healthcare professionals working with heart failure in Turkey	» Social media » Turkish nurses were reached by contacting cardiovascular clinics in Turkey	» Email » Video calls » Face-to-face for local contributors	» Providing context on the experience of heart failure symptoms, which influenced the design of studies » Reading and commenting on manuscripts » English and Turkish speakers reviewed participant information sheets and helped to ensure they retained their meaning when translated
ST	To examine the burden of symptoms on people undergoing palliative radiotherapy as well as the burden on their caregivers	2	» Living with advanced lung cancer or caring for someone with advanced lung cancer	» Social media » Structured patient and public involvement event at host university	» Mostly face-to-face » Social media, video calls and email during COVID-19 lockdowns	Reviewed questionnaires and helped improve accessibility

How will you keep in touch and maintain a good relationship?

If someone agrees to contribute to a nursing PhD study, they may be involved with it for several years, particularly if research is being conducted part-time alongside clinical practice. This is a significant commitment, so it is important to agree with contributors how you will communicate with them during the project and to be clear about what is expected of the contributor, and what should be expected of you, the researcher. UKPISDP (2019) emphasises the importance of working collaboratively by clearly defining roles, responsibilities, expectations and ways of working so that everyone's contribution is valued. Core components of nursing care are working in partnership with patients, valuing their contributions and communicating effectively (Nursing and Midwifery Council (NMC) 2018); they are also skills that can be developed when doing a PhD.

Face-to-face and remote approaches both have strengths and weaknesses, but the unifying strength of our group's projects was that we each agreed with contributors at their outset the approaches to communication we would use throughout our research.

BA's relationships with contributors required him to see them face-to-face, but the opposite was true for CM. CM conducted most of his research during the COVID-19 pandemic but his participants had multiple chronic conditions so many of them were self-isolating. CM therefore recruited his participants remotely and communicated with them using email, by phone or through videoconferencing. This arrangement still suited the contributors after lockdown restrictions were reduced, so CM maintained it for the rest of his project.

How will you reimburse contributors?

People who give their time to help with your research should be reimbursed. How this is done will depend on several factors,

including the level of their involvement, the time they spend and whether they will incur any direct costs such as travelling expenses.

It is also important to consider the effect reimbursement may have on contributors who receive state benefits, as any payment might result in their benefits being reduced or ended. NIHR (2023) recommends developing a payment plan that explains how much contributors will be paid and how they will be paid, as well as how they can avoid it affecting their benefits, for example by declining or requesting lower payments.

We stated in our initial contacts with participants that we would give them shopping vouchers for high-street and online retailers to reimburse them for their time. We gave a contributor a £20 voucher for each hour they helped with a task, such as reviewing documentation. We reimbursed any out-of-pocket expenses promptly or paid them in advance.

Small gestures, such as going to a café and buying them tea or coffee, can help to show your appreciation for the contributor's time in face-to-face meetings. MS had local contributors and would arrange lengthier meetings with local contributors over lunch and pay the bill.

How much will it cost?

Costs ultimately depend on the type and level of involvement required. For example, it will cost significantly less to consult with one or two contributors at the start of the research than to have a patient and public steering group for the duration of a project or to convene a focus group to co-design data collection tools.

Pizzo et al's (2015) economic analysis of patient and public involvement considered not only its monetary costs – such as materials and expenses – but also non-monetary costs, such as the time contributors spent. The authors concluded that patient and public involvement has many benefits, but its costs are less clear.

Building costs into grant applications helps to prevent future issues with reimbursement as well as communicating to the funder that you intend to conduct research that matters to patients. However, a funded nursing PhD may not have these costs considered.

The authors of Tomlinson et al (2019) applied for a small NIHR grant to fund patient and public involvement in their PhD projects. Our group had access to a small patient and public involvement grant held by our primary supervisor. Grants for this purpose can occasionally be found – we recommend checking the websites of major funders such as the Medical Research Council and NIHR, as well as relevant charities. Supervisors may also be able to highlight internal funding opportunities. If the costs are expected to be low for individual students, applying for a small grant as a research group may be more appropriate.

How much time can you dedicate to involvement?

Coordinating involvement activities can take a lot of time and it is best to overestimate rather than underestimate how long each activity will take.

Collaboration and co-production are particularly time-consuming, but even if you are only consulting patients and the public about your research it is important to give them plenty of time to think about and read any materials you have shared with them (NIHR 2021).

Initial meetings can be lengthy, as these involve establishing rapport and agreeing how to proceed. They are also important. For example, MD's first two meetings with her primary adviser each lasted two to three hours but cemented a strong, mutually beneficial relationship that lasted throughout her project.

How much experience do you have of patient and public involvement?

There is good reason to argue that all patient and public involvement should

strive towards partnership working and avoid tokenistic approaches (Ocloo and Matthews 2016). This argument is framed by the fact that such involvement often comprises consultation and occasionally collaboration in the early stages of a project, with little ongoing input from contributors (Pii et al 2019).

However, co-production requires that contributors are afforded the same ownership over decisions as the researcher (NIHR 2021). There are also ethical dimensions you must consider when embarking on this approach (Reddy and Ghosh-Jerath 2021).

PhD students should consider how much experience they and their supervisory team have in this area. The PhD study may be a nurse researcher's first sizable research project, and attempting co-production may be overambitious. But we have demonstrated throughout our projects that there is scope to collaborate with patients and members of the public throughout a research study. For example, BA involved collaborators in the analysis of interview transcripts, MD developed themes with her contributor, and several of the group's contributors assisted in designing tools to collect data.

Limited experience should not prevent collaboration or restrict students to tokenistic approaches. However, it is also important to be realistic about what you can achieve in your PhD – we must practise within our level of clinical competency (NMC 2018), and the same standard should apply to how we conduct research.

What do you want to achieve by involving patients and the public?

Patient and public involvement is often used to set the agenda of research (Price et al 2018), but for most nurses undertaking a PhD this will already have been agreed at the outset. It is important then to think about the reasons why you are involving patients and the public in your PhD project.

An area to consider is how engaging with contributors from a target population can help with understanding the nuances of their culture. Culture in this context is not limited to geographically close or demographically homogenous groups, but rather the shared norms and beliefs held by disparate groups with a common experience, such as living with a chronic condition (Morse 2014). Several of our group reported this benefit, although it is difficult to quantify.

Involvement may require time, funding and expertise but it can play a significant role in ensuring that a project proceeds as planned and generates findings that matter to patients. A separate project undertaken by members of our group and included as an exemplar in UK Public Involvement Standards (2020) explored palliative care for people in prison. We held patient and public involvement groups with incarcerated men and these enabled us to uncover unique challenges that would otherwise have frustrated our attempts to collect data.

Improvements resulting from patient and public involvement

We will now outline some of the ways patients, the public and researchers can benefit from involvement.

Patient-friendly documentation and approaches

Contributors often helped us to make patient documentation more comprehensible, including information sheets and consent forms. Taking simple steps such as using plain language and keeping documents succinct can help, but ultimately each target population may have specific needs that can only be met if contributors are involved in producing documentation. Some of CM's contributors faced complex barriers to communication. They helped to improve documentation and processes through measures such as producing large-text documentation, providing audio recordings of the documents being read aloud and ensuring

that participants could have a witness present when providing consent.

People with cognitive impairment requested having a picture of the researcher on the documentation so they could remember who they were dealing with; this was also requested by AF's contributors. Others who were registered blind used electronic reading software and could identify aspects of the documentation that did not work when read electronically.

MS faced the challenge of developing materials in English and Turkish that were appropriate for rural and urban populations with variable literacy. To resolve this, she recruited contributors who spoke Turkish, some of whom were bilingual or had lower literacy. The resulting documentation was more accessible to the target population. The involvement of bilingual speakers also made it possible to check that the English and Turkish study protocols and research questions were congruent.

More effective methods and better study design

Contributors could also advise on methods and the design of a study, often by refining tools designed by the researcher for collecting data. This was the case for CM, MD, AF and ST.

Contributors' input also significantly strengthened BA's qualitative focus group study. Difficulties accessing some cultural groups hampered initial recruitment, and when he piloted the questions to be asked during the focus groups they did not generate the depth of data anticipated.

Contributors supported the research team by acting as 'cultural brokers'. Discussions with the contributors led BA and the research team to rephrase the types of questions he was asking, so that he was approaching the topic of palliative and end of life care more obliquely, using hypothetical scenarios. This indirect approach enabled participants to engage with sensitive subjects that they had felt unable to when approached directly.

Sharing ownership of findings

Contributors were often involved in producing reports, including manuscripts for submission to academic journals. The motivations for this are different from involving patients in the production of patient-facing documentation, as most people who read academic papers are researchers and clinical staff. If patients or the public review such material, they can provide a useful sense check, as the potential readers of a manuscript may not have the same knowledge of a subject as its author.

Our group's contributors could often identify gaps in how we contextualised our research or challenged our assumptions. BA and MD's long-standing primary contributors helped to validate and identify themes in their qualitative data, reassuring them that their interpretations were accurate.

However, what motivated us most to involve patients and the public in this process was that we wanted to ensure that those who had contributed to earlier stages of the research retained ownership over how the findings were disseminated. It is important to follow International Committee of Medical Journal Editors' (2023) guidance when you are determining whether a contributor is an author. If they are not, it is still important to thank and acknowledge them for their help in the same way you would any other non-author collaborator.

Challenges and lessons learned

Patient and public involvement has many benefits. However, it requires commitment and can include challenges. It is important to acknowledge such challenges because these (and many others) have informed the recommendations we have made in this article.

A PhD can last a long time and circumstances can change. Some of our contributors had to withdraw their support prematurely because of worsening health, a bereavement or work and family commitments. Some of us struggled to recruit enough contributors. Some processes we had expected to take just a few days, such as reviewing documentation, lasted weeks, which affected our studies' timescales.

As with any other research activity, patient and public involvement does not always go to plan. As nurses, we must reflect on and learn from these instances, sharing what we have learned so we can improve how our profession approaches patient and public involvement in research.

Conclusion

Involving patients and members of the public throughout the research process is an essential skill to which nurse researchers should be introduced at an early stage in their careers. Involving patients and the public in a PhD study has its challenges, but these can be overcome with careful planning and adaptability. Factors such as time, funding and how much experience you have will influence what approach to take, as will the intended goals of involving patients and the public.

It is important to decide the level of involvement that best suits you, your project and your supervisory team, such as consulting, collaborating or co-production. Doing this effectively will not only provide nurses undertaking a PhD with better outcomes, it will also foster a more patient-oriented approach to research, which can continue throughout a nurse's research career.

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