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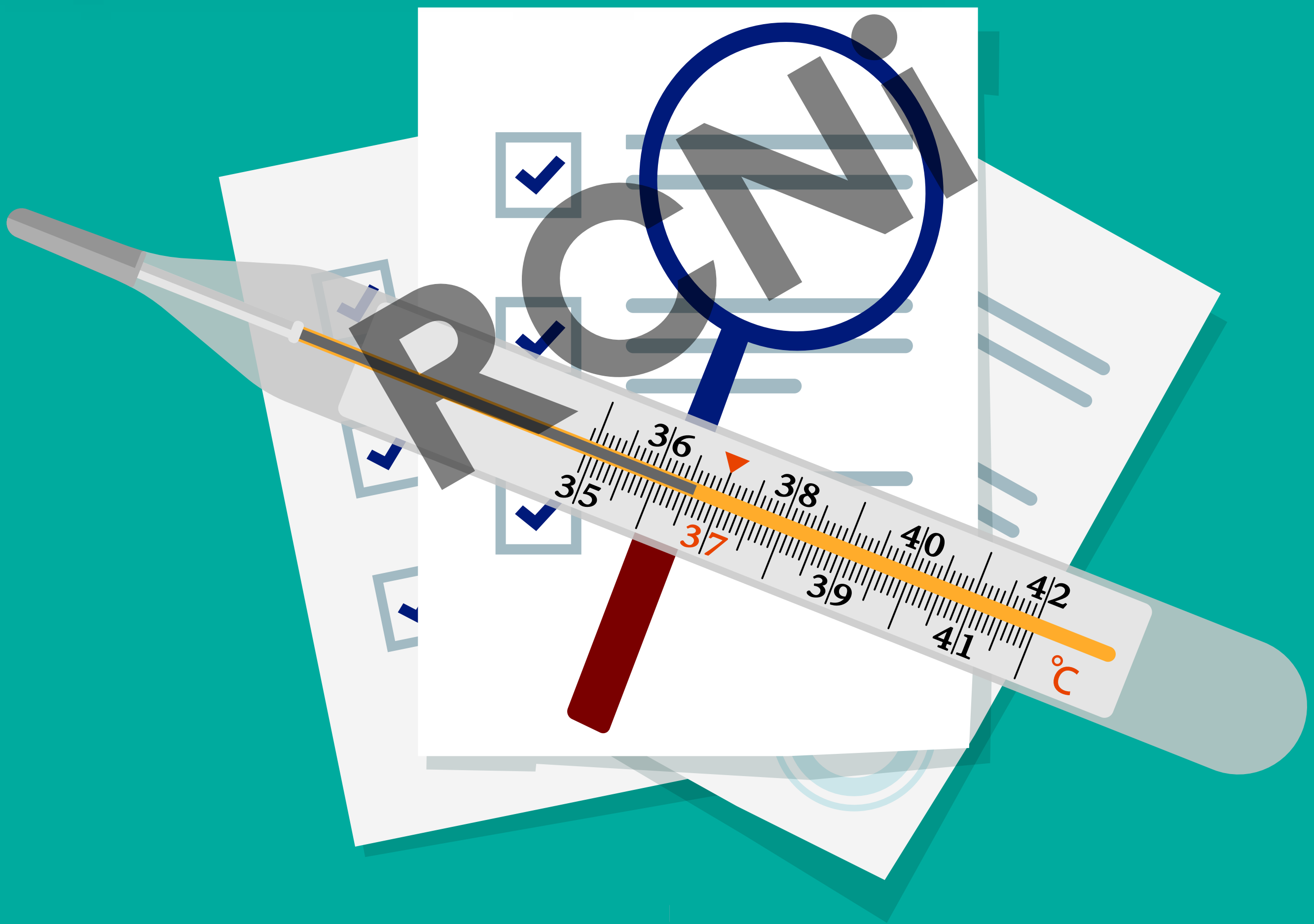

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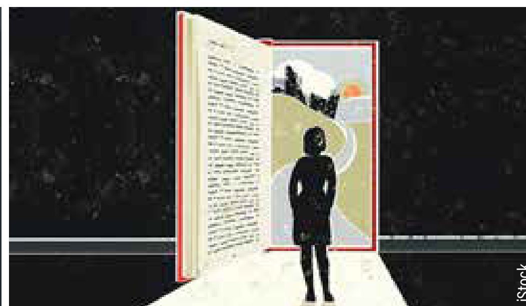

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Get ready for 2024's research challenge

Liz Halcomb
is editor of
Nurse Researcher
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In September, I was delighted to be able to attend the RCN International Research Conference in Manchester and to spend time with the international community of nurse researchers.

There is always something new to learn, be it a new topic idea, a different way of approaching research or engaging in a methodological debate. Just the chance to talk to other nurses about what they are doing is a great way to refocus and refresh your own thinking.

Under the theme 'Embedding a culture of research in nursing', presentations focused on strengthening the connections between nursing research and clinical nursing practice. Building research capacity in the clinical setting and embedding evidence into practice were also strong themes. However, limited collaboration between nurse academics/universities and nurses working in clinical settings meant missed opportunities.

As a profession, we are stronger because of the breadth and depth of our expertise across clinical and academic settings. We must not fall into the trap of siloing nurses into either clinical or academic posts but rather work in collaboration to optimise the quality and impact of our research and professions' contribution to healthcare. A key message from the conference's main speakers was the need for nurses to be continuously thinking creatively about how they can build, enhance, or optimise their work.

I challenge you to think about what you as an individual, and perhaps your research team as a group, could do differently in 2024. Could you build the way in which you incorporate co-design in your research? Could you enhance an intervention by incorporating an innovation? Could you optimise your research environment by changing the system to reduce a barrier? Could you just start the discussion and critically review your research and its trajectory?

I look forward to hearing about your research at the 2024 RCN International Research Conference.

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Why you should read this article:

- To gain insight into how ecomaps can be used effectively in research interviews
- To appreciate the dynamic nature of ecomaps
- To understand how using ecomaps in research interviews is congruent with the philosophical foundations of hermeneutic phenomenology

The ecomap: a tool for extending understanding in hermeneutic phenomenological research

Elizabeth Jestico, Bridget Taylor, Teresa Finlay et al

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Abstract

Background Ecomaps are tools used in nursing practice to assess families' social support systems. Ecomaps have been used effectively in qualitative research but little attention has been given to their use as a tool in the methodological approach of hermeneutic phenomenology.

Aim To demonstrate that the use of ecomaps is congruent with the Heideggerian philosophical foundations of hermeneutic phenomenology.

Discussion This article reflects on a study in which the researchers used ecomaps to explore how parents of children with cancer are supported with decision-making about their children's care. Exploration of the Heideggerian concepts of 'being in the world', 'being with' and 'temporality' prompted reflections about how constructing ecomaps furthers understanding of participants' unique contexts. Using an ecomap in an in-depth interview enabled interviewees to return to their experiences of being supported with decision-making; it also further developed the researcher's understanding of how each participant's experience was situated in their evolving relationships with others.

Conclusion Constructing ecomaps in hermeneutic phenomenology is in tune with Heideggerian philosophical concepts. Ecomaps can open a door to participants' experiences, deepen the researcher's understanding and find further meaning in those experiences.

Implications for practice Ecomaps are a useful way of shining a light on participants' experiences in hermeneutic phenomenological research. The article provides practical tips to optimise their use in future research.

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Keywords

data collection, interviews, methodology, narrative, phenomenology, qualitative research, research, research methods, study design

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Introduction

An ecomap is a valuable tool that is used in children's nursing practice to assess and understand a family's social support system (Hemphill and Dearmun 2010). It creates a visual representation of how the family interacts with its self-identified community and can help health and social care professionals to identify sources of support and stressful relationships that may affect the family (McCormick et al 2008).

The ecomap has also been used in more recent years as a research tool (Early et al 2000, Ray and Street 2005, Baumgartner et al 2012). Ecomaps are not commonly used in qualitative research but can improve understanding of families' experiences of social support (Rempel et al 2007).

Manja et al (2021) presented a useful overview of how qualitative health researchers have used ecomaps. The paper's integrative review identified that in line with Rempel et al's (2007) position, the ecomap can shed light on social interactions and relationships, which can act as a catalyst for further lines of enquiry. It also showed there were other benefits to ecomaps, such as improved rapport with research participants.

Moules et al (2015) proposed that ecomaps may be a useful aid in a hermeneutic interview. However, little attention has been given to how the ecomap may be congruent with the philosophical foundations of hermeneutic phenomenology. In this article we reflect on the experiences of the first author (EJ) of using an ecomap in hermeneutic phenomenological interviews and discuss how consistent the ecomap is with this approach. We draw on important underpinning philosophical perspectives in Heideggerian hermeneutic phenomenology to aid this reflection: 'being in the world', 'being with' and 'temporality'. We explore these reflections in the context of Heideggerian concepts and demonstrate that using ecomaps in hermeneutic phenomenology can shed light on the experiences of patients and families.

Background

Hermeneutic phenomenology

The aim of hermeneutic phenomenology is to illuminate a phenomenon and develop understanding of the way that we experience and exist in the world (Van Manen 2016). Heidegger is one of the most important philosophers of the 20th century and significantly influenced the philosophical movement 'hermeneutic phenomenology' (Van Manen 2016). He was fundamentally concerned with ontology: 'What does it mean to be?' He considered it inadequate to view 'being' as a self-sufficient entity with describable properties (Heidegger 1962).

Heidegger (1962) used a hammer as an example: the hammer exists and can be described in terms of its attributes such as its weight, dimensions and colour. Heidegger proposed that the hammer does not exist in isolation: it exists because it has a use and a meaning. The hammer is not a hammer until it interacts with other 'beings', such as nails, wood and the carpenter. These interactions define its purpose and this meaning is integral to the hammer's existence.

Meaning and existence are inseparable: we attach meaning to everything we experience and this is how we come to understand the world (Heidegger 1962). Our experiences are situated in a particular time and experienced within our relationships with others (Smythe et al 2008).

Hermeneutic phenomenology has been developed as a research approach from Heidegger's philosophy as a way of seeing the world by interpreting and searching for meaning ('hermeneutics') in our everyday experiences ('phenomenology') (Crowther and Thomson 2020). The application of Heideggerian philosophy in hermeneutic phenomenological research has provided valuable insights into nursing practice (Wilson 2014, Chesterton and Jack 2021).

A defining feature of hermeneutic phenomenology is that there is no prescribed method for approaching a research project (Smythe et al 2008). Everyone's story and experiences are unique, so the way we come to understand

Key points

- An ecomap is a visual representation of an individual's social network that is context-specific and has the potential to evolve over time
- Ecomaps are valuable in research interviews as they can help participants to reflect on their relationships
- They can shed light on participants' unique experiences and enable in-depth discussion about the complexity of social relationships
- The use of ecomaps in a research interview is consistent with the Heideggerian phenomenological concepts of 'being in the world,' 'being with' and 'temporality'

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participants' stories is also unique. This permits novel methodological approaches.

The study

EJ is a PhD student undertaking a hermeneutic phenomenological study. Her study explores the experiences of parents who receive support from their network of 'significant others' when faced with making decisions about their children, who have cancer.

In line with the findings of the literature review (Jestico et al 2022) it was important to allow participants to self-define their 'significant others' rather than make assumptions about these roles based on pre-defined groups. Gage (2013) distinguished between 'significant others' and 'similar others': the significant others in this study could have been parents' extended family and friends, while the similar others could have been parents of children with cancer with whom the participants had developed relationships since their children's diagnoses. However, to impose a predetermined framework in this way would conflict with the ethos of hermeneutic phenomenology: the researcher should encourage participants to talk freely about the experiences that are important to them, rather than direct or guide them to talk about certain topics or relationships.

Chesterton and Jack (2021) argued it is important for nursing research to be person-centred and this can be achieved using Heideggerian hermeneutic phenomenology. We hoped that co-creating ecomaps with participants during interviews would support this, as well as enable EJ to visualise each participant's support network and help her to direct her questions to understand the evolving relationships as participants talked about their experiences.

A fundamental aspect of hermeneutic phenomenology is for researchers to acknowledge their pre-existing understandings of a topic (Smythe 2011). They will often participate in pre-understandings interviews with a fellow researcher to help uncover their thoughts and feelings about the research topic.

In line with this approach, EJ created an ecomap at the start of the study to understand her own social support system. She repeated this process two years later, creating a new ecomap, which helped to really understand how fluid and temporal social support networks can be.

EJ also undertook four pilot interviews with fellow PhD students to refine her ecomapping skills. She gained valuable insight into participants' experiences of constructing ecomaps from conversations with these students after these pilot interviews.

This article includes reflections in the context of Heideggerian philosophy on constructing ecomaps in the pilot interviews and then the study interviews. It also discusses how ecomaps are not only helpful ways of furthering researchers' understanding of participants' experiences, but they are also in tune with the methodology of hermeneutic phenomenology.

Ecomaps in interviews

Six parents of children with cancer took part in one-to-one, in-depth interviews conducted using an online videoconferencing platform. Each interview started with an open-ended question that gave the participant the opportunity to tell the story of their child's cancer diagnosis and care. EJ also asked them to list decisions they had faced; these included social decisions and decisions about treatment and supportive care.

EJ then showed the participant an example of an ecomap and explained what the symbols represented (Figure 1). She used the videoconferencing platform's whiteboard function to enable them to create an ecomap. EJ left the ecomap on the screen once the participant had completed their first draft, and asked them questions along the lines of: 'Can you tell me a little more about one of the decisions that you mentioned?'; 'What was that experience like?'; and 'What role, if any, did the people

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on the ecomap play in your decision-making process?' As the participant talked about their decisions in greater depth, they modified their ecomap and added to the list of decisions they felt they had made.

Reflections informed by Heideggerian concepts

Methodology and method need to be congruent, and we were mindful of the interplay between Heidegger's philosophy and our interpretations of participants' experiences. We have therefore interwoven important Heideggerian concepts with extracts from the pilot interviews and research interviews throughout this discussion to illustrate our reflections more clearly.

'Being in the world'

At the foundation of Heidegger's philosophy is the question: 'What is it to "be" in the world?' (Heidegger 1962) Heidegger used the German word '*dasein*' (existence or 'being there') to express this concept of '*in der welt sein*' ('being in the world') (Heidegger 1962).

Heidegger argued that we exist as part of a world in which we attach meaning, thoughts and interpretation to all our experiences. It is through these interpretations that we come to understand the world as we experience it. Using the word *dasein* enabled Heidegger to emphasise our unique context, as we live through our experiences rather than simply observing and describing the world that had previously been conceptualised as separate to us (Smythe 2011).

To understand our experiences of being in the world we need to reflect on those experiences and – as Heidegger emphasised – return and stay close to the experiences themselves (Smythe 2011). Participants in research may not be attuned to reflection, so researchers should not assume that returning to an experience will come easily to them.

Several conversations during the pilot interviews demonstrated that constructing ecomaps helped the interviewees to reflect on decisions and to talk in more depth about those experiences. For example, one person said: 'I didn't think I would have anything to say about this – but once I saw my ecomap, I realised that there was more to making the decision than I had thought. I'd forgotten about the people who I'd talked to about this.'

It was evident during the research interview with 'Kerry' that she initially felt alone when she made decisions about her son's care. However, as the conversation focused more on specific decisions, EJ used the ecomap to ask her probing questions about others in her world, such as: 'Was anybody on the ecomap with you when you made this decision?' and 'Did you talk to anybody on your ecomap about this decision?'

This prompted Kerry to reflect that when she had to decide whether her son should have a nasogastric tube inserted, her mother was with her and supported her decision. On another occasion, it was her sister's offer of practical support that helped Kerry to decide whether to remove her son from nursery.

The ecomap proved a valuable tool in providing access to participants' unique experiences, enabling them to reflect while simultaneously enabling the researcher to obtain insights into their worlds.

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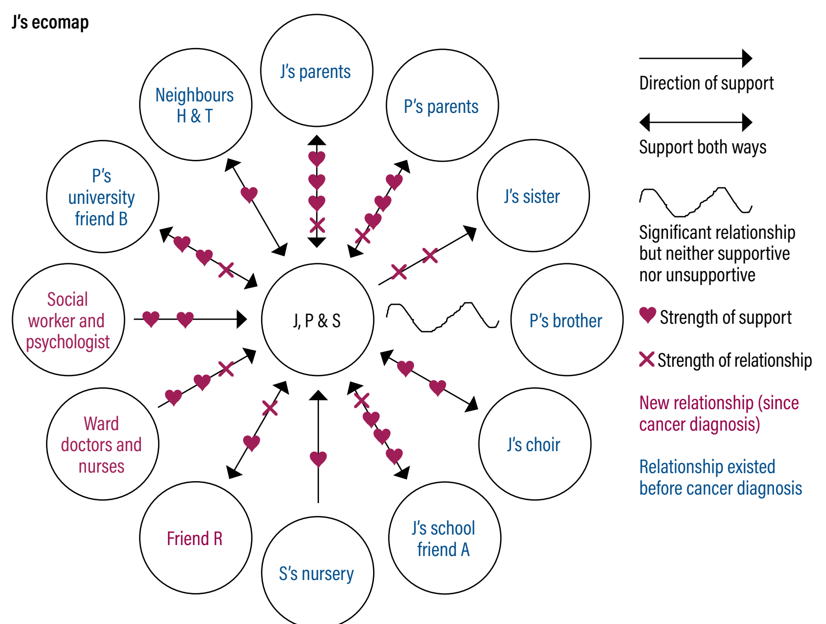
Figure 1. An ecomap developed for the study interviews



'Being with'

Each of us experiences our world uniquely, but we also inhabit and share our world with others. The world of *dasein* is therefore inevitably a social world (Mulhall 2005).

Heidegger used the word '*mitsein*' ('being with') to emphasise the fundamental influence that other people have on our own existence: 'Being with is an existential characteristic of *dasein* even when factually no other is present at hand or perceived. Even *dasein's* being alone is being with in the world' (Heidegger 1962). This does not mean that we are necessarily in the physical presence of others; rather, the existence of other people in the world – other *daseins* – affects our own experiences of our world (Blattner 2006) and our interpretations of it.

Heidegger proposed that our past and our present relationships with others fundamentally influences who we are (Heidegger 1962). The ecomap provides an illustration of these relationships. It identifies who these relationships are with, and the arrows and symbols on the ecomap demonstrate the direction and strength of support, which helps the viewer to understand how each relationship functions (Figure 1). Providing these details led participants to reflect on what those relationships felt like and how they affected their decision-making.

Methods of creating ecomaps are also individual. For example, EJ explained to Kerry that people usually put their household in their ecomap's central circle. In Kerry's case, that would be her husband ('Tony'), her oldest son ('Rory'), her younger son who has cancer ('Harry') and herself.

However, Kerry explained that the symbols presented did not accurately represent her relationships: 'Does it have to be like that? Because, based on what you just said, I would put me and Harry in the middle. Rory and Tony are, like, people who are coming out of our circle. Like, I don't know if this sounds harsh, but it has been me and Harry who have been through the journey.'

Kerry described her relationship with her husband's parents as 'two-way' but 'it's almost like on one we put, like, a dotted line, it's not so strong'. EJ was unsure how to represent this using the online package, so proposed using a wavy line. Kerry responded: 'Yeah. I wouldn't really say it's changed that much since cancer. Like, they've always been supportive and I've always been, but, like, sort of at a distance, like physically and emotionally.'

EJ suspected that the wavy line did not fully represent Kerry's description of her experience, so suggested: 'How about if I indicate something like that [inserting lines across the wavy line] to say it's kind of there but it's not, it's not a kind of close relationship?' Kerry confirmed that this accurately represented her experience of that relationship.

The co-creation of this new symbol is consistent with Heidegger's view that *dasein* does not exist in isolation and our everyday way of being in the world is one of engagement – we are always in relation with other *daseins* and other entities. However, if *dasein* is absorbed in its concern towards others, it becomes subsumed by '*das man*' ('the they'). It is no longer authentically itself – something Heidegger called '*uneigentlichkeit*' ('inauthenticity') (Heidegger 1962). As Scott (2010) explained: 'If I relate to myself as one is expected to do, if I see myself the way others see me, if I go along to get along, I make choices as though I were not my own life. I intend what they intend for me. We talk as one does.'

For example, the pull of *das man* compels us to laugh because they laugh and clap because they clap. *Dasein* might bathe their children before bed because that is what 'they' (other parents) do. We might not be feeling fine but if someone asks, 'How are you?', we might respond, 'Fine, thank you,' because this cultural norm is what 'they' do. The everyday self of *dasein* is subsumed into *das man* (Heidegger 1962) and it loses its authentic potential of choosing to choose. This was exemplified by 'Tom'

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in our study. While he was constructing his ecomap, he talked emphatically about the supportive role that church communities played in his life. As he talked about decision-making in more depth, he said: 'All our lives, we have been in the church, because we were born into the church. So, we know how our leaders would always say to follow the best medical advice. They wouldn't ever encourage you to sort of paddle your own canoe and try something unless it got really desperate.'

Nevertheless, the potential for *eigentlichkeit* ('authenticity') is always present (Taylor and de Vocht 2011). A moment of disruption releases *dasein* from its fixed habits to make the transition to authenticity (Heidegger 1962).

Kerry explained in our study that she was fearful of nurses' decision to allocate her son a bed in a communal bay rather than in a side room, and provided an example of how the family members who featured on her ecomap were not always supportive:

'I would always speak up for Harry and I will always say: "I don't care what you think of me, I'm not here to make friends, I am not putting Harry in the bay." And I know they [my family] don't agree with me, they wouldn't have backed me up, which is kind of all the more reason why I will speak up in the moment because I know if I went home and said, "Oh, you'll never guess what happened at the hospital today," that people would fly off and say, "Oh well, you should be grateful for the NHS" and "Maybe it was just busy", and people would sort of try and talk me out of speaking up… I think I'm more inclined now to say it in the moment, because I know that then it's real and I haven't had anyone try and make me feel guilty about speaking up.'

Tom and Kerry demonstrated that our relationships may pull us away or push us towards a position of authenticity. Our actions and decisions as *dasein* are situated in the context of our complex relationships with others; the ecomap can represent and aid rich conversation about the role these relationships play.

'Temporality'

It is *dasein's* openness to time that enables its potential authenticity to be realised (Heidegger 1962). *Dasein* seizes in the present the constraints and possibilities predetermined by its cultural-historical past, allowing it to project itself into the future authentically: 'The future is not later than having been, and having been is not earlier than the present. Temporality temporalises itself as a future which makes present in a process of having been' (Heidegger 1962).

In other words, we physically exist in the present moment, but *dasein* has a unique ability to consider the past and the future as well. We can reflect on past experiences – both our own and those that preceded our existence – and can look to the future and consider the consequences of our present moment.

'Saira' described the changing levels of support in the 'Cancer Mum' WhatsApp group she belonged to: 'I think just time has changed. Just, you know, a couple of the kids have finished their treatment, a couple of us are still on it… You realise as well that everyone's got their own journey and that you have got an understanding that other people [outside the group] don't have, and so it's a place really, just, it is sometimes active, it's sometimes not.'

Looking to the future and considering how new relationships would become significant in the context of making the next treatment decision, she added: 'I think this is probably the point at which we need to access some other kind of resources, I guess. And, you know, maybe sort of spread the net a bit wider to help us.'

It is important to stress that the ecomap cannot definitively represent each participant's network – with every revealing, there is also concealing (Heidegger 1962). We need to understand as we make sense of people's experiences that they undergo a constant process of revealing and concealing when they tell their stories (Davis 2010). This is not necessarily a conscious decision, as

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experiences that are omitted may be less important to the person telling their story.

Several factors played a part when participants described 'significant' people. These included the topic and context of what they were discussing. Participants mentioned people who played roles in their lives while their children were receiving cancer treatment. However, people who may have been significant at other times of their lives or in other circumstances did not appear on the ecomap.

For example, Kerry said: 'I have felt over the years that a lot of people haven't even acknowledged Harry has been through what he's been through. Like, people who I would have thought would have cared more haven't. And then people you think would never care have. Like, there's a friend that I was friends with about ten years ago I've, like, reconnected with because of Harry. He's reached out and said, like, you know, 'Can't believe what you're going through.' And then other people who I worked with for, like, seven years, have never said a single word.'

Understanding the concept of temporality highlighted the importance of using the ecomap to reflect the evolving nature of relationships. The ecomap was therefore adapted to represent this using different colours, with red text for new relationships that had emerged since the cancer diagnosis. It became apparent as each interview progressed that participants' relationships were ever-changing and that while the different colours on the ecomap could represent a degree of evolution, they could not fully portray the dynamic and contextual nature of relationships.

For example, 'Maggie' said: 'It's funny because I think if you would have done this [drawn the ecomap] when we were having the bone-marrow transplant, it probably would have been much more one-way from them giving me support. But I feel like now we've kind of like balanced out again.'

Combining the construction of the ecomap with an in-depth conversation therefore allowed for a deeper appreciation of the subtle changes in relationships that were occurring over time.

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Discussion and implications for practice

Understanding our relationships with others (being with) and how these evolve and are situated in time (temporality) can fundamentally enhance our understanding of individuals' unique existence in the world (being in the world).

Ecomaps provided a valuable opportunity in this study to shed light on research participants' unique contexts. The ecomaps completed during the study varied significantly and demonstrated each participant's unique social network of support and tension. The purpose of the ecomaps was not to draw comparisons between participants or derive generalisations, because this is not the purpose of a hermeneutic phenomenological study.

Just as we exist in time and are defined by time, our relationships are also situated in time. Every relationship is shaped by past relationships and we look to the future as we make decisions about how our relationships function. It is not always easy to represent visually the fluidity of relationships in time. However, the process of constructing each ecomap furthered conversation in all the interviews and contributed to a deeper understanding of the complexity of the decision-making these parents experienced.

Important considerations when using ecomaps in hermeneutic research include:

» The value of undertaking a pre-understandings interview, whereby you can create your own ecomap to understand the context in which you may come to interpret your participants' social support systems.

» It can be helpful to show participants an example of an ecomap. However, it is important to stress they can use symbols and content flexibly when creating their own ecomaps.

» The creation of an ecomap should be an iterative process. It is important to remain open to adding and removing people and changing symbols as the interview progresses.
» Relationships are dynamic, so each ecomap created will not be a definitive representation and is not generalisable.

Using ecomaps in hermeneutic phenomenological research can help to illuminate people's experiences and the nature of their relationships. By enhancing this understanding, healthcare professionals can consider patients' and families' support needs and ensure that processes are in place to empower patients and provide patient- and family-centred care.

Conclusion

Ecomaps are a useful research tool to elicit the complexity of social relationships and provide participants with the opportunity to create a visual representation of their perceived stressors and support networks. As a standalone illustration, the ecomap does little to further understanding; but when it is used as a tool within the context of an in-depth interview, an iterative dialogue can develop whereby participants provide deeper clarity about the ecomap's presentation. This process assists in obtaining richer descriptions of their experiences and their social networks.

Ecomaps can help participants reflect and talk in depth by opening a door to their experiences. Researchers can combine their understanding of Heideggerian philosophical concepts with ecomaps to help deepen their understanding in their search for meaning in the experiences of others. In the context of this study, ecomaps helped in understanding the temporal nature of relationships and how this informs participants' experiences of decision-making.

Exploring the use of ecomaps within a hermeneutic phenomenological study has demonstrated that using this approach is attuned with Heideggerian philosophical understandings. The ecomap can shine a light on our experiences by illustrating our unique context, situated through our relationships with others in a particular time, therefore furthering our understanding and insight into phenomena.

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Why you should read this article:

- To understand a collaborative learning model for developing 'training the trainer' courses
- To develop training programmes on indigenising systematic reviews to local contexts
- To gain insights into adult learning and teaching strategies

Indigenising systematic reviews with a collaborative model of 'training the trainers'

Preethy D'Souza, Baby Nayak, Bhumika TV et al

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Abstract

Background Developing a workforce with the skills to produce and make judicious use of evidence for policy and practice decisions requires trainers who can tailor evidence and training to policy and practice priorities.

Aim To describe how a collaborative learning model adapted a systematic review course to suit Indian nurse educators and research scholars in the conduct and use of systematic reviews.

Discussion A collaborative learning team of academics and research scholars brought together expertise in nursing education in India, and evidence synthesis in India and the UK. Participants found the course was highly beneficial, enhanced independent and critical thinking, and instilled them with the confidence and skills to deliver such courses to Indian researchers, nurses and other healthcare professionals.

Conclusion Contextualising materials and methods to participants' experiences made learning more relatable. The use of adult learning approaches enabled participants to apply the same approaches when leading training in their own institutions and underpinned long-term sustainable working relationships between facilitators and learners, leading to new studies and new resources to support evidence-informed decision-making.

Implications for practice An educational intervention on 'indigenising systematic reviews' with online collaborative learning can produce improvements in the knowledge and skills of participants. Advantages of this educational approach include its flexibility, active involvement of participants and sustainable partnership building. The principles and methods used could be replicated in any setting to train trainers.

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Keywords

clinical guidelines, course evaluation, culture, diversity, education, educational methods, evidence-based practice, nursing care, practice learning, research, systematic review, transcultural care, training, universities

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Introduction

The value of evidence-based practice (EBP) is widely recognised by health professionals (Melnyk et al 2014, Melnyk and Fineout-Overholt 2019). EBP requires timely access to high-quality research evidence that is relevant to the context in which it will be applied (Oliver et al 2014), researchers who can produce evidence that takes context into account and decision-makers who can appraise its relevance to their areas of responsibility. This, in turn, requires people who can train researchers and decision-makers in these methods.

An opportunity to address these challenges came from the Scheme for Promotion of Academic and Research Collaboration (SPARC) – an Indian government scheme for assisting international collaborations in solving problems of national and/or international relevance. SPARC supported us in convening a team of academics from Manipal College of Nursing (MCON), Public Health Evidence South Asia (PHESA), Manipal Academy of Higher Education (MAHE) and University College London's (UCL) EPPI Centre to develop a course to train people to engage Indian nurses and other health professionals in the conduct or use of systematic reviews.

Background

Tutoring for self-directed learning and longer-term mentoring are among the most effective educational interventions for increasing nurses' skills in EBP (Portela Dos Santos et al 2022). 'Training the trainers' programmes for qualified health and social care professionals can increase knowledge, improve clinical behaviour and provide better patient outcomes, particularly if they use a blended learning approach that combines group discussion, didactic teaching and digital resources for individual learning (Pearce et al 2012).

Training nurse educators in the conduct and use of systematic reviews can improve their knowledge, attitudes, practice and competency (D'Souza et al 2021). Training longer term mentors is effective in developing mentors' EBP skills (Spiva et al 2017). EBP mentor development programmes can lead to improvements in patient safety and clinicians' EBP beliefs, practices and abilities; this provides firm justification for investing in such programmes (Alves 2021). However, developing a competent cadre of EBP mentors also requires nurses to have sufficient time and organisational support (Wang et al 2021).

Generally, in 'training the trainers' approaches, numerous trainers deliver the same course simultaneously, giving new participants opportunities to observe experienced trainers' techniques, complete the exercises and then practise instructing parts of the course to other participants.

Some authors have emphasised the role of nurse educators in integrating EBP into nursing curricula in meaningful ways (Hung et al 2015, Sin and Bliquez 2017). This aligns with the EPPI Centre's track record of working collaboratively with stakeholders to produce and use systematic reviews for policy decisions. We therefore adopted a collaborative learning model to develop the course content and learning activities. Our aim was to generate a pool of qualified EBP instructors who would then be able to teach others about conducting and indigenising systematic reviews. We anticipated they would subsequently mentor others in conducting and indigenising systematic reviews.

Method

Course design

Our collaborative learning team of academics and research scholars combined expertise in nursing education (MCON and MAHE) and synthesising evidence (PHESA, MAHE and the EPPI Centre). The team designed a 'training the trainers' course inspired by research into how adults learn, the value of mentoring, reinforcing skills through practical application at work and online learning (Langer et al 2016).

We rapidly assessed our team to identify any learning needs deserving additional

Key points

- Contextualising systematic review evidence is vital to promote evidence-based practice
- This article describes a collaborative learning framework used for 'training the trainers' in indigenising systematic reviews
- The teams involved in this learning exercise benefited by working together and engaging in co-production activities

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emphasis. We found the MAHE team was familiar with systematic review methodology but wanted to understand better how to translate global evidence to local contexts. We also needed to clarify various concepts, find relevance and meaning for India, and explore local resources.

Two studies support the wider significance of these learning needs: Ziam et al's (2021) systematic review, which found that identifying relevant information and contextualising evidence are essential skills in making evidence-informed policy decisions; and Chambers et al's (2018) reflexive scoping review conducted by a team of Canadian researchers of colonial and indigenous heritages, which identified mismatches between ways of knowing, concepts and language, and relationships with literature and beyond.

UCL has an established MSc module in evidence for decision-making that was developed by a leading centre. The UCL team adapted this module to train MAHE's trainers, paying attention when designing the course to: developing culturally relevant course content; the choice of online platform to support distance learning; theories about how adults learn; and evaluation that supports as well as assesses learning.

We used Fellner's (2018) framework for decolonising and indigenising an existing curriculum and modified it, deconstructing the content to be relevant to India while retaining the principles of systematic review in the original curriculum and using local resources and knowledge. We also used Root et al's (2019) co-learning principles and a reflexive approach to indigenise and decolonise the content (Schmidt 2019) by considering its importance in Indian contexts.

The UCL team offered the new course across ten weeks. The curriculum introduced the core principles underlying systematic approaches to reviewing a body of research. It also looked at the ways in which systematic reviews vary – from different purposes and types of research questions to methods for synthesising and presenting both qualitative and quantitative research findings. Participants learned about tools that can assist in producing reviews as well as how to apply review methods to formulate review questions, identify research using bibliographic databases, classify and appraise studies, and plan syntheses of research findings.

Discussion explored the challenges encountered when designing and planning systematic reviews. This considered the Indian context through a worked example that investigated the effectiveness of school-based interventions in improving mental health in young people and explored young people's views and experiences of school-based mental health interventions. The MAHE team worked alongside the UCL team to develop a context-specific review question and identify applicable relevant studies from India.

The course activities included required and optional reading, work in small groups, weekly discussions, feedback of activities, hands-on training and bite-sized teaching materials. We made the course more relevant by emphasising research and systematic reviews about India or by Indian authors, qualitative synthesis, and using databases and software available in India to produce systematic reviews. Table 1 provides further details of the course's content.

The introductory session on systematic reviews prompted discussion of how systematic reviews influence policy and practice in India. It did this by drawing on systematic reviews cited by the National Health Programs (NHP) of India listed on the Ministry of Health and Family Welfare website.

Sessions addressed successive stages of systematic reviews. The session on 'formulating a review question' was designed for participants to identify topics relevant to themselves. Brainstorming discussions considered setting priorities for local needs and issues.

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An important learning objective of a later session was to build skills to conduct systematic searches and appraise existing searches. An integral part of indigenising evidence to a specific context is to identify local research literature and we used the well-researched field of contraception for this activity. We adapted systematic methods of searching international repositories for Indian studies to Indian resources concerning contraception choice and use. These activities were designed to enable the MAHE participants to apply their newly acquired skills to other topic areas, to fulfil the longer-term vision of their being able to prepare systematic reviews with more locally relevant evidence to inform practitioners' and policy-makers' decisions.

Table 1. Overview of the training the trainers course

Week	Title	Review methods content	Learning activities
1	Introducing systematic reviews	» Components and principles of systematic reviews » Comparing systematic reviews and other forms of literature review » Different types of systematic review » Benefits of conducting or using systematic reviews to inform policy and practice	» Small groups explored the use and value of systematic reviews to inform policy and practice in India » The groups also looked at the use of systematic review evidence in India's National Health Programs (NHPs) as well as the types of reviews commissioned by research and governmental organisations
2	Formulating review questions	» How to identify research and review questions relevant to India? » How do the review questions vary in the Indian context? » How to formulate review questions relevant to the Indian context? » Identify published reviews from Indian researchers – preferably reviews with different types of questions and scopes	» A brainstorming session on identifying research relevant to India » Groups discussed and critically reflected on how to formulate questions and set priorities
3	Systematic approaches to identifying relevant research	» Strategies for searching international and Indian databases for Indian studies » Principles and methods to follow to identify studies from India	» Skill-building activities in how to: » Develop search strategies for Indian studies in national and international databases » Explore websites and local resources to identify research information relevant to India » Appraise search strategies
4		» Evaluating searches and screening studies » Conceptualising the question further considering the Indian context » Identifying inclusion and exclusion criteria » Developing a search strategy and appraising the search strategy	» Group work and a presentation on Indian resources » A worked example as a case study
5	Extracting data from included studies	» Coding and extracting data	» Group work and a presentation » Hands-on activities in data extraction and coding
6	Method of analysing findings	» Designing and planning systematic reviews	» Hands-on experience in developing protocols » Smaller groups appraising protocols
7		» Critical appraisal and synthesis of quantitative studies in a systematic review » Tools, challenges in critical appraisal and quantitative synthesis	» The Indian team was oriented to different quality assessment checklists » They were guided through hands-on experience of exploring the quality-assessment checklist for qualitative and quantitative synthesis
8		» Critical appraisal and synthesis of qualitative studies in a systematic review	
9	Evaluating systematic review methods	» Comparing different tools	» Participant-led group discussion » Small group activity to make the participants identify and explore the various kinds of critical appraisal tools on their own instead of the trainers identifying it for the participants
10	Designing and planning systematic review	» Summative evaluation of the training programme	» Self-reflection and group reflection of the cumulative learning experience

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Throughout the training programme, participants strengthened their critical appraisal and synthesis skills for quantitative and qualitative research, in part by developing a protocol and seeking feedback from peers and mentors. Every week, in addition to the topics mentioned in Table 1, there was detailed brainstorming about and discussion of three issues:

1. How to adapt content for delivery at MAHE.
2. How to support adult learning.
3. How to decolonise teaching at UCL about systematic reviews.

This course enabled MAHE and UCL to modify their curricula to be more relevant to different local contexts.

Course evaluation

Evaluation looked at the module's content and teaching practices to establish whether teaching was effective and to assist with continuous improvement. Feedback was sought mid-course to support immediate changes to teaching practice and post-course to inform decisions about its future delivery (Elzubeir and Rizk 2002). Participants were invited to reflect on the module's structure, content, readings, articles, shared resources, materials and videos; the relevance of the module to an existing systematic review course at MAHE; group work and assignments; and the expertise of the UCL faculty.

The participants evaluated the teaching practices in terms of how to teach, not just what to teach. Equal importance was given to the 'content of teaching', 'format of teaching' (for example, platforms used for resource materials, activities and pacing the sessions) and the art and science of adult learning (andragogy) in being learner-centred, problem-focused and self-directed by learners who are intrinsically motivated (Smith 2002).

Results and discussion

Figure 1 illustrates the design and delivery of the course, as well as the collaborative learning and outputs that resulted from it.

Learning for MAHE

Participants from MAHE said the course brought in new perspectives and resulted in stimulating discussions about context, indigenising methodologies and customising the search and quality assessment tools. Overall, they felt that the course was highly informative, relevant, encouraged self-directed learning and team-learning, and gave Indian researchers the confidence and skills to conduct such courses in future. They acknowledged that the training programme helped them to adopt a broad approach when synthesising evidence, including in qualitative and mixed-methods studies, compared with the more usual focus on quantitative studies of effectiveness. They saw the programme as helping to strengthen their critical thinking skills and leading to new learning that would subsequently be incorporated into the day-to-day teaching and clinical practice of trainers.

MAHE trainers subsequently shared the skills and knowledge acquired during the programme to train and mentor their colleagues, early career researchers, and postgraduate and doctoral students at MAHE and other institutions from different states in India, such as the All India Institute of Medical Sciences. It was evident from the workshops the MAHE trainers subsequently organised that the course improved their confidence in leading systematic review training. They have been able to transform their training programmes to an adult learning approach, and they plan to hold two or more such training programmes annually for Indian researchers.

Learning for the EPPI Centre

Similarly, the EPPI Centre benefited from working closely with Indian colleagues. Developing the course enabled the EPPI Centre team to reflect critically on the UCL Master's degree systematic reviews module. They can now tailor its content to students from different parts of the world, including threading concepts of localising evidence in relevant sections, such as emphasising the importance of searching local resources

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for local, policy-relevant review questions. The course also provided a starting point to develop a similar programme, with teams from across the global south helping them localise evidence to support decision-makers in Brazil, Uganda, South Africa and Thailand.

Collaborative learning

Adult learning strategies ensured co-ownership and co-learning that enabled the teams to continue research in the area. The learners continued to work with evidence synthesis papers and to generate evidence. These are now at different stages of the publications process.

A significant long-term effect of the programme was to provide a strong, sustainable foundation for a cross-disciplinary, international research network for joint research between UCL and MAHE. For instance, the two institutions are involved in systematic reviews of public health topic areas such as contraception and COVID-19.

The collaborative team also conducted detailed analysis of how systematic review evidence is used in NHP guidance and policies in India (Rajwar et al 2023).

Success factors

It was vital when indigenising the course to have an Indian academic with appointments at UCL and MAHE to lead the work. This role aligned the work with pivotal components of a culturally responsive, adult learning approach: mutually supportive learning circles to discuss and apply newly acquired skills; peer mentoring for socio-emotional and academic support; and a teacher-learning relationship that creates a safe and respectful learning space (Ragoonaden and Mueller 2017).

Limitations

The programme's classes took place every week and busy participants found it hard to find the time to read all the required materials, do the activities and come prepared for the small and large group discussions. A subsequent course with another cohort met every two weeks, but this did not overcome the challenge. The fundamental barrier to such programmes may therefore be insufficient funding to protect the time required. Morrison et al (2022) similarly found this factor a barrier to research activity among nurses in clinical practice.

Crucially, training-the-trainer programmes face sustainability challenges as they rely on retaining trained staff (Pearce et al 2012). The EPPI Centre team tried to move from relying on the skills of individual members of staff to committing to organisational capacity in its subsequent course. Participants discussed how providing an environment conducive to learning can support learners formally and informally. This was inspired by what is known about strengthening organisational capacity of research close to policy or practice (Cooke 2005), particularly systematic reviews (Oliver et al 2015). It is unclear whether this approach can improve long-term sustainability.

Indigenising systematic reviews is an emerging area with multiple approaches and tools, but there is little consensus about the best methods to use (Munthe-Kaas et al 2019, 2020). We explored some methods during the course and as part of the wider partnership; however, it is not yet possible to give unequivocal guidance about

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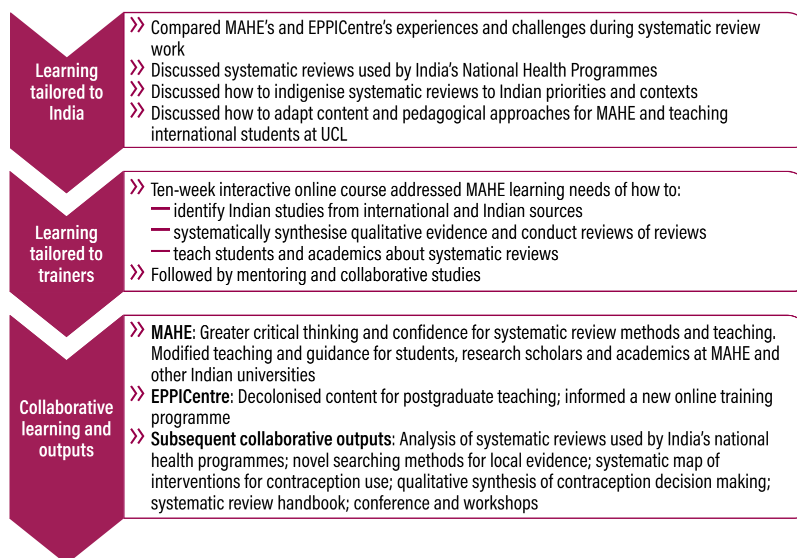
Figure 1. Overview of the module's design and consequent learning



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how to use systematic review evidence in ways that reliably and accurately consider differences between the contexts of study and informing decisions with the findings.

Although participants in the programme have since applied their new learning, we have not assessed how well they did so.

Conclusion

Our programme culminated in the co-production of indigenised learning materials and recommendations for modifying existing systematic review courses. Both teams benefited from this co-learning experience: the MAHE team learned about appraising evidence for its relevance to India, while the UCL team learned how to decolonise course content. Overall, the participants felt that the course was highly beneficial, enhanced independent and critical thinking, and instilled Indian researchers with the confidence and skill to conduct such courses in future. Contextualising evidence made learning more relatable and relevant, which resulted in a continued partnership and long-term sustainable working relationships between the facilitators and the learners.

Training health professionals in evidence synthesis is crucial to ensure that the next generation receives accurate, evidence-based information and to increase the number of healthcare professionals who base their practice on the best available evidence. Our programme enabled us to extend similar training opportunities to researchers, practitioners and educators from other institutions in different parts of the world.

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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

Chris McParland, Bridget Johnston, Bahaa Alassoud et al

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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

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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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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.

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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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

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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 outsets 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.

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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.

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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

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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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- To appreciate why changes in culture are needed in the health professions to support an evidence-base to better serve our populations
- To understand how to build research capacity and show the benefit of investing in training opportunities

Using the making Visible the ImpaCT Of Research (VICTOR) questionnaire to evaluate the benefits of a fellowship programme for nurses, midwives and allied health professionals

Carolyn Spring, Julie Hogg, Judith Holliday et al

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Abstract

Background There is increasing emphasis in the UK on developing a nurse, midwife and allied health professional (NMAHP) workforce that conducts research. Training for clinical academic careers is provided by the National Institute for Health and Care Research (NIHR). However, the low number of successful applicants suggested there were barriers to achieving this. The Centre for Nursing and Midwifery Led Research (CNMR) launched a fellowship programme in 2016 to backfill two days a week of NMAHPs' time for up to a year, to give them time to make competitive applications to the NIHR.

Aim To report a study evaluating the CNMR fellowship programme.

Discussion The making Visible the ImpaCT Of Research (VICTOR) tool (Cooke et al 2019) was developed to describe the organisational impact of research. The 2016-17 CNMR fellows completed VICTOR and their responses were analysed using a framework approach. The analysis found the main benefits of participating in the programme were protected time for research, opportunities to develop collaborations, increasing intra- and inter-professional awareness of NMAHPs' research, peer-reviewed publications, and conference presentations. Challenges included a lack of support from line managers, limited value placed on NMAHPs' research and failure to backfill posts.

Conclusion There were some challenges with the fellowship programme, but all recipients found it to be a positive experience and undertook significant scholarly activity.

Implications for practice A contractual agreement must be established to foster committed partnerships between higher education institutions (HEIs) and the NHS. HEIs and the NHS should conduct frank discussions of the challenges encountered in fellowship programmes. Positive initiatives and outcomes in tertiary education and clinical settings should be shared to improve fellows' experiences and enhance partnerships between HEIs and the NHS. Job descriptions should include time allocation to review fellowship candidates' applications regardless of outcome. The showcasing of research successes and the benefits of NMAHP research must evolve to secure organisational 'buy in', which is the precursor to widening access to clinical academic pathways.

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Keywords

academic careers, audit, career pathways, careers, education, funding and resources, nurse academics, organisational culture, professional development, professional issues, research, role development

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Introduction

It is increasingly important for the nurse, midwife and allied health professional (NMAHP) workforce to conduct research. Training for clinical academic careers is provided in the UK by the National Institute for Health and Care Research (NIHR). However, the low number of successful applicants for this training suggested there were barriers to achieving this aim.

A fellowship programme was launched in 2016 to backfill two days a week of NMAHPs' clinical commitments for up to a year, to give them time to make competitive applications to the NIHR. This article describes a study that evaluated the programme to determine its value.

Background

Integrating research into healthcare policy and practice is a global imperative (Uzochukwu et al 2016). NMAHPs have an integral role in undertaking research to enhance the quality, organisation and safety of patient care (Association of UK University Hospitals (AUKUH) 2016).

Historically, medicine and dentistry have universally valued research, with clinical academic research pathways embedded in those professions' career structures. But internationally, this culture of opportunity does not apply to NMAHPs (Smith et al 2018) and in the UK, 4.6% of medical consultants are clinical academics compared to only 0.1% of NMAHPs. The aspiration is for 1% of NMAHPs to be in clinical academic roles by 2030 (Baltruks and Callaghan 2018).

The extent of ongoing research by NMAHPs in the UK is currently uncharted. But two recent studies have explored the routes through which NMAHPs pursue careers in research: Trusson et al (2019) and Avery et al (2022).

Trusson et al (2019) surveyed 67 survey respondents and conducted 16 in-depth interviews to investigate NMAHPs' motivations for and experiences of embarking on academic pathways. The authors proposed interventions to support NMAHPs earlier in their career trajectories.

Avery et al (2022) investigated 134 doctoral and 96 post-doctoral NMAHP applicants at University Hospital, Southampton. The researchers found that the limited availability of research roles, clinical academic positions and funding presented barriers to career progression.

The two studies highlighted the competing demands of undertaking clinical and academic roles, and proposed action to enhance the visibility of and access to clinical academic career pathways. Neither study formally evaluated the benefits of undertaking research to the NMAHP, organisation or the patient.

Newington et al (2021) and Olive et al (2022) addressed this omission in their evaluations of NMAHP clinical academic

Key points

- While funding and time can be provided to assist nurses in writing fellowship funding applications, academics at HEIs need to provide the equivalent in supervisory time for these applications to be successful
- Giving nurses more time is not enough for them to progress as clinical academics; they also need research-related coaching and mentorship, preferably by people in clinically similar roles
- Working in a research role in clinical settings inspires other nurses to explore their own research potential
- It is not always possible for managers to backfill fellows' time, especially if they are in specialist roles, which potentially affects the workload of the wider clinical team

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programmes. These studies found there were tangible benefits for NMAHPs' professional development, clinical teams and patients; the programmes also aided in embedding a research culture.

The ICA fellowship programme

The emergence of clinical academic careers (CACs) in nursing can be determined from 2007. UKCRC's (2007) enquiry into research capability and capacity in nursing underpinned its three main recommendations: a structured, research-based educational pathway; a flexible career structure to enable nurses to work clinically as well as have a research role; and NHS careers advisors to promote the range of opportunities in research.

There was initially no funding or resources to accompany the proposed educational pathway to support nurses interested in research. The pathway did not progress until 2013, when the National Institute for Health Research (NIHR) and Health Education England (HEE) launched the Integrated Clinical Academic (ICA) fellowship programme.

Five levels of funding were introduced to support NMAHPs from pre-master's level to senior post-doctoral research (HEE 2015); this was akin to the well-established Clinical Academic Training fellowships for medics and dentists. The funding was initially for the research aspect of the role while training for the clinical role continued to be covered by the NHS; the ICA award today incorporates funding for the whole role, including clinical development.

Annually, approximately 170 healthcare professionals in England receive an ICA fellowship (NIHR 2019). But nurses have been less successful than other allied health professionals (AHPs) with their applications (NIHR 2017). Nursing cultures' emphasis on direct patient care can create conflicting expectations about roles for those undertaking clinical academic research (Van Oostveen et al 2017).

These professional asymmetries in CAC progression require further investigation.

Providing support for nurses and midwives in a university hospital

The NIHR provides funding for 13 biomedical research centres (BRCs) to support research activity in the NHS in England. In 2010, the University College London Hospitals NHS Foundation Trust (UCLH) BRC provided funding to establish the Centre for Nursing and Midwifery Led Research (CNMR), led by a senior clinical nurse supported by two professors of nursing. This accompanied the launch of UCLH's own nursing and midwifery research strategy, which focused on cancer, women's health and children, long-term conditions, ageing, and acute and critical care; each of these areas was led by a research-active senior nurse or midwife (Mitchell et al 2015).

The CNMR was intended to support the development of clinical academic careers and research capability for nurses and midwives in the trust through a host of activities (Table 1). The scope of the CNMR was extended to include AHPs in 2015, in line with contemporary guidance (AUKUH 2016), and the centre was rebranded as the CNMAR. No additional financial or operational resources were provided.

Establishment of the fellowship programme

The CNMAR successfully increased the visibility of research in the trust but had limited success with NIHR fellowship applications. Therefore, funding was provided in 2016 with the support of UCLH Charity and the UCL Midwifery Legacy Fund to launch a trust-based fellowship programme.

A CNMAR fellowship gave an NMAHP protected time to undertake research and prepare a competitive application to the NIHR (or equivalent) fellowship scheme; £1,500 was also available to the NMAHP to pay for directly incurred costs.

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The CNMAR determined the objectives and financial outlay of each fellowship, based on the NMAHP's academic level (doctoral or post-doctoral) and the requirements of achieving a competitive application, such as costs arising from pilot/feasibility studies, patient and public involvement, and education and training. Additional support included an honorary contract with the university so that the NMAHP could access electronic journals and databases more easily.

NMAHPs on a substantive UCLH contract and who had been in post for more than 12 months could apply for funding to backfill their jobs for up to two days a week for 12 months. Applicants required support from their line managers to be released from their clinical practice, as well as the engagement of an academic supervisor or mentor.

Candidates attended a formal interview and made a 10-minute presentation: 'How does your proposed research fit with the CNMAR, hospital and NIHR strategies?' The panel included the deputy chief nurse, the director of the CNMAR, a clinical academic psychologist and an academic nurse from a university.

No formal evaluation of the fellowship programme was proposed, only the submission of a final written report outlining the activity undertaken and achievements. The aim of this study was to evaluate the first two cohorts of fellows, using a questionnaire developed to measure the organisational impact of research.

Method

The making Visible the ImpaCT Of Research (VICTOR) tool (Cooke et al 2019) was developed with a community of practice and from a comprehensive review of the literature to evaluate the effects at the organisational (hospital) level of research being undertaken in the NHS. It is based on six pillars: participant and carer health benefits; service and workforce impacts; research capacity; economic impacts; influence and reputation; and knowledge generation and exchange (NIHR 2019). The questionnaire has 23 questions in total, with each pillar containing three to five questions (Table 2) that have prompts to guide reflection. The response to a question can be 'yes', 'no' or 'not yet'; respondents are also asked to provide examples and detail to support their answers.

VICTOR enables the assessment of the wider impact of a study by collating responses from and insight into the perspectives of members of the research team, such as the principal investigator, research nurses, clinical staff and laboratory staff. For example, if a clinical trial included a new piece of equipment, traditional methods of measuring impact would focus on whether it was effective, but VICTOR captures the impact on the wider workforce of the development of a new skill (learning how to use the new equipment). These multiple perspectives are important in identifying the 'hidden' impacts on the organisation – the benefits to the hospital over and above the primary outcome of the study.

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Table 1. Aims and activities of the CNMAR

Aims	Examples of activities
Increase research capability	» Providing research education through formal lectures, one-to-one personalised support and a series of handbooks » Distributing a monthly newsletter that includes training available for the following months » Holding a doctoral support group » Creating action learning sets for NMAHPs on intern and fellowship programmes
Increase research capacity	» Creating a fellowship and intern programme » Supporting the delivery of research – for example, by providing guidance through regulatory processes » Supporting applications for research grants and fellowships » Supporting CAC progression
Raise the visibility of research undertaken by NMAHPs	» Publishing *CONNECT*, the trust's in-house academic journal » Leading the annual research conference » Hosting a Royal Literary Fund Writing Fellow to support written communication » Including a synopsis of new publications by NMAHPs in the monthly newsletter » Publishing an annual report, including academic achievements in the previous 12 months

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VICTOR was developed to measure impact at the organisational level, but discussion with its development team and the head of research and innovation in a hospital who had extensive experience of using it indicated it could be used in other research activity as a guide for reflection.

In 2018, the research team emailed a Word version of VICTOR to the first two cohorts of CNMAR fellows: one nurse, two midwives, two physiotherapists and a dietician (*n*=6). The cohorts had all finished their fellowships at least 12 months earlier, which was enough time for outcomes to be realised from the fellowship: they had submitted 16 applications for fellowship or research grants (one to six applications per person); five (83%) had been shortlisted for fellowship interviews, of whom three (60%) had been successful; and they had published 14 manuscripts, made 15 conference presentations and attended 14 conferences or training days.

The research team sent a reminder three weeks later to anyone who had not completed the questionnaire and returned it.

Table 2. Summary of VICTOR's pillars and items

Pillar	Items
Health benefits, safety and quality improvements for research participants and carers	» Health benefit » Experience » Patient safety » Social capital
Service and workforce impacts	» Service change » Clinical or generic skills » Workforce » Collective action » Guidelines
Research profile and capacity	» Research culture » Research awareness » Research capacity » Networks and collaborations » Engagement
Economic impacts	» Cost saving/cost effectiveness changes » Commercialisation » Income
Influence and reputation	» Cohesion » Reputation » Recruitment and retention of staff
Knowledge generation and knowledge exchange	» Formal dissemination » Knowledge sharing » Actionable outputs

Results

Five fellows (83%) completed and returned the VICTOR questionnaire. Analysis of their responses followed the methodology stipulated in Cooke et al (2019). Text was analysed with content analysis and the results presented within the six pillars (Figure 1). Quotes from the responses are included in the following section.

Research activity

- The fellowship provided valuable time to develop an application: 'The fellowships help realise research potential, and without them I think it would make delivering the NMAHP strategy almost impossible aside from those consultant level roles.'
- There was also an increase in NMAHP research activity: 'Within [directorate] there is a lot of clinical research ongoing… little of this is currently [NMAHP]-led.'
- Colleagues were exposed to the option of a clinical academic career, as fellows were clinically based: 'Having the opportunity to participate in research I feel has improved staff morale and motivation.'

Challenges

The fellows were mostly positive about the scheme but reported several challenges:

- The 12-month honorary contract with the university during the fellowship had concluded when NIHR interviews were held and fellows had no access to library facilities to explore more recent evidence.
- Managers had authorised their support for the application but did not always honour this concord following appointment. Additional negotiations were therefore required for the appointee to be able to continue.

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- Some managers took receipt of the funding but did not backfill the post. Whether this was due to a lack of available applicants was unclear, but there was consequently additional pressure on the rest of the team.

Discussion

Operationalising the CNMAR fellowship scheme provided insight into the organisational and managerial structures available to support those combining academic research with clinical practice and the future commitment required. The programme granted awardees access to a network of professional role models including senior academics. These supportive clusters enabled fellows to discuss their aspirations and ambitions and to be directed to routes for progression in CACs.

The main benefits of the scheme included increasing research capability (the number of researchers) and capacity (more papers were published in peer-reviewed journals). These benefits – combined with the increased visibility of NMAHPs undertaking research – may affect how other NMAHPs see the role of research in relation to their own career choices. Collectively, these positive outcomes can influence perceptions of how a trust values research led by professionals outside medicine.

Nevertheless, fellowship benefits were largely driven opportunistically by individual practitioners, not organisational processes, as Nightingale et al (2020) and Olive et al (2022) also found. There were institutional barriers to the CNMAR fellowship programme:

- Those submitting a doctoral-level application needed to have identified a supervisor at a university to provide support and guidance on the fellowship application.
- Elected supervisors did not always provide regular meetings or the pastoral support needed to steer progression on the NIHR ICA application.
- Formal guidelines to frame the expectations and requirements of the supervisory role were not embedded at this time (but are now in place). Coaching and mentoring and peer support meetings were also later implemented by the CNMAR to bridge this gap.

Perhaps unsurprisingly, organisational preparedness and the internal visibility of the fellowships were limited. Uncertainty exists as to where research active NMAHPs 'sit' in higher education institutions (HEIs) and the NHS, and organisational responsibility for these groups remains ambivalent. Research undertaken in the UK and Sweden (Springett et al 2014, Nyström et al 2018) indicated that leadership of fellowship schemes can be compromised by differing priorities and a lack of integrated practices between HEIs and healthcare organisations. Conflicts can therefore arise through different role expectations and demands in the practitioner's and educator's contexts (Nyström et al 2018).

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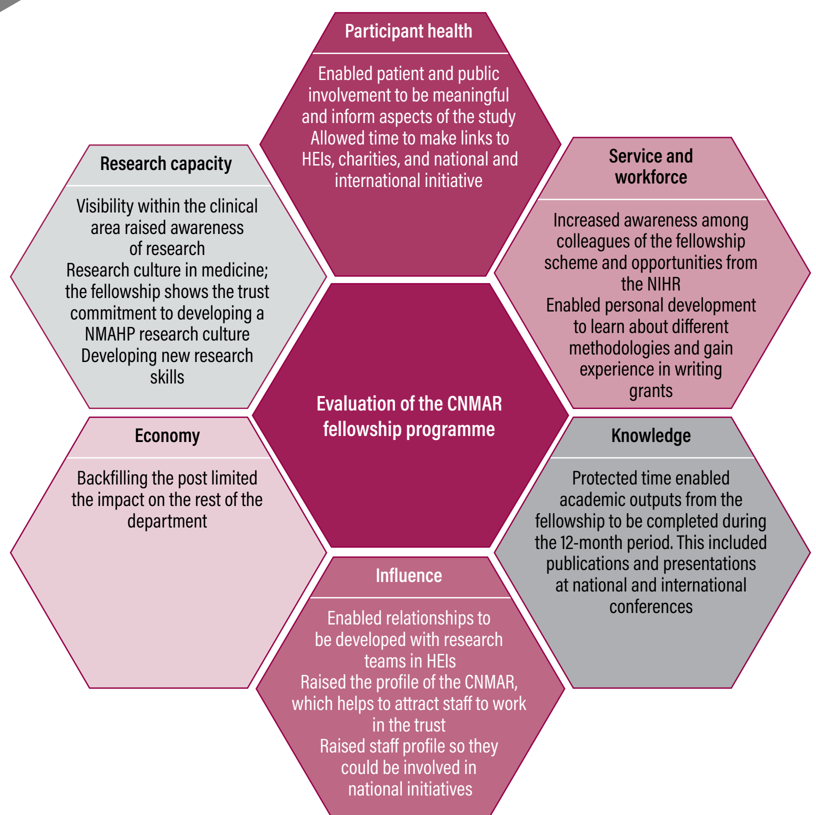
Figure 1. Summary of the impact of the fellowships



Greater focus should be given to brokering the education relationships to align education and health-service leadership to anchor clinical academic research pathways. This cannot rely on individual goodwill. Remuneration structures must ensure clinical research leaders in the NHS no longer spend significant time periods assessing fellowship applications outside their paid roles. NHS primary objectives reside with improvement in patient care outcomes, integration of services and cost efficiencies. HEIs compete to generate income through grants and enhanced reputation through peer-reviewed publications (Springett et al 2014). Competing organisational priorities and activities, economies, political decision-making, organisational changes and delays may undermine the infrastructure to support research.

The CNMAR fellowship experience revealed that research-aware, supportive, enthusiastic managers who understood the value of research played a significant role in the programme's success; Nightingale et al (2020) similarly identified managers as 'gatekeepers' to research.

In a climate of workforce shortfalls, effective planning prevents the burden of responsibility for backfilling the fellow's post falling to the clinical team. Development of new job descriptions with protected time for research could legitimise the research as 'fundamental' rather than 'optional', ensuring research time is planned from inception as an initiative conducted outside rostered clinical hours. Connecting the positive impacts of fellowships with staff recruitment and retention could assuage participation challenges centred on staffing concern (Newington et al 2021, Olive et al 2022).

Perceptions of the value of clinical academic NMAHPs in the NHS and their visibility have not evolved in line with the skilled professions themselves. Locally, the achievements captured in the CONNECT journal elevate the profile of NMAHPs' research, but this does not align with the limited organisational attention afforded to their efforts, activities and outputs. Internationally, the heterogeneous nature of NMAHPs' research should be illuminated and a deeper exploration should be conducted of their co-priorities – for example, high task volumes, patient advocacy expectations and time constraints. Wider evaluation is required of the impact of NMAHPs' research on patients' experiences and outcomes, the organisation of service delivery, and service efficiencies.

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Limitations

This evaluation was based on the perspectives of a small cohort of interns in one region so the findings may not be transferable to other organisations. Two members of the cohort left the trust following the programme; one remains research-active in the hospital; two NIHR fellowships are ongoing; and one is continuing in their professional role while retaining a research role.

Future research must address the longer term professional and organisational impact of fellowship and intern programmes and assess how they differ nationwide and internationally. The impact should also be explored in relation to the increasing prevalence of healthcare burnout (Montgomery et al 2019). Diverse professional role comparisons and investigation of NMAHP role symmetries in clinical academic successes should be undertaken.

Understanding better how dynamics in professional cultures, institutional narratives and structures can impede but also facilitate research engagement in different professional groups could assist in designing more enabling programmes for nurses and midwives. There is also potential to explore if positive practices and new collaborations can be gained from medical clinical academic pathways to support non-medics in their research journeys. The genders and ethnicity of participants should be recorded to determine if specific groups are leading or trailing in research.

Implications for practice

- A contractual agreement must be established to foster committed partnerships between HEIs and the NHS.
- HEIs and the NHS should conduct frank discussions of the challenges encountered in fellowship programmes.
- Positive initiatives and outcomes in tertiary education and clinical settings should be shared to improve fellows' experiences and enhance partnerships between HEIs and the NHS.
- Job descriptions should include time allocation to review fellowship candidates' applications regardless of outcome.
- The showcasing of research successes and the benefits of NMAHP research must evolve to secure organisational 'buy in', which is the precursor to widening access to clinical academic pathways.

Conclusion

VICTOR was developed to draw out and highlight the impact of a research project or portfolio but proved helpful in guiding reflection on the organisational impact of the fellowship programme. This small study revealed how leadership priorities, organisational values and culture affect academic research in clinical practice. Supervisors and mentors have a key role to play in providing pastoral support and navigating the parallel priorities of NMAHPs that arise from their clinical roles. Their investment must extend beyond academic support to provide encouragement, reflective discussion and, if necessary, intervention with partnering organisations to resolve issues arising from competing demands in practice and research.

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Why you should read this article

- To avoid underrepresentation of minority ethnic groups in clinical trials
- To ensure patients' perspectives of participation are considered in clinical trials
- To understand how a face-to-face approach and the research team's expertise can influence a patient's decision

Evaluating ethnically diverse patients' perspectives of considering participation in renal clinical research

Joy Oghogho Agbonmwandolor, Sarah Brand

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Abstract

Background Clinical trial cohorts do not often reflect target patient populations because minority ethnic groups are underrepresented in clinical trials.

Aim To increase minority ethnic groups' opportunities to participate in clinical trials, by evaluating ethnically diverse patients' perspectives of considering participation in renal clinical research.

Discussion The authors gave patients participating in at least one research study the opportunity to take part in a structured survey. The survey explored preferences, barriers and opportunities that patients considered when deciding whether to take part in a clinical trial. The authors included participants from multiple ethnic groups so they could compare data for different ethnicities.

Conclusion Participation was a positive experience for most patients, mostly because of the research team's flexibility and professionalism. Researchers' gender and ethnicity did not affect the participants' decision to participate. Cultural preferences were not obvious from the data as 80% of the participants were white.

Implications for practice Patients preferred a face-to-face approach and the expertise of the research team affected participation more than any other characteristics did. However, respondents were already research-engaged and conducting a similar study with those who have declined to participate in research may show different results.

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Keywords

black and minority ethnic, clinical trials, diversity, ethnicity, multiculturalism, research, study participation, study recruitment

Introduction

The diversity of Britain's population has been changing (Office for National Statistics 2011, 2021) and as it has continued to increase, so too have the health challenges. A significantly smaller proportion of minority ethnic individuals than of white individuals participates in

clinical trials (Zhang et al 2013). This underrepresentation of minority ethnic communities in clinical trials is a long-standing problem (Redwood and Gill 2013), as the diversity of a research study's cohort should reflect the demographics of the study's target population (Iqbal et al 2013, Zhang et al 2013) – if it does not, this can affect the generalisability of the trial's findings and lead to poorer treatment outcomes (Pan et al 2020).

This article describes a study that sought to understand research participants' experiences, to try to identify ways to enable more ethnically diverse participation in research. The study explored the preferences, barriers and facilitators to participation, so that further research can develop interventions to increase minority ethnic participation in research.

Background

There has been a drive since the COVID-19 pandemic to promote inclusion and diversity in clinical trials (Mohan and Freedman 2022). But there are unequal power dynamics that often lead to marginalisation and exclusion in research (Baah et al 2019, Sevelius et al 2020). Widespread institutional racism and systemic inequalities across society have played a significant part in widening health inequality, leading to poorer health outcomes in minority ethnic communities (Chew et al 2021).

Researchers may draw participants from a less diverse pool of patients for several reasons. It has become more prevalent since the pandemic to conduct studies remotely (Fisher et al 2021, Lampa et al 2021), which may be a barrier to underserved communities' participation. Studies' inclusion and exclusion criteria may make their cohorts less diverse, and researchers may only target patients who are research-engaged (Dowd et al 2000), as this can help to meet recruitment targets and develop trust with participants. However, it can have a negative effect as well, as participants may become overwhelmed by research activities (Schmotzer 2012) or reluctant to withdraw from trials as they may not want to let down the researchers.

It is important that participants in clinical trials have a positive experience and are not unduly burdened by the responsibilities involved. It is also essential that they feel safe and can articulate their concerns at any point. International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (1996) generally maintains equipoise in studies between answering the research question and ensuring that the health and well-being of participants is of the utmost priority (Dixon 1998). However, questions remain about the safety of clinical trials (Yao et al 2013) and the unethical history associated with them (Paul and Brookes 2015). There is also a history of minority ethnic participants being unsafe in clinical trials (Beskow 2016, Nix 2017), which may have a bearing on how the minority ethnic population views participation in research.

Russell et al (2022) suggested there has been a substantial decline in the number of people agreeing to take part in research. Barriers to participation have been heavily researched (Wright 2020, Farooqi et al 2022) and most are rooted in four factors: socio-economics, language and communication, culture, and the researchers themselves. Participation in research is affected by socio-economic status including immigration status (Occa et al 2018), mistrust (Luebbert and Perez 2016), the burden of participation (Schmotzer 2012), concerns about language, culture and religion (Rooney et al 2011), the use of personal data and the effects of treatments (Lip et al 2022). The marginalisation of minority ethnic communities in clinical trials has most often been because of the design of the research, socio-economic factors and their experiences (Chew et al 2021).

The question of what can be done to reduce the lack of diversity in recruitment should be explored at every stage of a study (Hamel et al 2016). Researchers and research delivery teams should think about

Key points

- The experience of taking part in research is not significantly different for white and minority ethnic populations
- The research team's professionalism, expertise and communication skills were the biggest determinants of participation
- Patients significantly preferred being approached face to face when being asked to participate in research
- More work is needed to determine how participants' positive experiences can be used to engage others, particularly minority ethnic individuals

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not only meeting their participation targets but also ensuring participation is ethnically diverse (Treweek et al 2021). They should design and conduct studies so they are easily understood by and readily accessible to underrepresented communities. For example, conducting clinical studies in environments familiar to them might increase their participation (Wright 2020).

Patients' experiences are followed closely in healthcare (Luxford and Sutton 2014), but they are not always explored within the context of participation in research. Having a good understanding of how participants feel about taking part in studies could be helpful in developing a user-friendly research delivery service well-suited to different communities. This will assist in creating a more adaptive approach to delivering research (Pallmann et al 2018).

Method

A survey was conducted between January 2022 and April 2022 at the renal units and satellite centres of a renal centre in the East Midlands in England. Permission to carry out the study was obtained from the renal centre's NHS trust and it was undertaken as a service evaluation.

A questionnaire was developed to determine patients' preferences concerning participation, as well as potential facilitators and barriers to considering participation in clinical trials. The research team and staff at various units offered the questionnaires to patients who met the inclusion criterion – patients involved in at least one clinical trial were eligible to participate. Patients from all the ethnic groups involved in the trials were included to allow for comparison of the results for different ethnicities.

Participants could complete the questionnaire on-site or at home. Participation was voluntary and no financial incentives were offered. Completion of the questionnaire was an indicator of implied consent. Data from the completed questionnaires were transposed into an Excel spreadsheet and analysed. Responses were anonymous.

Results

A total of 120 questionnaires were distributed; 55% (*n*=66) were completed and returned. Only 6% (*n*=4) of the respondents failed to answer all the survey's demographic questions, while 94% (*n*=62) completed the survey in full (Table 1). The average age of the respondents was 62 and those in older age groups were more likely to respond.

The responses were grouped into three categories based on the independent variable of ethnicity: white, minority ethnic and unknown ethnicity. The analysis then focused on three potentially dependent variables: participants' preferences, and the barriers and facilitators to participation in renal research that the participants had considered.

It was necessary to determine the probability that any relationships between the independent and the dependent variables that the analysis obtained were

Table 1. Analysis of respondent demographics

Demographic variable		n	%
Ethnicity	White	53	80
	Minority ethnic	9	14
	Unknown ethnicity	4	6
Age	18-30	0	0
	31-40	6	9
	41-50	8	12
	51-60	14	21
	61-70	15	23
	71-80	14	21
	81-90	6	9
	91-100	1	2
	Unknown	2	3
Gender	Male	43	65
	Female	21	32
	Unknown	2	3

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not due to chance and were statistically significant. A hypothesis was therefore formulated about the effect of the independent variable on the dependent variables: the null hypothesis was that the independent variable did not influence the dependent variables; the research hypothesis was that they did have an effect.

Descriptive statistical analysis was conducted using the statistical software Minitab. One-way ANOVA was used to analyse the null and research hypotheses. The *P*-value of each survey question was calculated, with $P \leq 0.05$ considered statistically significant (Harris and Taylor 2014). A 95% CI was calculated for each ethnic group's responses to each survey question, to understand the variability of the data and its statistical relevance and because a 95% confidence interval is more informative than a *P*-value (O'Brien and Yi 2016).

Participants' preferences

Most respondents did not have a preference about the gender or ethnicity of the person approaching them concerning participation (Table 2). However, they did prefer a face-to-face approach ($P=0.047$). The 95% CIs for white and minority ethnic individuals overlap, indicating the variability in their preferences is not statistically different.

Figure 1 shows the factors identified that would encourage participants to take part in research.

Barriers to participation

The data show that people from white and minority ethnic backgrounds were equally likely not to discuss participation in research with family, friends or their medical team. Someone's support system can influence their decision-making (George et al 2014) and some participants confirmed others had influenced their decision to take part in research. Recommendations by family or friends can promote participation in research (George et al 2014). A few participants indicated they would not recommend participation in research because the process can be overwhelming.

Table 2. Analysis of participants' preferences

Question		White	Minority ethnic	Unknown ethnicity	*P*-value
How would you prefer to be approached about a clinical trial?	Face to face	44%	12%	6%	0.047
	Telephone	3%	0%	0%	
	Email	5%	1%	0%	
	No preference	29%	0%	0%	
	95% CI	(7.28, 9.29)	(8.79, 13.78)	(7.35, 14.65)	
Would you have preferred to have been approached by someone from your ethnic background?	Yes	5%	0%	2%	0.226
	No	3%	0%	0%	
	Don't mind	71%	12%	5%	
	Prefer not to say	1%	1%	0%	
	95% CI	(2.78, 3.22)	(2.80, 3.87)	(1.69, 3.31)	
Would you have preferred to have been approached by a male or a female member of the research team?	Male	0%	0%	0%	0.688
	Female	3%	2%	0%	
	Don't mind	74%	12%	6%	
	Prefer not to say	3%	0%	0%	
	95% CI	(2.96, 3.83)	(2.72, 4.83)	(1.42, 4.58)	

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Figure 2 shows the barriers identified to taking part in research. An analysis of the barriers is shown in Table 3.

Facilitators to participation

The main facilitator to participation was a positive research experience created by the research team's expertise. The data show respondents were not pressured to consent to participate, as they felt they were given enough time to make a decision (Table 4).

Figure 3 shows the facilitators identified to taking part in research.

Figure 1. What participants preferred

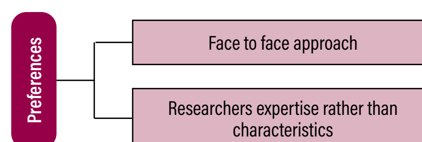

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Table 3. Analysis of barriers to participation

Questions		White	Minority ethnic	Unknown ethnicity	*P*-value
Did you discuss the research study with your family, friends or medical team?	Yes	33%	5%	1%	0.118
	No	41%	8%	1%	
	Don't remember	3%	2%	3%	
	Not applicable	3%	0%	0%	
	95% CI	(2.45, 3.59)	(2.06, 4.83)	(3.17, 7.33)	
Did your family, friends or medical team influence or contribute to your decision to participate in the study?	Yes	11%	2%	1%	0.218
	No	39%	2%	0%	
	Don't remember	3%	0%	3%	
	Did not discuss study participation with anyone	29%	9%	1%	
	95% CI	(4.17, 5.34)	(4.46, 7.32)	(3.86, 8.14)	
Did you find the research information sheet given to you easy to read and understand?	Extremely easy to read and understand	26%	1%	1%	0.898
	Easy to read and understand	48%	11%	3%	
	Neither easy to read nor understand	1%	2%	0%	
	Difficult to read and understand	0%	0%	2%	
	Extremely difficult to read and understand	0%	0%	0%	
	Prefer not to say	3%	0%	0%	
	95% CI	(1.63, 2.29)	(1.20, 2.80)	(1.05, 3.45)	
If English is not your first language, would you have preferred to receive information in your own language?	Yes	8%	0%	1%	0.217
	No	0%	0%	0%	
	Don't mind	5%	1%	1%	
	Prefer not to say	1%	1%	0%	
	Not applicable	67%	11%	3%	
	95% CI	(5.66, 6.7)	(5.16, 7.7)	(2.57, 6.43)	
Would you recommend taking part in research to family and friends?	Yes	58%	8%	5%	0.187
	No	1%	3%	0%	
	Don't mind	20%	1%	2%	
	Prefer not to say	1%	1%	0%	
	95% CI	(1.30, 1.98)	(1.63, 3.26)	(0.27, 2.73)	

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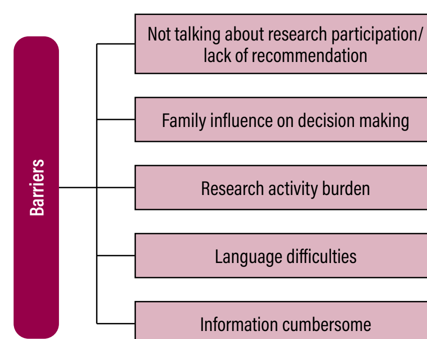
Discussion

This study shows that the experience of taking part in research is not significantly different for white and minority ethnic populations – minority ethnic individuals did not experience any greater issues than their white counterparts did and their profile of satisfaction was similar to other ethnicities'. People's willingness to engage is also unaffected by a researcher's gender or ethnicity. Rather, the research team's professionalism, expertise and communication skills were the biggest determinants of participation. This finding supports Bourke (2002), which highlighted that a practitioner's expertise affects participation more than participants' demographic characteristics do.

Literature suggests researchers' cultural competence is important (Papadopoulos and Lees 2002). Researchers must therefore be aware of minority ethnic individuals' basic cultural values when approaching them to take part in research (Papadopoulos and Lees 2002), as this facilitates a more positive experience for potential participants.

Half the respondents to this study's survey said they did not discuss with their family members whether to participate in research. However, the study's sample size was small compared with the overall renal patient population, so it cannot be assumed this is the case for a wider group of patients. It may be worth exploring how best to educate people to talk about research, to minimise the unease certain communities feel about clinical trials.

Figure 2. Barriers to participation



This study has shown patients significantly prefer to be approached face to face, when being asked to participate in research. This can be explored qualitatively in future research, with a view to identifying methods that researchers can adopt to increase minority ethnic individuals' participation in research.

It might be useful to explore if negative healthcare experiences influence patients' decisions to take part in clinical trials. It may also be useful to sample the views of people in the community about their experiences of research, as well as the views of healthcare professionals in primary and secondary care about their experiences of delivering research. This may provide a broader view of the best strategy for improving ethnic diversity in research.

There is also a need to explore and understand the views of those who decline to participate in research, as these may paint a different picture. One of the limitations of this study is that only patients already participating in research were approached; the views of those who have declined to take part in studies are therefore not represented. They may hold views different to research participants', as the barriers they have experienced have been sufficiently great to prevent their participation.

Conclusion

The aim of this study was to evaluate the experiences of participants in research and to understand how researchers can ensure they have positive experiences of research.

Figure 3. Facilitators to participation

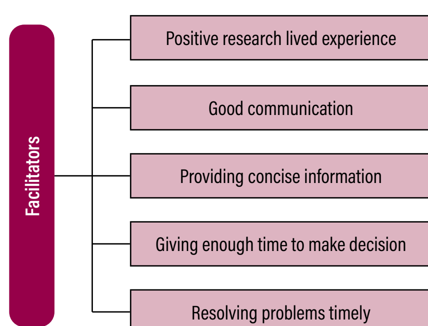


Table 4. Analysis of facilitators to participation

Questions		White	Minority ethnic	Unknown ethnicity	*P*-value
Are you satisfied with your overall research experience?	Extremely satisfied	35%	2%	2%	0.231
	Satisfied	38%	11%	3%	
	Neither satisfied nor dissatisfied	5%	1%	1%	
	Dissatisfied	2%	0%	0%	
	95% CI	(1.46, 1.83)	(1.55, 2.45)	(1.33, 2.67)	
When you were approached about a research study, were you able to ask questions?	Yes	74%	12%	3%	0.06
	No	3%	0%	2%	
	Don't remember	3%	2%	1%	
	95% CI	(0.91, 1.85)	(0.64, 2.92)	(1.79, 5.2)	
Were you satisfied with the answers provided to your questions?	Extremely satisfied	39%	3%	0%	0.707
	Satisfied	35%	9%	5%	
	Neither satisfied nor dissatisfied	3%	2%	1%	
	Not applicable/ Don't remember	3%	0%	0%	
	Unsatisfied	0%	0%	0%	
	95% CI	(1.43, 2.08)	(1.10, 2.68)	(1.06, 3.41)	
Do you feel you were given enough time to make your decision about research participation?	Yes	74%	11%	6%	0.173
	No	1%	0%	0%	
	Not applicable/ Don't remember	5%	3%	0%	
	95% CI	(0.93, 1.90)	(1.38, 3.73)	(-0.77, 2.77)	
If you have had any problems during the research study, are you satisfied with the way they were resolved?	Extremely satisfied	26%	0%	2%	0.557
	Satisfied	30%	8%	3%	
	Neither satisfied nor dissatisfied	9%	3%	1%	
	Dissatisfied	0%	0%	0%	
	Didn't have any problems	15%	3%	0%	
	95% CI	(2.16, 3.32)	(1.92, 4.74)	(-0.12, 4.12)	

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The study has gone some way in exploring whether different ethnicities have different experiences of research. There did not appear to be significant differences between the study's cohorts, but more research is required to understand what the issues are.

This study has shown that patients already engaged in research generally have good experiences. But more work is needed to determine how to engage patients in research in the first place and how participants' positive experiences can be used to engage others. Researchers' awareness of minority ethnic communities' experiences of participating in studies is necessary for services to be continually improved. This will pave the way to making clinical trial participation more equitable and accessible to all communities.

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