

PATIENT AND PUBLIC ENGAGEMENT IN HEALTH RESEARCH: LEARNING FROM UK IDEAS

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ABSTRACT

One of the new ideas in health and social care research in the UK is around involving patients and the general public in all aspects of research. This paper led by seven MSc students from Manmohan Memorial Institute of Health Sciences in Nepal. They attended Bournemouth University modules as part of the Erasmus+ exchange programme in 2022 and worked with two UK-based academics. The authors outline the thinking behind this process, and offer an example. They address its importance in improving the quality of the research as well as adding value to its societal relevance.

BACKGROUND

There are different approaches to doing health research, not only in terms of qualitative, quantitative or mixed-methods approaches but also in terms of how the question is conceived, how and where the research is conducted and the findings are disseminated. Active and meaningful patient or service user/beneficiaries group and public involvement (also known as PPI) throughout a research process is a hallmark of good research.¹ It is also considered as mandatory by many funding bodies in the UK and other high-income countries (HIC) when applying for research grants.² In research with PPI, people with pertinent experiences, together with the patients or service users, are effectively involved in designing, developing, and disseminating the research, thereby making the research approach ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.³ PPI has both ethical and practical importance in research. It is a moral obligation to respect the right of people who are most affected by the research to have their say in the decision-making process, likewise, on pragmatic grounds, public involvement makes the research more relevant, accessible, acceptable, and enhances communication.⁴

Although the prominence of PPI in research is growing in many HICs, it is still a very new concept, thus its application and impact are still rare in low and middle-income countries (LMICs).⁵ Simkhada and colleagues⁶ argue that in South Asian countries, the common form of public involvement in research is mostly collaboration early on during the planning phase of a study. The collaboration usually involves key stakeholders such as practitioners, leaders in the local community, policy-makers, or other key informants. Views of the service users are rarely sought and incorporated. The lack of guidelines from funder and ethics committees on PPI, means researchers are missing out the term 'patient' when describing any public involvement. As a result, if there is any discussion about involvement in research it is more focused on community engagement, resulting in an unclear concept of PPI in LMICs.⁵ Similarly, the lack of standardized tools and adaptation guidelines for intervention for diverse cultures is another limiting factor to apply PPI effectively.^{4,7-9}

Very limited research and review have been attempted and published regarding the PPI in health research in LMICs, and rarely any work has been done solely focusing on Nepal. However, the interest in PPI in health research in Nepal is likely to increase in the near future. Therefore, it is highly timely and relevant to share the PPI concept, approaches, impacts, and challenges in the Nepalese context so that early career researchers in Nepal and other LMICs may benefit from this.

Why PPI is needed in research?

The involvement of public in research is crucial as it helps to ensure that research focuses on topics that affect people's lives and that the research is conducted in ways that are ethical and acceptable to participants. This involvement is to be made from the conceptualization to the dissemination stage. First, the contributions provided by service users hold significant importance as they offer researchers a fresh perspective on the subject matter and present alternative approaches to the ongoing processes. Additionally, they provide valuable assessments regarding the outcome's significance, which may have been overlooked by the research team despite its crucial relevance to the patient.¹⁰

Secondly, the involvement of the public in various stages of the research process helps to introduce the research team with the real-life training, which is very valuable in identifying the merits and challenges associated with it in the early stage. It helps to know how deep the research is required in order to benefit the public which ultimately supports in increasing the value and quality of research.¹¹

Lastly, the nature of involvement depends on the type of research to be conducted. Haphazard involvement of the public may be tragic to the family and patient in some cases. In order to avoid this, systematic involvement with proper planning for the involvement should be made. Having

public in the early stage helps to pave the pathway for the research.^{10, 12} Another important aspect is, public involvement helps to understand the ethical considerations to be made and can come up with meaningful solutions to the issues that may arise at the time of research. This also helps to make a clear informed consent with the participants.¹²

Thus, public involvement in research in a meaningful and productive manner is a win-win approach, with many benefits, including, user-focused objectives, user-friendly information, public friendly interpretation of data.¹² The funding bodies can also be convinced by showing different aspects of research like the importance of the topic chosen, and beneficiaries being part of research involvement which helps to flow the research with ease.

An example of PPI applied in the UK

The University College London Hospitals (UCLH) and University College London (UCL) National Institute for Health Research Comprehensive Biomedical Research Centre is a partnership between UCLH and UCL and is part of the National Institute for Health Research. Researchers at UCLH/UCL have created novel approaches to precisely diagnose prostate cancer and use less intrusive therapies. But in order to bring these new alternatives closer to becoming a reality, patient feedback has been crucial. One of the most important ways that patients contributed was by encouraging researchers to be open and truthful about the procedures used in their studies and the perseverance of therapies. This has made it possible for researchers to recruit participants to take part in their study. Additionally, researchers have figured out which treatments people choose and why.

Additionally, patients are collaborating with researchers to create novel therapies. In this way patients play a significant part in directing the course of UCLH research into novel treatments: "They are very good at pushing us to be clear about the therapeutic objectives and advantages." Because traditional prostate cancer therapies like surgery and radiotherapy might harm nearby nerves and muscles and have unfavourable side effects including erectile dysfunction, incontinence, or bowel issues, finding novel treatments is crucial.

High-intensity focused ultrasound, photodynamic treatment, and cryotherapy are some of the latest minimally invasive techniques being tested at UCLH/UCL. These treatments are known as focused therapies because they minimise harm to healthy tissue by only treating the malignant tissue and not the entire prostate gland. However, it was important for Professor Emberton's team to understand which of these various treatment approaches patients preferred and why. They employed a method known as "discrete choice," which is utilised in business, to accomplish this.

Patients were asked to provide a value to many aspects of resolution, including length of hospital stay, number of surgeries necessary, likelihood and type of side effects, complications after surgery/treatment, and radiotherapy-related toxicity. Patient preferences can be specifically inferred from the values patients place on various treatment-related aspects.

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MODELS

There are different models/frameworks used for PPI in health research. A concept analysis by Hughes and Duffy¹⁴ has classified the models of PPI into 5 different categories.

1. Undefined involvement: Public get involved as respondents or subjects only and are not significantly consulted.
2. Targeted consultation: Public contribution is confined to specific tasks or request only. They are not involved in selecting the design or nature of the study.
3. Embedded consultation: The research team is the owner and controller, with regular and wide range of meaningful consultation with public.
4. Co-production: This is a collaborative process between public and researcher. Public are co-producers or co-author and contribute to major outputs as they receive sufficient training, supervision and support.
5. User-led research: Control over research is given to public. Directing the research according to the public's areas of expertise and experience.

BARRIERS AND CHALLENGES

It is crucial to consider that PPI is not always easy, and a range of barriers and challenges are identified. They can be personal factors, health professionals' relationship with patients, clarity of roles and expectations, trainings, information and communication approach with users.¹⁵ Patient and public need to be aware about the existing opportunities along with their crucial role in research and raising awareness about it can be the foremost challenge.¹⁶ PPI can cause elevated time and price within the research process.¹⁷ The insufficiency of appropriate financial resources along with insufficient understanding of what motivates PPI contributors causes hindrance to effective PPI.¹⁸

If we look from patients and public view it can be difficult for them to get involved in research due to their own physical, mental or emotional conditions, organizational barriers such as timing and locations of meeting, feeling of exclusion, lack of bonding with the researcher and inadequate feedback from researchers side.¹⁹ The overuse of scientific jargon by researchers leading to ineffective communication, language barrier, lack of empathy and issue of confidentiality are also other reasons why people may find it difficult to get involved in health research.^{17,19,20} Being unable to understand cultural sensitivity can also hinder PPI in research.²¹ It is worth noting that major issues can arise with jeopardization of academic publication as research findings are disseminated publicly before the journal papers are actually published.¹⁷

WAY TO FORWARD

There are strong movements globally towards co-production in research due to change in paradigm, content and nature of a research. In Nepal, due to traditional patient-professional hierarchical structure it is quite challenging. Rather than relying on the old traditional concept a broader, more systematic approach is needed.

For this, we need to think in a different way for example: strengthening the capacity of PPI by training community people for the role of the researcher and participants in shaping or piloting interventions; this type of involvement may develop local research capacity.²² There is no current international agreement on best practices and guidance is developing across countries and research disciplines. Evidence is, therefore, required to demonstrate how different methods of involving people can improve research, healthcare outcomes and impact.²³ Miah and colleagues²⁴ argue that PPI must be acknowledged as a crucial component of applied research in LMIC countries in order to ensure that the research outcome is relevant to intended beneficiaries.

CONCLUSION

PPI is very important in research as it improves the quality and relevance of the research. Public involvement revolves around the concept of respecting the right of people who are most affected by the research to have their say and thoughts in the decision-making process. It means research done with public or patients. Public involvement in research in a meaningful and productive manner and to the extent of involvement needed, as undefined involvement, targeted, user-led and so on, is a win-win approach, with many benefits. When providing this crucial role to public and patient in research, raising awareness about it can be the foremost challenge but the end game is totally worth it. PPI in research has effective 'impact' on the research process itself as well as on health outcomes.

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