

Perspective

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Importance of involving patients and public in health research in Bangladesh and Nepal

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Abstract

Patient and public involvement/engagement (PPI/E) in public health research and health technology assessment (HTA) in high-income countries (HICs) have significantly increased over the past decade. PPI/E helps to improve research and HTA, ultimately benefitting patients and service users. PPI/E is a very new concept in many low- and middle-income countries (LMICs). This paper considers the importance of PPI in public health research and HTA in the development and implementation of technology in the health sector in South Asia. Currently, in this region, health technology is frequently adopted from HICs without local research and HTA. It also discusses the importance of local co-creation of technology to reflect the needs of users within a culturally appropriate setting. It is important for LMIC-based researchers to understand the potential of PPI/E and how it can contribute to it to improve health care and research, especially perhaps in the era of COVID-19.

Background

Patient and public involvement/engagement (PPI/E) is vital in research and health technology assessment (HTA) supporting a patient/person-centered care approach. There is a growing interest in implementing PPI/E in health research in low- and middle-income countries (LMICs) because it benefits the following: (i) research question, (ii) conduct of the research, and (iii) beneficiaries (1;2). The UK organization INVOLVE (3) defines public involvement as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.” Public can refer to patients, potential patients, carers, and people from organizations that represent service users as well as members of the public. Thus, PPI “occurs when individuals meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge” (4).

HTA is a systematic approach to evaluate the properties, effects, and impacts of health technologies or interventions (5), to inform policy and clinical decision-making in the application of health technologies. HTA involves interdisciplinary research to assess cost-effectiveness, budget impact, programmatic feasibility, and social and ethical issues of health interventions (6). Health technology is a critical element in universal health coverage (UHC) (7) and HTA is recognized as key to securing UHC through the efficient and equitable allocation of health care and resources (8). Therefore, promoting patient and public perspectives on the technologies being used is essential to assess the overall societal impact of health technologies. Integrating the patient perspective in public health research and HTA activities has the potential to improve the quality of healthcare services through meaningful contributions from and to the patient and the public.

PPI/E could be used in South Asia, considering, as Cook et al. (1) describe, “the variations in research infrastructure, cultural differences, the power differential between researched and researcher and often, lower research budgets.” Similarly, the growing use of technology in South Asia could be co-created locally to meet the literacy needs of users.

Need for PPI/E

One aspect of PPI/E is advising on and writing lay summaries; describing the research in language that ordinary people can understand and is relevant to their context. Involving people with local knowledge and experience of the area of research not only increases the potential outcome of the research but also achieves academic, economic, and societal impact in the wider community (9).

PPI can occur in specific or all phases of the research cycle, from prioritizing research area, research design, assisting with the recruitment of study participants, data collection and analysis, and monitoring and evaluation to dissemination (10;11). Starting with developing the research proposal, PPI/E could start with preliminary discussions to identify research priorities. During the research process, PPI/E could help in assessing the research instrument being used such as the appropriateness, wording, language, and timing of research instruments (e.g., questionnaires and interview schedules) to the public. They can be consulted to see whether they understand or interpret the data/findings in the same way as the research team. At the dissemination stage people could help to develop patient information leaflets/websites or other research materials for awareness-raising of the research through various media.

What and whom to ask

In PPI/E as in any part of research and in HTA you need to make sure you ask the right kind of questions for the right reasons and technology being tested. In other words, “What are you asking, and why are you asking it?” Also you need to consider which subgroup in the population represents your PPI best.

Some see PPI/E as a burden, perhaps as another obstacle in research in a generally risk-averse society. Others, more positive toward PPI/E, fear an element of tokenism, the rise of the so-called professional patient. Examples of that can be seen in the grant application process in the UK, where the same paid member of staff of a health charity appears as a PPI/E representative on several competing grants.

PPI/E in South Asia

There has been limited application of PPI/E in the more traditional patriarchal countries of South Asia. PPI is less patriarchal and more democratic, as it gives people a voice in shaping services, decision-making, and research. The latter can be a threat to highly trained researchers (as PPI was for some in Europe 25 years ago), who may fail to see the value of the “lay person’s” voice or fear that involving patients may include, what may be deemed, irrelevant remark, only offers a few unrepresentative perspectives and threaten the scientific rigor of their research, which could make the research unfeasible (12).

We have been researching health in South Asia, mainly Nepal and Bangladesh for 15 years, but we have only recently started to include users part of the research process early on. PPI/E is not common in the health research landscape in South Asia. A recent systematic review on health research in LMICs considered involvement and impact (1) found 62 studies and that PPI was mostly used in the planning stage and collaborations were the most common level of involvement. The review found little evidence of effectiveness and impact tended to relate to increased relevance to the community, empowerment of participants, and alterations in the study design. Cook *et al.*’s (1) overall conclusion was that proper PPI involvement in health research in LMICs is still rare.

Nepal

We are involving users to develop nursing continuous professional development (CPD). Nurses provided the PPI/E part of the research proposal development. PPI/E has helped us to understand the need of nurses; however, we still feel we have failed to

recognize the patient and public perspective. We planned the recommendations with the PPI/E input around dissemination events with nurse practitioners and policy-makers in Kathmandu to achieve acceptance by national nursing/health policy-makers. We shared what works and what is feasible in CPD to enhance nurses’ knowledge and skills. The nurses valued their involvement in dissemination event and reported that it provided them with ownership in the CPD framework development. We now realized that involving patients could have given us insight in their perceptions of CPD training from the research proposal stage, i.e., how it can benefit nurse–patient interactions, for example to help nurses understand patients’ perspectives in the CPD training. The main idea of CPD is to offer the opportunity to maintain, improve, and broaden knowledge, expertise and enhance nurses’ practice, and improve nurse’s interpersonal relationships with multidisciplinary team, patients, and family for better quality of care (13;14)

Bangladesh

A multicomponent hypertension control program in Bangladesh driven by rural community health workers (CHWs) in collaboration with government doctors has set an example of the value of PPE in strengthening primary health systems for delivery of hypertension (15). A group of researchers in Bangladesh, Pakistan, Sri Lanka, and Singapore evaluated the impact of a multicomponent hypertension control program titled “Control of Blood Pressure and Risk Attenuation in Bangladesh, Pakistan, and Sri Lanka (COBRA-BPS)” (16). The CHWs were trained to use a digital blood pressure monitor (Omron: HEM-7300) to measure blood pressure of the hypertensive study participants during routine home visit. The CHWs also conducted home-based health education with these patients and their family to modify lifestyle as well as to promote medication adherence. The CHWs in Bangladesh detected patients with uncontrolled blood pressure and mobilized the family to refer them to government primary health facilities for management of uncontrolled blood pressure by trained doctors. A significant reduction of blood pressure was observed among the patients in the intervention areas compared with those in the usual care after 2 years (2016–2018).

The proactive engagement of the CHWs with the patients in the community and primary-care doctors created a high demand for hypertension care and subsequently antihypertensive medicines were made available at the primary health facilities throughout the country. PPI/E was a key part of the COBRA-BPS program’s implementation and has demonstrated the value of involving PPI/E in improving the quality of care as well as the acceptability of health interventions in low resource settings in South Asia.

Developing PPI/E in a culturally appropriate way

In South Asia, health workers are often seen as experts in patients’ conditions. It is important for researchers to understand this context. Therefore, it is important to consider practical questions when planning for PPI/E, i.e., how do we change this culture? How do we empower patients to see that they have a very unique expertise of their own building rapport and creating opportunities for collaboration takes time (and should be factored/costed into any bids). How and where do we create an environment where people feel safe and it is familiar to them? Are there barriers to break through where only “community leaders” are consulted?

One key way to involve people is to “go to where they are,” but will there be issues of trust—unless of course, there is someone from that culture/community as part of the research team or the people themselves are trained as researchers.

Cultural influences, politics, and economic status can play a big role in South Asia, and as such would affect PPI/E in public health and HTA research. There is increasing interest in human-centric design in the public health and HTA research to test locally the new technology adopted from HICs. In Nepal and Bangladesh, health workers are seen as experts; they know “everything” about the patient’s condition and the patient follow what is being said; having little/no voice in their own healthcare planning. Therefore, it is important to explore how PPI/E could effectively work in a South Asian context and ascertain whether people value being involved in research design, processes, and dissemination.

Challenges of PPI/E may be avoided through clear planning of the PPI/E activity in the early-planning stages of the proposed study (17) and more importantly there is need for awareness on the importance of the patient involvement in the research in South Asia. Researchers also need to understand the users feeling of empowered, valued, listened to, and generally more positive about their experiences when they engage in the research process (18). When researchers planned PPI/E, it is important to communicate in a culturally appropriate way and educate the public that their views are important and useful in the service provision. However, creating a mechanism for accountability of the healthcare providers to patients and public would remain a challenge as well as an essential element for promoting PPI/E in South Asian settings. The patients and the public can provide valuable input, offering a unique perspective in the project.

In Nepal and Bangladesh, there is lay involvement in the process of dissemination, often with stakeholders (service providers); however, there is some notion of community engagement in health education/promotion programs. There may be a highly educated representative of the community acting as the voice of the people, for example inclusion of different ethnicity, rural and urban, and gender.

It is important to have a representative and diverse people in the group to avoid the over-emphasizing of particular problems; groups being dominated by strong characters and their perspectives; and groups being overshadowed by personal experience stories. Representation of the population is not only the element of the PPI, it is important they have some kind of decision-making around the research process. They should have a key role on dissemination of research findings, as they are able to provide access to a wider audience than traditional academic circles. We believe PPI/E can improve the quality of research projects, particularly develop health interventions and strengthen their relevance and increase the likelihood of achieving impact. The global pandemic COVID-19 also adds to the value of PPI/E in designing research grants or surveys in Nepal and Bangladesh, including some South Asian countries as there are some similarities in their cultural practice and health research environments.

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