

## The need to establish sustainable public and patient involvement in research in low and middle income countries

Global health research continues to face enormous inequities. While low and middle income countries (LMICs) face an inordinate burden of preventable mortality and morbidity very little research funding is directed to address these problems. This has historically been called the 10/90 divide, that is, only 10% of research funding is devoted to addressing over 90% of the global disease burden <sup>1</sup>. The recognition of the nature and extent of this disparity has shaped the discussion about the ethics of research in LMICs. A central question of this discussion relates to what researchers and funders from high income countries owe participants and others impacted by research in LMICs <sup>2</sup>. This comes from a growing awareness that research conducted in LMICs, even under the best of circumstances is potentially exploitative <sup>3</sup>, with its benefits often unfairly distributed. While there has been an expansion in international guidelines and growing awareness of these issues, these inequities remain. In attempting to address these issues Costello and Zumla <sup>4</sup> call for researchers to move away from more traditional ‘semicolonial’ approaches to research, to models that emphasise more equal partnerships and collaboration that empowers patients and the public in the research process, emphasising ownership, sustainability and the development of research capacity.

The establishment of sustainable institutions and policy to promote greater patient and public involvement (PPI) in research has the potential to address some of these concerns and is now considered non-negotiable in the context of research in higher income countries. PPI in research can be defined as research that is carried out ‘with’ or ‘by’ patients or members of the public rather than ‘to’, ‘about’ or ‘for’ them <sup>5</sup>. In other words, this means that patients and the public are active partners in research, rather than simply being used as participants in research. Patient and public involvement in research can thus involve a range of activities and different types of engagement throughout the research process. Practically, patients or the public could be involved in identifying key research questions, assisting with study design, defining outcomes, collecting and analysing data and disseminating and implementing results. The similar concept of community engagement involves engaging “potential participants and

communities in a meaningful participatory process that involves them in an early and sustained manner in the design, development, implementation, design of the informed consent process and monitoring of research, and in the dissemination of its results”<sup>6</sup>.

PPI in research has become increasingly common in a number of high income countries, including the UK, Europe, Canada, Australia and the USA. A growing number of organisations exist to support the expansion of PPI in research; for example the Patient Centred Outcomes Research Institute (PCORI)<sup>1</sup> in the USA and INVOLVE<sup>2</sup> in the UK. While PPI in research in LMICs has been called for in international guidelines (e.g., The Council for International Organizations of Medical Sciences (CIOMS), International Ethical Guidelines for Health-related Research Involving Humans)<sup>6</sup> and its importance long recognised<sup>7</sup>, there remain few institutions and limited policy to support sustainable PPI in LMICs themselves.

There are a number of good reasons to support the establishment of institutions and policy to promote sustainable PPI in research and why high income countries have a responsibility to assist. The first are ethical. Already alluded to above, PPI in research is increasingly viewed as a meaningful response to the potentially exploitative nature of research and in addressing the unfair distribution of its benefits<sup>7</sup>. PPI has the potential to enhance the protection of individuals and others impacted by research; it can ensure the social value of research and enhance the potential benefits for participants; it also creates legitimacy and promotes shared responsibility with researchers<sup>8,9</sup>. Put another way, PPI allows those directly affected by the research to have a say in how research is conducted, how any risks should be mediated and how any potential benefits should be distributed. In addition to this there is growing empirical evidence which documents the benefits of PPI for individuals and communities. These include greater health literacy and contributions to improvements in the delivery of healthcare<sup>10</sup>.

Second, there is already a substantial pool of expertise and evidence that can be drawn upon to assist in the development of policy and the establishment of institutions to support PPI. This includes a range of guidance, best practice standards<sup>11</sup> and empirical research<sup>10,12</sup> that could

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<sup>1</sup> <https://www.pcori.org/>

<sup>2</sup> <https://www.invo.org.uk>

be used to inform the creation of PPI policy in LMICs. This is not to say that research in this area is not without its shortcomings or that the extent of these benefits are settled <sup>13</sup>, further research is needed into the range of contextual factors that impact on PPI in research and its success or otherwise. In addition to this, there is also a vast literature that discusses and critiques PPI in healthcare in LMICs. As well as offering practical insights like the above literature, it provides a valuable account of the lessons learnt in relation to engaging with individuals and communities in LMICs, that can be used to develop more equal research partnerships <sup>14</sup>.

Finally, research itself benefits from PPI. In the context of the UK, there has been growing criticism of the way in which PPI in research excludes Black, Asian and minority ethnic (BAME) communities and their perspectives <sup>15, 16</sup>. PPI has been shown to increase the participation of BAME and other marginalised groups, creating research that is more relevant to all individuals and communities <sup>17</sup>. The knowledge and experiences of researchers will often be very different to those utilising health services or living with a medical condition and thus patients and the public will have insights and experiences that would otherwise be overlooked. For research conducted in LMICs researchers may also be faced with a range of cultural and linguistic differences. In a systematic review exploring the impact of patient and public involvement in research Brett, Staniszezwska <sup>10</sup> found that among other benefits of PPI, researchers gained “new insights into their work and ... a greater understanding of the area under study”. Furthermore PPI can facilitate improvements in recruitment, “the quality and relevance of data collected... and wider dissemination of the results”. In addition to this, the lessons learnt from implementing PPI in LMICs could also serve to inform more inclusive and relevant research in higher income countries.

In saying all of this, while institutionalising PPI in LMICs could address a number of shortcomings in global health research, caution is still warranted. While a number of models could be applied to shape PPI in LMICs, it cannot be taken for granted that these will ‘work’ when employed in different circumstances. Care is also needed to ensure that policies and institutions don’t re-enforce existing hierarchy or undermine the participation of the most vulnerable <sup>18 19</sup>.

With these caveats in mind, establishing PPI policies and institutions in LMICs has promise to move toward justice and greater inclusivity in research, going some of the way to addressing the well documented inequities and exploitation that remain pervasive issues. This more inclusive model could also benefit the development of more diverse models of PPI in higher income countries<sup>15</sup>, help enable a greater understanding about the factors influencing BAME involvement in health and social care research<sup>20</sup> and in producing research that is more relevant not only to otherwise marginalised individuals and communities<sup>17</sup> but to broader populations and society more generally. PPI is a meaningful and practical response that has the potential to empower patients and the public, contributing to greater ownership, sustainability and the development of research capacity. Funders and those working in LMICs should give serious consideration to not just how they can involve potential participants in research but how they can promote more sustainable, methods of PPI based upon empowerment, diversity and inclusivity.

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