

Commentary

Patient and public involvement for ethnic minority research: an urgent need for improvement

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Inequalities in health by ethnicity persist in the UK, and there is a history of health research failing to address the needs of ethnic minorities. The COVID-19 pandemic has further highlighted ethnic health disparities¹ and emphasised the need for a greater ethnic minority contribution to all aspects of research. Ethnic minority patient and public involvement (EM-PPI) needs to go beyond just inclusion in research design but, to encompass active involvement in setting research questions, helping shape study design, be co-applicants, actively inform study implementation, data analysis and interpretation, and dissemination of findings^{2,3}. A prerequisite for this is the development of a wider patient and public involvement community which is reflective of our growing population diversity.

The tokenistic nature of PPI

To date, PPI in research has often been 'tokenistic', from the perspective of both researchers and participants⁴. As funding bodies increasingly request inclusion of PPI in grant applications, researchers often include PPI for the primary purpose of improving the success of the bid and recruiting participants, without placing sufficient value on PPI as an important part of the complete research process. Subsequently, PPI is rarely designed to address the needs of all groups or the entire research process, and it often attracts particularly motivated community members, which can limit diversity and equitable representation from seldom-heard communities. As well as increasing representation of ethnic minorities, enabling more evenly distributed power dynamics, with all stakeholders being accountable, is needed to reduce tokenism. Involvement should be anchored on respect for participants, including ethnic minorities, and their ability to make contributions at all stages of research^{5,6}.

Working with ethnic minority communities

A fundamental point to consider when engaging EM-PPI is the need to understand the diversity within ethnic minority groups (e.g. South Asian consists of Pakistani, Bangladeshi, Indian, etc.). There is wide heterogeneity among ethnic minorities that reflect differences in culture, language, genetics, health status and service use. These factors are also reflected slightly differently across different age groups and migration status⁷. To adequately capture the broad range of communities among ethnic minorities, researchers have recently advocated for the improvement of ethnicity categorisation in health and social care research⁸.

Involvement should be reflected in the entire research cycle⁹. Core areas to consider when engaging ethnic minorities include addressing barriers to involvement, such as payment for time or accessible locations for meetings; providing clear information about opportunities shared in formats that appeal to different communities; presenting a PPI process that reflects equality and diversity duties of different groups; and offering flexible engagement options. Additionally, the use of plain language for well-timed and relevant communications, with a broad range of approaches, should be part of the involvement plans and activities. Development of relevant skills among individuals in research management, regulation, leadership and decision-making will also help enhance transparency and gain trust among minority communities. Further suggestions on conducting PPI with ethnic minority populations include: establishing a rationale for involving EM-PPI contributors specifically; utilising involvement and engagement strategies which take into account ethnic minority differences; setting up EM-PPI registers; conducting culturally sensitive PPI open recruitment and training; using EM-PPI contributors' language skills to discuss research relevance and findings; and, broadening dissemination beyond academic and policy spaces and into community settings.

Insert Text Box 1 here

The role of ethnic minority community members in PPI groups and panels, should not simply be for the direct and back translation of the research agenda to plain English, but should also reflect culturally relevant translation which is only achievable through focused engagement¹⁰. For instance, patient information sheet (PIS) need to have content validity through focus groups and consultations with community representatives. Including ethnic minorities in this process, would ensure cultural, religious, and social considerations related to these groups are adequately considered. In addition, co-design approaches to adapt and develop suitable engagement strategies should also be valued, as some ethnic minorities feel over-researched but neglected in research planning, and see little benefit from this to their communities¹¹.

Increased representation is needed

Adequate representation of all ethnicity groups needs to be an integral part of research^{12,13}. This is particularly important for PPI relating to applied health research, as this should reflect the population that the research is designed to benefit.

Scientific journals, funders, policymakers and stakeholders should actively encourage and support the presentation of EM-PPI evidence in research planning and dissemination using guidelines for assessing study quality and impact¹⁴.

Inclusion of EM-PPI, which should comprise both environmental and social planning, may increase researcher and resource burden. Therefore a commitment to EM-PPI will need to be reflected in resources requested in research funding applications, as additional funds would be required for professional translation into different languages¹⁵, and funders need to be receptive to this. EM-PPI is also vital at the dissemination stage of research outputs. Having PPI opinions on research outputs enhances credibility, transparency and validity among the target population.

Insert Table 1 here

Now more than ever, we need to address the health inequalities faced by ethnic minorities. To aid the prevention and reduction of these health inequalities, we suggest all future research should, where appropriate, consider how to increase the quality and representativeness of PPI activities with ethnic minority populations. All types of research need to reflect the population it intends to benefit through diverse and inclusive public involvement and working partnerships with researchers, for mutual advantage. We provide a series of recommendations (**Table 1 and Text Box 1**) that can be used to encourage increased EM-PPI contribution in research.

Considering these factors will help address reported barriers to EM-PPI, such as time constraints, lack of previous experience in research, compensation and diversity, usually experienced in research.

Contributors

All authors conceived the idea for the article and the recommendations that form the basis for the article. WE, AR and KK led on drafting, editing and revising the content. All other authors contributed to editing the content, and all authors approved the final version and are accountable for all aspects of this work.

Conflicts of Interest

KK is director of the Centre for Black Minority Health, University of Leicester, and is a trustee of the charity South Asian Health Foundation and co-chair of their Diabetes Working Group. KK is Chair of the SAGE Ethncity subgroup and member of Independent SAGE.

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Table 1: Recommendations for increased engagement and evidence of ethnic minority contribution in PPI

Group	Recommendation
Funders and Policymakers	<ul style="list-style-type: none"> - Encourage explicit consideration for diversity in PPI - Demand for robust PPI plan and evidence in research - Include ethnic representation and distribution plan in research grant applications - Advocate for at least one EM-PPI contributor - Provide additional monetary support for EM-PPI such as allowing cost for language and culturally appropriate methodology - Allow adequate time and adequate flexible resources - celebrate success and achievements
Researchers	<ul style="list-style-type: none"> - Engage communities in partnership with the PPI contributors and PPI-related activities mainly occurred at the design stage - Establish, over time, a robust ethnic PPI profile database - Explore various participatory approaches which adopts more co-produced partnership EM-PPI involvement enhance the probability of greater inclusivity - Increase reporting of the extent of involvement of PPI contributors and their contributions at the different stages of the research process - Provide specific details on barriers, inhibitors and facilitators to ethnic minority involvement, showing perspectives of both EM-PPI contributors and study participants - Outline recommendations on the best practice of BME involvement or how BME involvement could be improved or performed differently from research experience
Ethnic minorities (EM-PPI contributors)	<ul style="list-style-type: none"> - Enrolment as Service User Peer Researchers - Identification specific group for research engagement - Offer insights into personal, social or cultural factors, needs and priorities specifically relevant to groups represented

	<ul style="list-style-type: none"> - Engagement in training, capacity building, co-design of documents, fieldwork, co-analyse data and presentation at conferences and public meetings - Share experience of impact from involvement to encourage wider participation from more EM communities
Journal publishers	<ul style="list-style-type: none"> - Increase priority for reporting ethnic PPI representation evidence - Provide a consistent form of reporting PPI activities in order to facilitate better quality assessment - Inclusion criteria for reporting on intended PPI involvement versus actual PPI involvement - Encourage PPI reporting section in methods, results and discussion sections - Permit extra word count in peer-reviewed journals

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Text Box 1: How to conduct PPI with ethnic minorities

1. Provide rationale for involving EM-PPI contributors specifically
2. Embed involvement at all stages and outline added value of EM-PPI to the different stages of the research process
3. Utilize engagement strategies that take into account the differences between ethnic minority groups
4. Establish, regularly update EM-PPI register and offer open recruitment portals, which can be advertised on community platforms
5. Offer training and capacity building support in formats easily understood by ethnic minorities
6. Use of EM-PPI contributors for developing data interpretation that offer different insights and identify aspects of research relevant intended EM users of that research
7. Use EM-PPI contributors' language skills to discuss research findings more widely within the target population(s) and to devise culturally appropriate dissemination strategies.
8. Broaden view of dissemination beyond academic and policy spaces