**Title:** Building trust and increasing inclusion in public health research: co-produced strategies for engaging UK ethnic minority communities in research

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**Summary**

Patient and Public Involvement and Engagement (PPIE) is essential for improved research outcomes and reduced research waste. To be effective, PPIE should provide opportunities for diverse groups to contribute to all research stages. However, UK ethnic minority communities remain underrepresented in research. This paper describes strategies adopted in a public health research project that were effective in building trust and increasing inclusion of ethnic minority communities.

The study team of researchers and PPIE partners reflects lessons learnt during the project and describe six main strategies that built meaningful levels of trust and inclusion: 1) early start to recruitment of PPIE partners; 2) relationship-focused engagement; 3) co-production and consultation activities; 4) open communication and iterative feedback; 5) co-production of project closure activities, and; 6) diverse research team.

Meaningful outcomes for the community included the involvement of people from ethnic minorities as research participants and PPIE partners, community wellbeing, co-production of public health recommendations co-presented at the UK Houses of Parliament, and consortium-wide impact evidenced by the enrolment of 51 active PPIE partners.

PPIE partners reflect on their research involvement, offering advice to researchers and encouraging people from ethnic minority communities to take part in research. An important message from PPIE partners is that involvement should not be restricted to projects specific to ethnic minorities but become a routine part of general population research, recognising ethnic minorities as an integral part of UK society.

In conclusion, this paper demonstrates that with appropriate strategies, inclusion and diversity can be achieved in public health research. We recommend researchers, practitioners and policy makers adopt these strategies when planning their public health projects.

**Keywords**

Patient and public involvement and engagement, ethnic minorities, public health, trust, inclusion, diversity.

**Introduction**

Involving members of the public in health and medical research is important to improve quality, outcomes and applicability of research.1 Public involvement contributes to an effective translation of research findings for public health improvement, therefore improving health equity and reducing health research waste.2 Although different terminologies are used to formally describe the involvement of the public in research, the term Patient and Public Involvement and Engagement (PPIE), most widely used in the UK is adopted for the purposes of the present paper. This paper is to suggest methods for addressing the lack of diversity in public representation in research.

The National Institute for Health and Care Research (NIHR) defines PPIE as “research being carried out with or by members of the public, rather than to, about or for them”.3 This means that members of the public are not sources of data but are collaborators, adding value to the research project. For PPIE to be effective and equitable, opportunities need to be provided for diverse population groups to contribute to the research process from start to finish. Despite the rise in PPIE and a high profile agenda to increase diversity within PPIE and research,3,4 specific underserved groups in the population including ethnic minority communities continue to be underrepresented.5,6 When PPIE and research do not include the views and experiences of diverse population groups, especially those that have been exposed to social and economic inequalities and injustices, the research outputs may not meet the needs of these groups, leading to research ineffectiveness and persisting inequalities.

There are many possible reasons for the underrepresentation of ethnic minorities in research as both participants and PPIE partners. Firstly, ethnic minority communities are faced with health inequalities which reflect a long history of social and economic inequalities and injustices.7 These inequalities were exacerbated during the COVID-19 pandemic, when ethnic minorities experienced higher infection and death rates than white communities in the UK,8 as well as disproportionate social, mental and economic impacts recorded.9,10 This experience is likely to have added to the lack of trust in the system already felt by many in such marginalised groups11. This dis- and mistrust coupled with previous negative experiences may result in an unwillingness by ethnic minority communities to be involved in research or public health programmes. 4,6,12 An example of this was observed during the COVID-19 vaccination programme.13 Being a high need group, an immediate acceptance of the COVID-19 vaccination as soon as it became available might have been expected but the opposite was observed.14 It is important to understand how to increase trust and involvement of these ethnic minority groups in research.

Evidence has also shown that the way research and PPIE are organised and designed can result in the exclusion of specific population groups, such as ethnic minorities.15 Issues that can reduce research involvement include: differences in cultures; differences in literacy levels; lengthy and technical research documents in English (e.g., ethics documents, participant information sheet); lack of clarity on how involvement in PPIE affects payments for people on benefits; and conflicting priorities between researchers and public partners.16,17

Tokenistic diversity in PPIE is a risk, especially as PPIE is now a mandatory requirement of most research funding bodies.16 Researchers sometimes include PPIE partners from ethnic minority communities to ensure the success of their bid or public acceptance of their project without adequately valuing the individuals, their life contexts and their contributions.18 This approach to PPIE can lead to inadequate planning to ensure PPIE partners feel their contribution to research is valued, resulting in many leaving with negative experiences.12,19 This may prevent the subsequent engagement in research of them and other members of their communities.

Another reason for low ethnic diversity may be inadequate knowledge among researchers on how to approach and engage effectively with diverse communities.6,18,20 Despite the abundance of guidelines on best practices for PPIE, the reality is that these practices are difficult to implement in real world situations. Perhaps, as a consequence, case studies documenting PPIE in practice with ethnic minority communities are rare.21 Researchers may also feel uncomfortable when issues relating to race, discrimination and biases are brought up. In a bid to avoid this discomfort, researchers may choose to work with groups with whom they are already familiar. The fact that these issues are avoided means that published guidance and evaluation of strategies to deal with them are scarce.

The project underpinning this viewpoint paper was the Southampton-led Physical Activity and Nutrition (PAN) work package of the UKRI-ESRC funded multi-centre project entitled “Consortium on practices for wellbeing and resilience among BAME families and communities” (Co-POWeR). For clarity, the project is henceforth referred to as the PAN-Co-POWeR project. A core group of five PPIE partners was recruited and members were actively involved in steering project activities and decision making on PAN-Co-POWeR. Successful PPIE efforts led to the growth of the PPIE group across the UK-wide consortium, totalling 51 members. Whilst the core group was actively involved in steering project activity, other members of the Consortium PPIE Group were invited to take part in all events held, engaged in consultation activities based on their interest and were kept up-to-date with project activities through a newsletter.

This commentary presents the strategies we found to be effective in achieving engagement of a large number of people from ethnic minority communities in the research project. We also present first-hand reflections from PPIE co-authors, demonstrating the extent of co-production processes and offering insights for the research community.

**Strategies for building trust and increasing inclusion of ethnic minority communities in public health research**

The study team identified six main strategies as being key to building trust and increasing inclusion of ethnic minority communities in the PAN-Co-POWeR project (Figure 1).

*Figure 1. Six strategies for building trust and increasing inclusion of ethnic minority communities in public health research*

**1: Early recruitment and engagement of PPIE partners**

Effective PPIE requires the involvement of public members at all stages of a research project.3 This includes the early phases of research prioritisation and decision-making. In PAN-Co-POWeR, a PPIE partner (RP) had been involved in the grant application and submission process, making it easier to initiate PPIE plans. However, having just one PPIE partner was not sufficient to help steer such a large project involving diverse communities, so active recruitment of PPIE partners began as soon as the grant was awarded.

To recruit PPIE partners, the research team reached out to networks from previous projects and to members of the public using emails, posters and posts on social media platforms. Two members of the team (OG and MB-H) also visited various public venues in Southampton, distributing flyers and having conversations with the community. The team was also invited to discuss the project with community groups serving ethnic minority communities. The focus of these efforts was to inform people about the project and invite them to get involved. This resulted in the recruitment of only one PPIE partner (JN).

These usual ways of recruiting PPIE partners and research participants to research projects22 were not sufficient to foster engagement and build trust with enough members of the public for this urgent 18-month project. People who had previously been involved in research were unwilling to spend more time on something that their experience suggested they would hear nothing more about once they had provided their expertise and insights.

Early start to recruitment of PPIE partners was however, important to allow time and flexibility for changes to recruitment strategies to be implemented. Early contributions from PPIE partners played an important role in shifting the researchers’ approach to recruitment (explained in the next section), resulting in an overall positive experience for PPIE partners and research participants.

**2: Relationship-focused engagement: face-to-face *with* the community and *in* the community**

Recruitment activities often focus solely on the delivery of the research project. Recently, there has been a move towards allowing members of the public to drive the research agenda.1,23 This has led to people being gathered to share their research interests and priorities. Whilst these are all beneficial approaches, recruitment into such opportunities is still often centred around “the research”, rather than building relationships.

Following recommendations from PPIE partners, we decided to adopt a “relationships-focused” approach to recruitment. This involved reaching out face-to-face with communities with the primary purpose of building relationships.

A practical example of this relationship-focused engagement approach is demonstrated in the case study of relationship-building with a community group for older people shown in Table 1.

*Table 1. Case study of relationship-focused engagement with a community group*

Building relationships is important to ensure robust community involvement in research not just for the sole purpose of answering research questions but for ensuring research is fit, tailored and relevant to meeting the needs of community – which is what research is meant to be. Relationship-focused engagement is not easy but is important to ensure greater inclusion and diversity within a research project.

It is almost impossible to have meaningful relationship-focused engagement simply through a computer. It involves being out *with* the community *in* the community. This, together with continued engagement, results in multiple gains. For example, it was during our community visits that a PPIE partner shared that they sometimes felt excluded when they received generic emails addressed to “all” or “PPIE partners”, which we immediately corrected.

Another example was with a group of young people in Wales. The PAN-Co-POWeR team was introduced to the community group by Co-POWeR consortium colleagues in Wales via email. Although the community group had been engaging with the researchers in Wales, they did not automatically have the same relationship of trust with the PAN-Co-POWeR researchers based in Southampton. We had assumed that as they were young, they would be comfortable with virtual engagement, especially as travel and face-to-face meetings were only just beginning to open up after the first wave of the COVID-19 pandemic. However, the group of young men specifically requested we travel to Wales to meet face-to-face before deciding whether they could trust us enough to be involved in the research project.

These different experiences highlight the importance of continuous engagement with communities within their own environment and on their terms to nurture inclusion and trust. While virtual engagement offers opportunities for diverse groups including those with caring responsibilities, chronic conditions and disabilities, to engage, the initial approach to kickstarting these virtual engagements starts by building relationships with them face-to-face in their own communities. This kind of engagement can outlast the specific research project and opens up an opportunity for continued collaboration.

**3: Effective engagement involves both consultation and co-production**

The simplest way to include PPIE in a research project is through consultation activities; where researchers seek feedback and comments from the public on specific documents24 e.g., ethics forms, recruitment posters or topic guides for focus groups. Evidence suggests that this alone does not constitute effective PPIE.1,25 We recommend that consultation activities *ride on the backbone of coproduction*, i.e., done alongside each other. The NIHR defines co-production as “an approach where researchers, practitioners and members of the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge”.26

Researchers can face challenges when carrying out consultation activities as part of PPIE. This includes contrasting opinions of public members (e.g., not having consensus about recruitment poster colour and visuals), handling a large volume of responses from PPIE partners, or deciding on approaches to gaining consensus. These concerns were often raised by other academics following presentations about the PAN-Co-POWeR approach to PPIE; but can be managed when consultation activities are hinged on co-production and active engagement during the research project.

In PAN-Co-POWeR, the five core PPIE partners were engaged robustly through involvement in planning and decision-making meetings, developing and reviewing documents and dissemination materials (flyers), opportunities to co-chair meetings, participatory workshops, public workshops; and facilitating discussion sessions with the wider public. They were regularly kept up-to-date with project’s progress through newsletters distributed by email and handed out during face-to-face meetings and community visits. This continuous communication led to PPIE partners feeling a sense of belonging to, trust in and ownership of the project, motivating them to be committed towards ensuring the project’s overall joint goal was achieved. Researchers (OG, MB and MS) would sometimes also meet with partners before larger project, strategic or decision-making meetings to reassure them about their role and importance in these meetings and to encourage them to freely comment when they wished to.

A case study is presented in Table 2 describing how the project team of researchers and PPIE partners planned a public engagement activity for Black History Month together in 2021.

*Table 2. A case study describing co-production of a Black History Month Public Engagement event.*

**4: Iterative feedback process and fostering open communication**

The PPIE process is centred around feedback; researchers seek input from PPIE partners to ensure their work is relevant to the population. Our experience suggests that iterative feedback should also be focused on the actual PPIE process to ensure that people who have volunteered their contributions have a rewarding experience; further facilitating trustful relationships.

In PAN-Co-POWeR, researchers regularly asked PPIE partners how they felt about the PPIE process and recommendations on how to improve the process. The iterative nature of this communication involves frequently seeking, being receptive to and immediately actioning feedback. It also involves being open and honest about things that cannot easily be addressed. For example, we received a request to remove some technical terms on data protection in the participant information sheet. Unfortunately, as this is part of the General Data Protection Regulation (GDPR) governing research in the UK and Europe, this was not possible. However, rather than dismissing the feedback, we had a transparent conversation with the PPIE partner, brainstorming how the challenge may be resolved to satisfy both ethical research requirements and the community. This led to them understanding the constraints but more importantly, led to us working together to find an innovative solution to the problem; we offered phone calls to explain the content of the information sheet with participants prior to data collection.

Three example scenarios within PAN-Co-POWeR where PPIE feedback led to either immediate action or collaborative ways to find a solution are outlined in Table 3.

*Table 3. Examples of PPIE feedback and how suggestions were actioned in PAN-Co-POWeR*

**5: Active involvement of PPIE partners in project closure activities**

One of the negative experiences reported by PPIE partners in previous research projects was that they were often unaware of how the research project ended, i.e., what the project found, whether findings had any impact or whether grant applications were successful. Some described this as being “used and dumped” by researchers. This experience has also been described by both PPIE partners and research participants in previously published studies.16,17

Typically, during research project closure, efforts concentrate on disseminating outputs. This may involve scientific conferences or public engagement events. For PAN-Co-POWeR, the project team (researchers and PPIE partners) aimed to share project findings with two distinct audiences: academics and communities.

PPIE partners were asked to suggest what the closure activity should look like. This led to the co-development of a Transformative Action Workshop. A comparison between the initial dissemination event idea proposed by researchers and the changes to this plan following the suggestions by the PPIE partners can be seen in Table 4.

*Table 4. Impact of PPIE contributions on the co-production of PAN-Co-POWeR’s Transformative Action Workshop*

There are many benefits of having members of the community as champions for a research while it is in progress, and additional benefits when they remain champions after the project. For example, a PPIE partner described the level of engagement they experienced in Co-POWeR, resulting in the PAN-Co-POWeR team being invited to present their PPIE approach to a different research team, so that they could achieve a similar level of engagement. Involvement in closure activities can result in the sustainability of PPIE as partners are more likely to engage in future projects or recommend others to do so, creating a virtuous circle of engagement, benefit and re-engagement.

**6: Importance of a diverse research team**

Research has shown that diversity within the research team is important for improved inclusion and diversity within the research project. 11,29,30 This was also highlighted by PAN-Co-POWeR PPIE partners and researchers. Prior experience of the absence of diversity in research teams contributed to the lack of trust from communities at the start of the study. In PAN-Co-POWeR, PPIE partners and participants welcomed the presence of investigators from ethnic minority backgrounds in the research team, who they could identify with. This unusual feature enabled trust to develop to achieve effective engagement. PPIE partners and research participants, however, emphasised the importance of diversity and not segregation in research, i.e., not just including them in studies focused on ethnic minorities but also ensuring ethnic minorities are represented routinely in studies in general, both as participants and as researchers, to reflect the UK population.

**Reflections from PPIE partners**

In the section below (Box 1), PPIE partners provide their candid reflections on being a part of the PAN-Co-POWeR project, advice to the research community and a message to other members of the public encouraging them on the benefits of being involved in research.

*Box 1: Reflections from PPIE partners*

|  |
| --- |
| The opportunity to be a part of the PAN-Co-POWeR project was a valued and positive one for PPIE partners. The project enabled us and the rest of the community to feel and experience inclusion. Everyone, regardless of their backgrounds, age or other protected characteristics, was encouraged to be involved and share their voice. We believe this is essentially best practice. The inadequacies and inferiorities people thought they had which prevented them from taking part in university research (e.g., not having a degree, right skills or knowledge etc.,) were removed and all were made to feel that what we had to say mattered. This was particularly true for many of the older adults who took part in the project as participants. Many of them had been in the country since the 1950s and 1960s and had never been to the University in their city, but at this stage of their lives were able to be involved in a community-based academic project. This is significant because it creates intergenerational links. Many of them have gone on to speak about this work to their children and grandchildren, and it is incredible how we are seeing and hearing of more younger people in our community talking about research. This is often not the case with research projects and it is time for things to change. Words like ‘representation’ and ‘inclusion’ are used but not met with action. People are made to feel included in a community that is “less than”. In PAN-Co-POWeR, it was obvious in the actions that true inclusion was desired. It was also a learning curve for the researchers but those initial challenges were addressed rapidly in order to ensure true inclusion and for the voices of the community to be amplified. This true inclusion was tangibly reflected in: 1) seeing in real life how suggestions from the community about the importance of culture in food were visibly translated into public health messaging in posters; 2) having the opportunity to co-present recommendations at the UK Houses of Parliament and; 3) months after the project end, still being supported to co-author this paper to ensure the lessons learnt can be disseminated widely. We present our reflections in two main areas: 1) advice to the research community and 2) a message to our community. 1. **Advice to the research community**

Coupled with the key strategies shared in this paper, our reflections and advice for the research community are summarised in five main points presented in Table 5. One of the key messages we share is the need for researchers to be more comfortable with the discomfort that comes when conversations like race, ethnicity and discrimination are had. These topics are sensitive and so, sometimes uncomfortable, however, the fact that they are uncomfortable do not make them less worthy of conversation. Those conversations must be had for positive change to occur. Personal quotes, which include experiences we have had are also shared to emphasise the five main points we share *Table 5. Advice from PPIE partners to the research community*1. **A message to our community**

Up until joining the PAN-Co-POWeR project, we as PPIE partners never realised the amount of work that went into research and how these research activities impact on day-to-day lives. Having been involved in PAN-Co-POWeR and gone on to contribute to other research projects since then, we can testify how important it is to get involved in research. This is our opportunity to share our voices and create a positive change in society. Using the analogy of voting in elections, if we do not get involved in voting, then we cannot really actively comment or make a demand on government actions. Likewise in research, not being involved is almost as though we are losing our voices. Firstly, to those who are already involved in research, we encourage you to actively share your experiences and encourage other people in your community to get involved. We have a responsibility for championing our research involvement effectively. Change starts with us. For those who have never been involved, this is also a call to give it a try. We all have a responsibility to get involved so that the uniqueness of the various communities we represent can be emphasised. This is also our opportunity to overcome being underrepresented.  |

**Effects of adopting these strategies in PAN-Co-POWeR**

The outcomes of using these strategies in PAN-Co-POWeR are described in Table 6.

*Table 6. Outcomes of adopting these engagement strategies in the PAN-Co-POWeR project*

**Conclusions**

The six strategies described in this paper are: 1) early PPIE recruitment start; 2) relationship-focused engagement; 3) co-production and consultation; 4) iterative feedback throughout the process; 5) involvement in project closure; and, 6) a diverse research team.

For effective PPIE to be achieved, motivation to engage with communities must not just be to recruit people into a project but be based on relationship building for genuine engagement to occur. Effective PPIE can be challenging, and time and resource consuming. In PAN-Co-POWeR, adequate funds requested during the funding application process ensured the desired level of engagement could be attained. It is therefore important, when planning research projects, to adequately cost in time and resources for effective engagement.

Lack of willingness to take part in research by ethnic minority communities is often regarded as the reason for their underrepresentation in research. Evidence suggests otherwise.11 Our paper has described how, with appropriate strategies, inclusion and diversity can be achieved in public health research. We recommend researchers and public health practitioners put these strategies in place when planning their research projects.

The strategies described in this paper are likely to be useful when engaging any population group. There is no one size fits all approach to engagement but treating people as people, creating genuine partnerships and tailoring research activities to meet their needs are key approaches to effective engagement and trust building.

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For open access, the authors have applied a Creative Commons attribution license (CC BY) to any author accepted manuscript version arising from this submission.

**Statement of ethical approval**

The research study (Co-POWeR) on which this commentary is based was conducted in accordance with the guidelines of the Declaration of Helsinki. Ethics approval for the Co-POWeR study was received from the AREA Research Ethics Committee (no. 20-120), University of Leeds and the Faculty of Environmental and Life Sciences Ethics Committee (no. 65351.A1), University of Southampton. Written and verbal informed consent was obtained from all participants who took part in the Co-POWeR study. Quotes included in this paper were from co-authors.

**Competing interests**

The authors declare that they have no competing interests.

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