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## Commentary

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



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## ABSTRACT

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 article 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 article 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.

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## Introduction

Involving members of the public in health and medical research is important to improve quality, outcomes and applicability of research.<sup>1</sup> Public involvement contributes to an effective translation of research findings for public health improvement, therefore improving health equity and reducing health research waste.<sup>2</sup>

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 article. This article 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’.<sup>3</sup> 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,<sup>3,4</sup> specific underserved groups in the population including ethnic minority communities continue to be underrepresented.<sup>5,6</sup> 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.<sup>7</sup> These inequalities were exacerbated during the COVID-19 pandemic, when ethnic minorities experienced higher infection and death rates than White communities in the UK,<sup>8</sup> as well as disproportionate social, mental and economic impacts recorded.<sup>9,10</sup> This experience is likely to have added to the lack of trust in the system already felt by many in such marginalised groups.<sup>11</sup> This dis- and mistrust coupled with previous negative experiences may result in unwillingness by ethnic minority communities to be involved in research or public health programmes.<sup>4,6,12</sup> An example of this was observed during the COVID-19 vaccination programme.<sup>13</sup> 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.<sup>14</sup> 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.<sup>15</sup> 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.<sup>16,17</sup>

Tokenistic diversity in PPIE is a risk, especially as PPIE is now a mandatory requirement of most research funding bodies.<sup>16</sup> 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.<sup>18</sup> 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.<sup>12,19</sup> 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.<sup>6,18,20</sup> 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.<sup>21</sup> 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, article was the Southampton-led Physical Activity and Nutrition (PAN) work package of the UKRI-ESRC funded multi-centre project entitled ‘Consortium on practices for well-being 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**

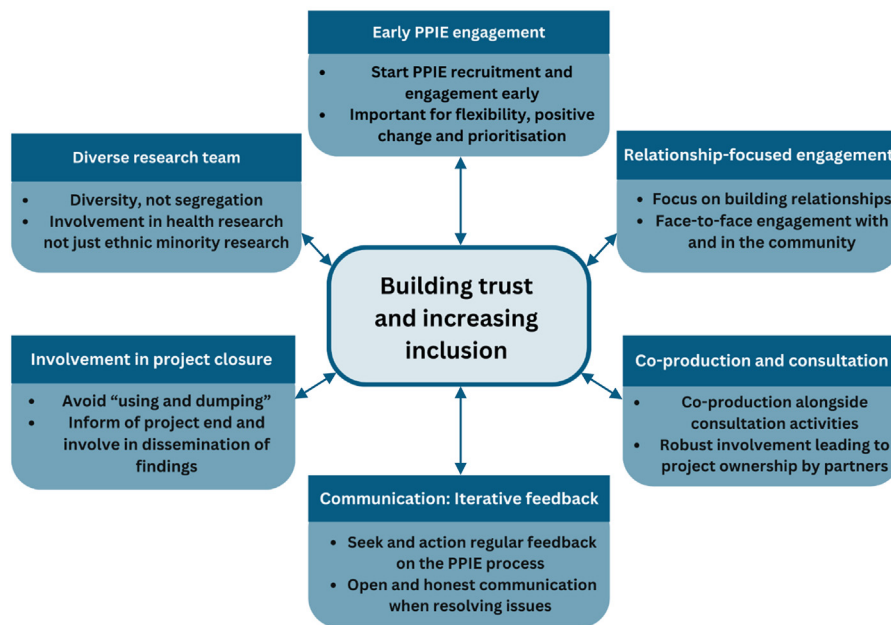
The study team identified six main strategies as being key to building trust and increasing inclusion of ethnic minority communities in the PAN-Co-POWeR project (Fig. 1).

#### *Early recruitment and engagement of PPIE partners*

Effective PPIE requires the involvement of public members at all stages of a research project.<sup>3</sup> 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 projects<sup>22</sup> 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



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

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.

*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.<sup>1,23</sup> 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.

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.

*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 documents<sup>24</sup> e.g., ethics forms, recruitment posters or topic guides for focus groups. Evidence suggests that this alone does not constitute effective PPIE.<sup>1,25</sup>

**Table 1**  
Case study describing activities promoting relationship-focused engagement with a community group.

Activity	Description
Introductory emails to the community group leader	Introductions limited to name, institution and broad research area (e.g., nutrition, physical activity). Request to have an introductory meeting virtually or face-to-face depending on their preference. Contact who connected researchers to leader of the community group (also known as “introducer”) copied into email.
Introductory meeting (V)	Meeting lasted 30 min. Community group leader (MH), the introducer and two members of the research team (OG and MS) present. Meeting was focused on introductions and planning a face-to-face meeting with the community. The group expressed interest in seeing the university campus, so we invited them to lunch at the University to discuss opportunities for working together in a mutually beneficial way
Meeting at the University at the request of the group (F2F)	Three members of the community group and two members of the research team (OG and MS) present. Meeting focused on getting to know the community better. We asked questions on the history of the group, aims and activities, how they fared during the COVID-19 pandemic and any current challenges. In return, the research team also shared ideas and suggestions on how some of the challenges might be addressed. For example, they sought engaging and fun activities for group members during meetings. OG volunteered to visit the club with friends to sing for and with the elders. MS also suggested exploring holding physical activity sessions with elders by physiotherapy students. Group members also asked questions about the University and the roles of the research team. They expressed gratitude for hosting them at the University as some of them had never been, despite living in the area for years. Conversations continued about the city (Southampton) and the UK and how things (shops, food, racism, fashion) have changed over the years. <i>Initial hesitation to engage</i> The PAN-Co-POWeR project was then explained by OG and MS, providing details on why it was set up and its aim. This resulted in some group members describing some of their negative experiences with research. Some had taken part in research and never heard anything back about what the research found, so they felt used and disrespected. They described examples of receiving pages from research projects all in small prints without any support on how to complete them but with a request to send the completed form back. These experiences led to hesitancy in being involved with the project. We assured them that the intention was to avoid these issues, hence the need for engaging with the community as partners on the project. They eventually were open to being involved and emphasised that it was due to how the research team had been organised, respectful and attentive to their concerns during the meeting.
Introductory visit to community group (F2F)	The leaders of the community group were pleased with the meeting and invited the researchers to visit the community group at their own venue the following week. OG paid a visit to meet with members and have individual conversations. OG also participated in group activities with members like dancing, playing games and helping to serve lunch to the elders. By the end of the visit, the members of the group individually were more open and receptive to OG and a relationship was starting to be built. They invited OG to come again the next week. It was also at this point that the community leader volunteered to become a PPIE partner
Recruitment visit to the community group (F2F). Start of participant recruitment	The leaders gave OG the opportunity to address the group, sharing about the research project, its relevance and giving room for comments, questions and suggestions. It was at this point that active recruitment of research participants began. Based on different conversations with OG, some members were already interested in the project but many were still sceptical, believing that nothing would improve even if they tried.
Continued engagement visits to the community group (V, F2F)	This is the most important part of relationship-focused engagement. Although, some group members had taken part in PAN-Co-POWeR, either as participants or as PPIE partners, the researchers maintained communication with the group, visiting at different points of the study. This led to the building of a thriving relationship with the group, evidenced through invites from the group to special activities like Christmas parties as well as the group taking part in research activities including visiting the House of Parliaments to co-present project recommendations.

V, Virtual; F2F, Face-to-face.

We recommend that consultation activities *ride on the backbone of coproduction*, i.e., done alongside each other. The NIHR defines coproduction 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’.<sup>26</sup>

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.

*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.

PPIE Feedback	Response	Action
Use of 'dear all' or 'dear PPIE partners' in emails made people feel they were excluded from the discussion and they were then unsure whether a response was expected from them	Immediate action	Addressed emails with name of recipient. Directing emails to people based on previous personal conversations where available.
Changes to wording of official documents and statements including information sheets	Joint solution	Lay documents produced to accompany official ones, explanatory zoom or phone calls with participants pre-interviews/focus groups
Payments for PPIE affecting people on benefits and tax implications for those working or retired	Joint solution	Support provided to PPIE partners through Citizen's Advice Bureau; official letter of support provided by PAN-Co-POWeR for Job Centres explaining that PPIE activity differs from employment <sup>28</sup> ; public workshop in collaboration with NIHR 5-Nations Project to discuss solutions to manage the complexity of this problem in future research

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

<p><b>Aim:</b> To hold a public engagement activity to mark Black History month in October 2021, because of its relevance to the PAN-Co-POWeR research project.</p> <p><b>Co-production approach:</b></p> <ol style="list-style-type: none"> <li>1) Emails from researchers to two PPIE partners about the idea and requesting a meeting to discuss. The two PPIE partners volunteered to be involved in this activity following an email to the core PPIE group.</li> <li>2) First meeting: a) researchers explained the idea of the event to PPIE partners; b) sought their opinions on whether they agreed with the need for such an event; c) all explored ideas on what the event might entail.</li> <li>3) The meeting produced an idea and a joint decision to invite another work package within the wider Co-POWeR consortium, focused on creative arts, to collaborate so the event would be engaging and exciting for members of the public to take part in.</li> <li>4) Colleagues in the creative arts work package accepted the invitation to collaborate.</li> <li>5) A joint planning meeting with all members of the team in attendance: PPIE partners (JN, RP), OG and MS from the PAN-Co-POWeR research team and creative arts colleagues (see acknowledgements).</li> </ol> <p><b>Valuable contributions from PPIE partners:</b></p> <ol style="list-style-type: none"> <li>1) Making the meeting Co-POWeR focused rather than Black history focused to avoid tensions. This meant discussing issues affecting ethnic minority communities during the COVID-19 pandemic. This also meant all members of the public felt welcome to attend the event without thinking it was for a specific ethnic group.</li> <li>2) Using the event as an opportunity to invite members of the public to take part in the research project as research participants.</li> <li>3) A focus on wellbeing and providing support during the event, due to sensitivity of how sharing experiences (verbally or through visual or written art) can evoke painful emotions.</li> <li>4) Offering a debriefing session afterwards for people who may need one.</li> </ol> <p><b>Co-produced event:</b></p> <p>Event title: 'Telling your Untold Pandemic Stories through Art'</p> <p>Date: 14 October, 2021</p> <p>Platform: Virtually via Zoom.</p> <p>Chairs: Co-chaired by OG (lead researcher) and JN (PPIE partner)</p> <p>Event content: 1) Introductions and a short creative video about the project; 2) The rainbow of Wishes activity<sup>27</sup> and; 3) Creative conversations using documentary videos.</p> <p>Feedback: 23 people attended the event. A feedback poll completed by 17 attendees, gave the activity an overall satisfaction rating of 88%. Through this activity, a member of the public who attended the event contacted the research team to express interest in participating in the PAN-Co-POWeR project as a research participant.</p>
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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.<sup>16,17</sup>

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.

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.

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.<sup>11,29,30</sup> 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.

**Table 4**  
Impact of PPIE contributions on the co-production of PAN-Co-POWeR’s transformative action workshop.

	Initial idea for project closure activity by the researchers	Co-produced project closure activity
Workshop type	Dissemination event	Transformative Action Workshop
Workshop aims	Disseminate research findings including a presentation on methods, outputs and results	1) Give an overview of PAN-Co-POWeR research findings and recommendations, and 2) Kick-start the recommendations being transformed into action through joint efforts by the government, community and relevant stakeholders
Event format	Conference or seminar style	Round-table discussions
	Virtual	Hybrid
Attendees	Researchers, members of the public, research participants, PPIE partners and relevant stakeholders	Three groups of attendees: 1) Community groups and members of the public, including PPIE partners and research participants 2) Policy makers and stakeholders from national, community or local charities, organisations and councils 3) Research and academic community
Session chair	Co-chaired by researchers and PPIE partners	Co-chaired by researchers and PPIE partners and a team of facilitators comprising representatives from each attendee group
Session structure	Research presentations, question-and-answer and discussions	1) Research presentation shared with attendees before the session via email 2) Brief overview of research presentation at the start of the session 3) Questions and answers 4) Round-table discussions 5) Feedback from round-table discussions 6) Reflections on the session allowing each attendee group to reflect on what they could do to kickstart the translation into action of recommendations from the project into their own settings 7) Lunch and end
Session outcomes		Positive feedback from attendees. Attendee groups left with a clear plan and commitment towards reducing inequalities and promoting physical activity and nutrition. Continued communication from attendees and PPIE partners for a whole variety of reasons, including possible project ideas that could be impactful for their communities; interest in taking part in future research projects; or just heart-warming check-in messages. PPIE partners could also see that they had contributed towards ensuring the co-produced recommendations from this project which they had taken ownership of from the start were not just ‘left on the shelf’ but were effectively shared with relevant stakeholders who committed to taking action.

### 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.

**Table 5**  
Advice from PPIE partners to the research community.

Advice	Explanation	Illustrative quotes of experiences
True inclusion	True inclusion is in diversity and not segregation. People from ethnic minority backgrounds form an integral part of the general community and should be treated as such and not as an opportunity to fill up a quota. Underrepresentation exists but it is time to take actions to get it right. If the word 'community' is being used, then it needs to be the whole community; not a separate community, or a disadvantaged community. Most research projects where active PPIE with ethnic minorities occurs are often projects focused on ethnic minorities. So, these communities are being reached because the focus is on us. This is still a form of unequal treatment. True inclusion involves carrying out projects that include every group in the community.	<i>'I find it interesting that the only projects you see making efforts to reach us are those targeted to us. So these are equality, ethnicity, diversity related projects. That is fine but that is not enough. What about the general UK population projects on cancer, on diabetes, on health, on wellbeing etc? We don't see those projects making the same efforts. So it is almost as if we are being included to be separated again. We want to take part in ethnic minority projects but we also want to take part in projects for the general UK population because we are a part of the general UK population.'</i>
Building Relationships	PPIE is about building relationships with community and this was prioritised by PAN-Co-POWeR. This relationship allowed honest conversations and reflections months after project end. Researchers need to prioritise building honest and trustworthy relationships with the community.	<i>'On other projects I have been on, I often do not bother to engage anymore because that relationship was not there'.</i>
Two-way Reach	The importance of engaging diverse communities in research is far-reaching. There seems to be fear about reaching specific underserved communities but this fear needs to be overcome. Researchers often claim they want to reach underrepresented groups but the key question is: "Have they put the right things in place in order to reach these groups? Are meetings well planned or are we being reached as an afterthought?" Reaching out to communities is a two-way process. Things must be put in place to ensure the people you want to reach can also reach you. Following on from the example in the quote, sending the one message to about 200 people is fantastic but the question is, when that message reaches them, are they able to engage with the information? Is it in the right language, are the right words being used? How will interested people contact you? These are all important questions to address.	<i>'I was in a meeting focused on developing policies and documents to address stroke but that meeting was so much geared towards the typical middle class 50-60 year old White man. I knew this was not representing the whole community and I suggested that they go into the community. It was amazing what they found out when they did so. They visited a temple and were able to access this WhatsApp group with over 200-300 people and just like that more people in the community were getting to know more about the stroke services. That wouldn't have happened if they remained in that typical meeting room'.</i>
Reciprocity	Reciprocity in relationships is important. One-sided relationships and engagement should be avoided. As much as PPIE partners can give to a project, they can also receive from the project. This type of mutually beneficial relationship promotes that sense of belonging and true community, which fosters better engagement	<i>'I was involved in one PPIE activity and it became apparent that the reason they wanted me in the room was because they wanted the one person who looked different. It was a complete waste of my time. The wordings and invite for the activity didn't seem like that because it had the usual inclusive, diverse and representation words but in reality, it was token play. I had to step out because I had more important things to do'.</i>
Time	Good engagement and building relationships takes time. PAN-Co-POWeR researchers didn't get it right from the start. There were periods of no engagement, no relationships but the way out is to keep at it and be ready to build those honest relationships. Researchers need to take the time to plan engagement, to build relationships, to do the work, to seek feedback and to be flexible in their approach. Some things need to take a lengthier and different route from your plan and that is okay. Time is critical and taking time to work with communities is important	—
Prepare to be uncomfortable	Learn to be comfortable with discomfort. Conversations about race, ethnicity, and experiences of discrimination are uncomfortable and they are lived experiences that cannot be silenced. So, researchers need to be prepared to hear people's truth. This sort of discomfort is sometimes necessary to drive change. Being uncomfortable, however, is not a negative thing and should not prevent engagement. Have compassion for that part of you that is growing in a positive way. This can be managed by getting the right training and tools to manage such situations.	<i>In a previous project: 'I once attended a PPIE meeting and someone was expressing an experience that was real and authentic to them but it was very obvious that the researchers were uncomfortable because it was racial. They just didn't have the tools to manage that situation and it left an awkward situation. This eventually made me and other public partners feel uncomfortable as well and we started to question whether we should be there'.</i>

All quotes were from PPIE co-authors who consented to having their quotes reproduced in this article.

**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 article, 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.

**2) 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.

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

Outcome	Description
Inclusion of ethnic minorities	Widespread inclusion of ethnic minority communities (six PPIE partners and 48 research participants from Asian, Black and Mixed ethnicities, aged 18–86 years)
Trust-building	Evident in the active participation of people who had initially declined to take part in the project.
Community well-being and impact	Qualitative feedback indicated that study participation increased confidence, wellbeing and willingness to engage in future research among research participants and PPIE partners. Example quote: ‘I heard someone refer to us as hard to reach groups but now this project has given me the confidence to speak up and tell them that PAN-CO-POWeR did it. They reached us and made us feel valued. Other projects can do the same’ PPIE co-author.
Co-production	Active engagement and support to ensure project aims were achieved. Co-production of messaging (posters) and strategies to improve physical activity and healthy eating among ethnic minority communities in the UK.
Active engagement	Four PPIE partners from PAN-Co-POWeR and 14 from the Co-POWeR consortium attended a policy event at the UK Houses of Parliament in Westminster in June 2022 to co-disseminate project recommendations with policy makers. <sup>31</sup> Four PPIE partners (one virtually) also attended the final project conference in Leeds in January 2023.
Consortium-wide impact	Overall enrolment of 51 PPIE partners from ethnic minority communities across the Co-POWeR consortium (overseen by Southampton PPIE Unit) achieved by joint efforts by the researchers and PPIE partners across institutions in the consortium

(continued on next page)



Table 6 (continued)

Outcome	Description
Future engagement of PPIE partners	Following recommendations for continuity of engagement by PPIE partners, an initiative was set up (with internal funding from the University of Southampton) to co-produce a PPIE database of partners from ethnic minorities, termed the Co-DICE project (Co-production of a diverse community engagement database). The purpose was to support development of research projects by enabling more diverse PPIE to better reflect the general population in research.

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

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

### Conclusions

The six strategies described in this article 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.<sup>11</sup> Our article 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 article 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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### 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 article were from co-authors.

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### Competing interests

The authors declare that they have no competing interests.

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