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# Diversity, community engagement and co-design in research: a rapid review

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## ABSTRACT

There is increasing recognition in the field of health and social care research that community-engaged methods should include patients and the public throughout the research process. Therefore, individuals from all backgrounds should be involved in the research. We explored the public and patient engagement experience in research and how researchers and community groups can work together to make the research process more inclusive and sustainable. We carried out a rapid review and we present three themes from our results as a narrative summary. We found that partnerships and peer support was important for individuals, and it helped them to understand their role and the expectations of stakeholders. Also, using inclusive environments for diverse communities to participate helped individuals to access research training in their communities enabling them to co-create and co-design with facilitators and their community together. Trust was an important factor for diverse community participation in research and was linked to past experiences of taking part in research. We also found that partnerships, innovative methods of information sharing and context of the individual were important facilitators of inclusion. Analysis also indicated that the design of the studies and recruitment approaches such as using flyers, word of mouth, attending health fairs and partnering with nonprofit community, led to an increase in diverse population participation in research.

## BACKGROUND

In the UK, the local populations are made up of a wide range of communities, groups and individuals from different backgrounds. The National Health Service (NHS) 'Our Strategy' recommends that health and social care research should be done with and for everyone.<sup>1</sup> Health and social care research necessitates the involvement of those that are impacted by the outcomes of research investigations.<sup>2</sup> Therefore, individuals from all backgrounds should be involved from the initial idea, plan and conception of the design.<sup>3</sup> There is increasing recognition in the field of health and social care research that community-engaged methods can be used throughout the research process (e.g., when developing the research question, designing and conducting the study, dissemination of findings).<sup>1</sup> Co-design and co-production are gaining traction in the field of healthcare, research and policy methods. The main reasons for including people from under-served groups and supporting

opportunities for them to take part in research can ensure that people in the targeted groups can get optimum benefit from the research outcomes. In community research projects, all members of the research team should be aware of, and should train in how they can safeguard those who are likely to benefit from the research and involve those groups/communities in the design stages of the research process. This strategy would ensure that the research is more inclusive of the target groups.<sup>4</sup> There are distinctive approaches to constructing interventions for groups that have traditionally never been included in research, to become both partners or participants in supporting research and being part of the research team.<sup>2</sup> Cornwall and Jewkes (1995) compare participatory and conventional research processes and note that 'the key difference between participatory and other research methodologies lies in the location of power in the various stages of the research process'.<sup>3</sup> It is presently more common to undertake research where the study sample population in health research reflects the communities that are projected to benefit, hence ensuring the opportunity for equitable healthcare is maximised and to comprehensively appreciate the variances in treatment responses, cultural background and application.<sup>4-6</sup>

In the current literature, there is much cited on the benefits of patient engagement, please see table 1.

Patient, public involvement and engagement (PPIE) is a recognised method to confirm 'fair play' in health research.<sup>7</sup> Still, methods by tradition utilised in PPIE have excluded some communities and aggravated existing discrimination, suggesting an importance for the need to develop inclusive processes.<sup>7</sup> Developing inclusive community involvement in health research requires methods that include racially marginalised groups, who remain underserved in healthcare and under-represented in health and social care research are reached.<sup>8</sup>

Patient engagement is meaningful if active collaboration in governance be made part of the priorities that are agreed at conception stages of a research project. PPIE has been used in conducting research and for knowledge translation materials for patient partners as 'real' team members, rather than participants in clinical care/research.

The Canadian Institutes of Health Research's defines patient engagement in research as 'meaningful and active collaboration in governance, priority setting, conducting research and knowledge

**Table 1** Benefits of patient engagement

► Facilitation of recruitment. <sup>5</sup>	Witham MD, Anderson E, Carroll C, Dark PM, Down K, Hall AS, <i>et al.</i> Developing a roadmap to improve trial delivery for under-served groups: Results from a UK multi-stakeholder process. <i>Trials</i> . 2020 Aug 1;21(1).
► Maintaining participation in research studies and clinical trials. <sup>4</sup>	NIHR. (2024). Clinical Research Network   NIHR. <a href="https://www.nihr.ac.uk/explore-nihr/support/clinical-research-network.htm">https://www.nihr.ac.uk/explore-nihr/support/clinical-research-network.htm</a>
► Utilising individuals' specific experiences and insights to bring context to objectives and treatment outcomes being researched. <sup>6</sup>	Witham MD, Anderson E, Carroll CB, Dark PM, Down K, Hall AS, <i>et al.</i> Ensuring that COVID-19 research is inclusive: Guidance from the NIHR INCLUDE project [Internet]. Vol. 10, <i>BMJ Open</i> . 2020 [cited 2024 Mar 12]. Available from: <a href="https://www.nihr.ac.uk/documents/ensuring-that-covid-19-research-is-inclusive-guidance-from-the-nihr-crn-include-project/32647">https://www.nihr.ac.uk/documents/ensuring-that-covid-19-research-is-inclusive-guidance-from-the-nihr-crn-include-project/32647</a>
► Facilitating knowledge translation such as, presenting and distributing findings that are more applicable and reliable to study populations and in theory providing better and/or changed effects. <sup>8</sup>	Naeem, F, Khan, N., Ahmed, S., Sanches, M., Lamoureux-Lamarche, C., Vasiliadis, H.-M., Thandi, G., Baldev Mutta, A. K., Tello, K., Husain, M. I., Husain, M. O., Kidd, S. A. & McKenzie, K. (2023). Development and Evaluation of Culturally Adapted CBT to Improve Community Mental Health Services for Canadians of South Asian Origin: Final Report.

translation' (p1).<sup>7</sup> Though, the National Institute for Health and Care Research's (NIHR) definition of patient and public involvement in research draws on an active partnership between members of the public and researchers.<sup>9</sup> This suggests that members of the public work alongside the research team and are actively involved in contributing to the research process, in roles that form part of the core research team or as an adviser.

While there are many definitions and much has been written in literature about the positive and negative encounters related to patient engagement, there remains a lack of understanding or clarity from the perspective of those who participate as partners, or collaborators in research and then move into roles as advocates.

The objective of our review was to:

1. Explore the public and patient engagement experience in research and
2. How can researchers and community groups work together to make the research process not only more inclusive but sustainable?

The rationale for this review was to use the findings of this review to inform our research which is a part of the Research Engagement Network (REN) programme collaboration through the Community Research Engagement Network (CREN), an NHS investment in developing engagement at integrated care systems (ICSs) level.<sup>10</sup>

## METHOD

### Rapid review

#### Search strategy

The rapid search strategy was created to retrieve both published and unpublished studies as part of the NIHR-funded CREN in Kent, which had internally funded a short (6-month) project for quick completion. Despite the short deadline, we envisaged developing a training workshop package (TWP) that was evidenced-based to implement in collaboration with the Voluntary Community Social Enterprise Sector (VCSE). An initial search of CINAHL, MEDLINE, ERIC, SocIndex and British Education Index was undertaken to identify articles on the topic.<sup>9</sup> We utilised the help of a medical librarian in constructing the search and running the search. The terms used were: ("community involvement" or "community engagement" or co-production or "service learning" or "expert patient" or "social participation" or advocacy or "community group" or "user agreement" or "voluntary sector") AND ("hard-to-reach groups" or "hard-to-reach communities" or "under-served" or un-engaged or BAME or "black Asian minority ethnic" or roma or "traveling communities" or gypsy or "global majority" or women or disabilit\* or minorities or "protected characteristics" or "lived

experience") AND ("recruitment strategies" or "involvement with research" or "engagement with research"). The keywords contained in the titles and abstracts of relevant articles, as well as the index terms used to describe the articles, were applied to develop a basic search strategy for the five databases above. The terms we used were Boolean/phrase, apply related words, apply equivalent subjects. Search within the full text of the articles. We searched the publication date 2006–2023, references available and peer-reviewed articles. We limited to the English language. We included, websites, reports, reviews, peer-reviewed articles and both qualitative and quantitative research. We conducted the coding and analysis using NVivo V.14 software. We generated the themes from the coded data that were extracted and analysed on the Word documents by the researchers NK and SP.

A rapid review is a form of knowledge synthesis that accelerates the process of conducting a traditional systematic review through streamlining or omitting specific methods to produce evidence for stakeholders in a resource-efficient manner (p1).<sup>10</sup> The purpose of the rapid review was to identify and summarise available information regarding public and patient engagement and elicit evidence to make the research process more diverse and sustainable. We aimed to understand, by what means researchers and community groups can work together to make the research process not only more inclusive but sustainable through a robust infrastructure. We used the Cochrane rapid review methods recommendation to report this rapid review.<sup>11</sup>

### Inclusion criteria

Once the articles were identified, our inclusion criteria were kept simple to identify the most relevant articles. We included:

- Publication date 2006–2023.
- References available.
- Peer-reviewed articles both qualitative and quantitative research
- Websites, reports, reviews.
- Limited to the English language.

To carry out the coding and analysis we used the NVivo V.14 software, for storage of the data and for coding. The software did not generate any themes from the coded data and was used to code and extract the data only. The themes generated by the researchers NK and SP were coded and analysed on the Word documents.

## RESULTS

This rapid review explored published articles on the experiences of diverse groups taking part in research and to identify the strategies that researchers and community groups working

together utilised to make the research process more accessible and inclusive for future sustainability. The results of our review are presented as a narrative summary. We found that  $n=9$  studies were from the USA,  $n=5$  was from the UK and  $n=1$  from South Africa. The study methods were  $n=3$  intervention/new approach development,  $n=3$  were mixed methods studies,  $n=2$  were qualitative studies,  $n=2$  were reviews,  $n=2$  were case studies, there was one population-based data linkage—clerical (ie, manual), deterministic and probabilistic method study and one quantitative and survey study. See online supplemental table 1 for the included articles and their characteristics.

The analysis approach was created in relation to the NIHR lens and the ICS who had received funding for a second phase of the REN programme from NHS England.<sup>11</sup> The themes we derived from the data analysis of the published articles, were: (1) Partnerships and peers' support, (2) Creating inclusive environments for diverse communities and (3) Trust as an important construct for diverse community participation in research.

These themes are discussed in the sections below using quotations elicited from those studies and are referenced according to the studies they were extracted from.

### (1) PARTNERSHIPS AND PEER SUPPORT FOR CO-DESIGN

There were many typologies of inclusive partnerships. For the purpose of our work, we envisaged inclusivity, as building a community voice and a consensus, hence the partnership definition we accepted was defined as.

'Action focusing on an operational framework, action-based partnerships are committed to direct actions and building community consensus and orientation. These partnerships are often comprised of independent organisations and non-profit entities and are led by community leaders and citizens. "Often-times, due to the capacity of members, resources are scarce as this model is essentially a grassroots approach to partnership (p1)".<sup>12</sup>

Partnership in medical, health and social care environments have shown negative impact in some contexts. However, in the papers we reviewed, we found that partnerships with other participants and active involvement in the research co-design were linked to confidence in taking part in research.

'I'm judging confidence through my level of participation—and I have felt confident to do so—even to initiate group activity because by doing so I can then get others to convey their views, from which I and the others can benefit'.<sup>13</sup>

The partnership identity was important for individuals who were engaged in the research process, despite their professional roles, as this brought clarity to their role and the expectations which surrounded them.

'It's really important for me to be identified as a patient partner. I would never entertain putting down an institution because I'm not an academic and I don't want people to identify me as an academic. When I look at an article, I always look to see who is the PPI in it, and sometimes I can't tell. And I think that's really bad. I'm not doing this to be melted down into a sea of academics. I want to be identified for what I'm doing'.<sup>14</sup>

Peer support was subsequently of principal importance for engagement purposes of groups that had no prior experience of research.

'When you're in something which is perhaps outside the comfort zone—you can't bring a specific lived experience to methodology research. So, it's thinking more what do I bring? That can seed doubts and then you might not speak up. Whereas we're encouraged by others, we're all very frank. So I think

it's (peer support) possibly more important in areas that aren't related to your lived experience than it is in areas that are'.<sup>14</sup>

Contextual information, flexibility and support were exemplified in the articles included in our review, suggesting varying requirements and forms that were implemented at the different stages of involvement, co-design, engagement, recruitment and retention of diverse groups in research.<sup>14–16</sup>

'I was very much a novice, and when (researcher) approached me, I did ask for some guidance and help and they pointed me in the direction of a couple of examples of rapid reviews. That was very useful. I felt I understood—well not enough—but sufficient to get by'.<sup>14</sup>

### (2) CREATING INCLUSIVE ENVIRONMENTS FOR DIVERSE COMMUNITIES

Zittleman *et al*, indicate in their work that researchers should be aware of and learn the fundamentals and benefits of community engagement and community-based participatory research. They have suggested the following methods:

- ▶ To learn through offering multiple venues, as these were experienced as safe spaces for learning and education.
- ▶ It was important to explore first-hand the history, geography and culture of a particular community in the area of interest.
- ▶ Real and genuine connections with local residents to gain trust and using good. Communication skills for engaging communities of interest communities in research.
- ▶ Sharing stories and perspectives with community members and within their communities was important for reducing hearsay and stigma of accepting support from outside agencies.
- ▶ Work with an experienced team of supportive health researchers who understand the community settings and how to be respectful and engaging respectfully.<sup>17</sup>

It appears that the above would impact the strategies used in any training and the methods used by the facilitators should engage the public in various research roles and capacity. Such as facilitators, advocates and community champions would oversee that presenters prepare relevant and up to date, rich, thoughtful content and take part in exercises that require active participation from people interested in gaining experience in taking part in research. Making sure that positive and negative feedback from individuals is utilised with interest and not defensively. This information is valuable for learning from people who take part and participated in training workshops and courses. In the papers reviewed, we found that people presenting from perspective of lived experience and research involvement were received well and it was beneficial to both the research process and outcomes, with all, researchers, peers and others benefitting from the outcomes. Skinner *et al*, in their article highlighted the top three indicators of community engagement:

- ▶ Integrating community members into all phases of the research process.
- ▶ Results should be disseminated to the community in a culturally appropriate manner.
- ▶ Community members should be able to identify that their input in research had an impact on the community.<sup>18</sup>

There was evidence in the papers reviewed that an ambient and safe learning environment should be enabled and co-created by the tutors and community facilitators, delivering the training and in particular the use of reflective practice was advocated. This was linked to creating the individuals' ability to relax and engage with their experience, despite other factors that may have acted as barriers such as the awareness



of diversity in the group experience or experience level of community of research. The learning environment influenced individuals positively, especially if it was welcoming of feedback, questions and thoughts during the delivery of the research training workshop and the equitable equalisation of the learning process.<sup>13 19</sup>

### (3) TRUST WAS IMPORTANT FOR DIVERSE COMMUNITY PARTICIPATION IN RESEARCH

Diversity was understood in terms of inclusivity in the papers included:

'By inclusive we meant that all sandpit (intervention) participants felt they could contribute equally to the sandpit process and outcome, that their views and voices were heard and that they were positive that they could work collaboratively and effectively with participants from other backgrounds.' Data from the evaluation questionnaires suggested that attendees found the event inclusive.<sup>16 20</sup>

The fundamental reasons for inclusion of the concept of diversity was related to enabling research that had the capacity to access those would gain advantage the most, and those, who research had excluded in the past, thus to address issues of health equity and relevance of research outcomes.<sup>15 21 22</sup> Taking part in research and gaining experience was explained in relation to recruitment and retention, which was shown to be influenced by the individuals experience of taking part in research and research training.

'I have learnt a lot from the course, and it has raised my level of confidence about research and would definitely recommend it to others.'<sup>13</sup>

Trust was reported as a major barrier identified in the literature amidst likely partakers of research from minority communities.<sup>23</sup> Trust building and diversity of researchers, who were from the same ethnic or racial backgrounds as the members of the communities under study were distinctively well placed to connect those community members in various circumstances. The benefits were that these researchers typically had increased awareness of cultural nuances and cultural sensitivity. It is well documented that minority individuals often seek physicians of the same race. Similarly, minorities are often suspicious of researchers of a different race.<sup>13 24</sup> However, a lack of minority researchers exists, especially principal investigators. The barriers most strongly endorsed as a large or very large problem in the field were; a lack of funding for stakeholder-led mental health services research (76%), a lack of researcher training in participatory methods (74%) and a lack of diverse backgrounds among stakeholders (69%).<sup>16</sup> Jones *et al*, in their study, identified barriers to and the scope of stakeholder involvement in participatory research. Two of the most frequently identified and recognised high-priority steps to ensure training and continuing education for both researchers and stakeholders was to implement the use of lived experience in valid equitable ways to reduce tokenism (symbolic effort) in research (26%).<sup>16</sup> The recruitment approaches in the data highlighted for engaging diverse groups were through the use of; using flyers, word of mouth testimonials, attending health fairs and partnering with non-profit community-based organisations to sponsor targeted recruitment events. Face-to-face contact with community residents and partnerships with community-based organisations were most effective in enrolling caregivers into the studies.<sup>25 26</sup>

### DISCUSSION

There is mounting interest in developing community membership in health and social care research, along with eliciting a better understanding of how community stakeholders perceive their involvement in research activities.<sup>18</sup> There is evidence that the majority of public contributors in NIHR research are older (62% 50–79—UK-34.8%), women (58%; UK-50.6%) and White British (77%—UK-87.2%).<sup>20</sup> Therefore, it is apparent that minority ethnic groups and young individuals were and have been under-represented in NIHR research.<sup>20</sup> Research carried out by the Health Research Authority has indicated that people from ethnic minority groups and lower socioeconomic groups also have less confidence in their treatment, because they feel they will not be treated with dignity and respect by services or in research due to their ethnicity and socioeconomic status.<sup>20</sup> Similarly, in this way—communication of science, and science education has been shown to be selective over the years, increasing healthcare inequalities resulting in many diverse audiences remaining underserved during research and science development.<sup>20</sup> For this reason, voluntary community stakeholder input and engagement is a necessity. Community groups are uniquely positioned to not only support a wider community engagement in research and science development but also exhibit awareness and respect of community knowledge and perspectives. Evidence suggests that such partnerships can enrich the researcher's insight of the community's cultural attributes.

The main recruitment strategies highlighted as effective in data were innovative and ranged from collaborating with community organisations, targeting recruitment events to face-to-face contact with community participants, locally, appearing at community events such as health and social fairs and handing out flyers and utilising information tables. Flyers were featured at various locations in local areas where individuals lived, including local markets, bakeries and laundromats, a weekly bulletin at local Catholic parish and other religious building as well as communication in the bulletin of the religious places if they had this resource. Indicating that there is a requirement in research community for being innovative in the way they communicate information, carry out research, using innovation and strategy that fits the demographics of the region under study, especially those communities that have never been reached due to lack of innovation or appropriate strategy on the part of researchers, health and social care, government and funders, hence, remaining overlooked in the research processes in certain deprived areas of the UK.

Community participation in research was key and to optimally influence this was central central phases of research - the design phase, so that the conceptual development of the research plan was relevant of the overall research outcomes so that they would accurately benefit the community. Partnerships were important to facilitate valuable membership and roles in research, helping to build a diverse community and preserve those links through community champions so that building research capacity could be sustainable through these relationships and links for future research. Such links can add to sustaining health and social care support systems in research, endorsing interventions that develop training and policy initiatives for positive community change based on evidence from local communities. The ambient nature of the community environment, where diverse groups could communicate and feel safe or respected and had dignity was important and was linked to inclusion and positive engagement of those communities. Creating a learning environment where critical feedback was important given that under-represented

groups had strong emotional reaction to negative engagement experiences with health and social care in the UK.

The above findings and strategies highlighted for increasing diversity in research are not a fashion statement or fad, but in reality of working with diverse a group a true genuine approach based on evidence from community projects nationally and internationally, suggest leading to successful diverse engagement in community research. We found through our analysis that this was related to the fact that these studies were better 'designed' to include groups that were traditionally viewed as hard to reach.

## CONCLUSIONS

NHS England and NIHR recognise the need to engage with diverse groups in the UK population when conducting research to build accurate evidence for reducing healthcare inequalities, to maintain engagement with communities, and to build sustainable partnerships for community participation. This literature review suggests a necessity for researcher innovation in collaborating and communicating research involvement opportunities for diverse communities.<sup>27</sup>

The CREN proposed establishing resources, funding to develop community networks, links and relationships that can be tapped into, suggesting a need to embed these in the infrastructure for sustainability of research enagement and capacity buidling. This review contributes to the learning for the Kent and Medway CREN as well as lessons more generally. Further research is required to continue the work that has been undertaken as part of the REN, local development, by the CREN to inform ongoing health and social care research impacting the needs of diverse communities in the UK.

## Recommendations

The findings suggest:

- ▶ The partnership identity was important for individuals who were engaged in the research process, despite their professional roles, as this brought clarity to the expectations, which surrounded them.
- ▶ Trust was reported as a major barrier identified in the literature midst likely partakers of research from minority communities.<sup>23</sup>
- ▶ The diversity of researchers, occurring from the same ethnic or racial backgrounds as the members of the communities under study were distinctively placed to connect with those community members.
- ▶ Offering multiple venues in the community, as these were experienced as safe spaces for learning and education.
- ▶ Working with experienced teams of supportive health researchers who understand the community settings and how to be respectful and engaging respectfully.<sup>17</sup>
- ▶ Integrating community members into all phases of the research process.
- ▶ Results should be disseminated to the community in a culturally appropriate manner.
- ▶ Community members should be able to identify that their input in research had an impact on the community.<sup>18,28</sup>

## Limitations

Rapid reviews can inform specific clinical, research and policy decisions in a timely and resource-effective approach.<sup>9</sup> Our objective was to understand the experiences of diverse communities who can engage in the research process. Exploring how researchers and community groups can work together to make the research process not only more inclusive but sustainable for

diverse communities. Our results show that partnerships, peer support and context of the individual were important and were facilitators of inclusion, impacting the barriers to recruit or retain groups that traditionally have been overlooked in these selective processes. Rapid reviews can be undertaken at an accelerated pace to inform such fast paced projects. However, they are not less systematic than standard systematic reviews.<sup>9</sup> Although rapid reviews do not meet the gold standard of systematic reviews, they frequently provide adequate advice on which to base clinical and policy decisions.<sup>9</sup>

Health and social care leaders need to be aware of using outcomes derived from White British population and applying them for other groups. As they may not be applicable for use for the entire population across their services and the results will not be representative of the communities they serve. Disengagement of diverse communities has been legitimate and so we must allow diverse groups to question 'How can someone from a community whose needs are often under-represented and underserved by health or social care research and services benefit from accessing or using such a service?' Consequently disengaging from service input and research is a result of under investment in health of certain groups. Health and social care leaders have a responsibility to better support the research community, to reduce this social injustice, while improving equity of healsth and social care. Fundamental to any success is - trust in services, meaning that leaders should want people to get involved in research and so they can use findings for such groups to provide treatments that work for all groups . Therefore, working in partnership across the UK, between regulators, other agencies, the research community, service providers, leaders and the community is also a necessity.

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