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Research Involvement
and Engagement

REVIEW **Open Access**

What approaches are used to facilitate people from under-served communities getting involved with health research? A public contributor led review

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Abstract

Evidence indicates that people from under-served groups are likely to bear the greatest burden of ill-health but are often not included in research involvement activities. It is a requirement of funders (i.e. NIHR) for research funding applications to demonstrate that inclusive patient and public involvement (PPI) has supported the application and is embedded throughout the project. This review was led by PPI contributors from the NIHR Oxford and Oxford Health Biomedical Research Centres' Diversity in Research Group (DiR Group). Group members are from under-served communities and the Group exists to support researchers to make their research more inclusive. The PPI contributor authors were trained in reviewing methods and worked on all aspects of this project. We followed a standard approach to literature searching and in June 2022 identified eight papers from the UK relevant to our topic. An additional ten papers were identified from a repeated search in May 2024. From these publications we found three key themes that are important for successful PPI with under-served groups: Population (people relevant to the research are involved); Relationship Building (between researchers and PPI contributors); Practicalities (payment, venues and activities). We found that the approaches in the literature reflected the UK Standards for Public Involvement, "Inclusive Opportunities" although, in general, authors did not directly reference the standards. We have also demonstrated that PPI contributors can have a direct role in conducting research activities when given appropriate training and support.

Plain English summary

This review looked at the literature to see what approaches researchers use to involve people from under-served communities in research. The review was led by PPI contributors who are part of the Diversity in Research (DiR) Group. The PPI contributors learned how to carry out an academic review and were involved with all aspects of the project. We found that researcher approaches for successful PPI with under-served communities were centred around ensuring the right people were involved, building relationships, and being mindful of practicalities, such as payment and accessible venues. We also found that most successful PPI activities reflect the UK Public Involvement guidance, although this is usually not referenced. We have also shown that PPI contributors can have a direct role in research activities when given training and support.

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Background

This review was initiated and led by the patient and public involvement (PPI) members of the NIHR Oxford and Oxford Health Biomedical Research Centres' (OBRC and OHBRC) Diversity in Research Group (DiR Group)[1]. The aims of this project were to explore approaches taken by researchers to involve under-served communities in their PPI activities and to develop recommendations for researchers.

"Public involvement in research means research that is done 'with' or 'by' the public, not 'to', 'for' or 'about' them" [1]. Public involvement (or PPI) has the overall aim of ensuring health research benefits the people it is designed to help or treat. There is evidence for the benefits of PPI, such as improved recruitment into trials [2] and research that is more cost-effective [3] and ethical [4]. It is now a requirement of funders such as the NIHR that research funding applications demonstrate how PPI has supported the application and is embedded throughout the proposed project.

The NIHR describes under-served communities as: "A group that is less well represented in research than would be desirable from population prevalence and healthcare burden." [5] Under-served groups are identified in the NIHR INCLUDE guidance under four categories: "demographic" (e.g. from minority ethnic backgrounds); "socio-economic" (e.g. living in socio-economically deprived areas); "health status" (e.g. learning disabled) or "condition specific" (e.g. cancer) [5]. People from these communities are more likely to bear the greatest burden of ill-health but are less likely to be involved in health research [6, 7].

Evidence suggests that people from under-served groups are not usually involved in research. For example, a systematic review exploring black and minority involvement in health research found only a few studies outside the US to have involved these communities in research [8]. To address this imbalance for all under-served communities, inclusivity is now a focus for the NIHR [9] and "Inclusive Opportunities" is the first of the six UK Standards for Public Involvement (referred to in this paper as "the UK PI Standards" [10].

People from under-served communities were previously under-represented in the two Oxford Biomedical Research Centres' PPI groups as, traditionally, PPI contributors tend to be white, middle-class and retired [11]. The Diversity in Research (DiR) Group was established in 2021 to increase the involvement of people from under-served groups in the work of the NIHR Oxford (Oxford BRC/OBRC) and Oxford Health BRCs (OHBRC). The DiR Group includes people with Black African, Asian and Caribbean heritage, LGBTQ + people, people with long term conditions and disabilities, and people who are at different stages of life – students, employed, and retired - as well as people with significant caring responsibilities.

Around a year after the DiR Group was established and following many discussions between members of the group and researchers about how to increase involvement of people from under-served communities, the group wanted to know more about what approaches the literature recommended. In particular, the group members were interested to find evidence of researchers successfully applying the UK PI Standards [10] as this would give group members, and other PPI contributors, confidence to refer to the NIHR Standards when working with researchers. The group felt it was important that the review findings were disseminated to researchers via an academic paper as they thought that researchers would take the findings seriously if they were published.

The DiR Group was particularly motivated to do this piece of work because during the Covid-19 pandemic group members were hearing more about the health inequalities exposed by the pandemic, revealing that people from some minority ethnic communities were more adversely affected [12, 13]. Several group members had health conditions themselves and/or had family members in the UK or abroad (e.g. India and Pakistan) who were potentially more vulnerable to the harmful effects of the virus. The DiR Group was supported by a small team of academic researchers. The review was therefore undertaken as a co-produced piece of work.

Methods

Research team

The DiR Group thought that as the review was about under-served communities it should be led by people from these communities to ensure this perspective was strongly embedded throughout. In addition, undertaking a review was identified as an opportunity for members of the group to learn how to access and engage with academic literature. A GRIPP2 checklist has been completed and submitted to the journal alongside this publication.

Following advertisement and informal interviews, four DiR Group members were appointed to the review team (Appendix 1). Two group members led the review (the lead patient contributors), and two others provided input at key points, such as identifying the research question and reflecting on identification of initial themes. Those appointed were from British Pakistani and mixed British Indian heritage and all had personal experience of mental and physical health conditions. Following NIHR guidance, we offered payment and expenses reimbursement [14].

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[1] The DiR Group members chose the group name, preferring the term "diversity" which they felt was more positive rather than another identifier, such as "under-served" or "underrepresented".

The research team included a senior researcher (JLD) and the patient and public involvement lead for the Oxford BRC PPI Lead (RT) and the initial phase was also supported by the Oxford Health BRC PPI manager at that time (AA). Regular meetings were held at key points, such as devising the research question, analysis and discussion of themes. All meetings were hosted online, partly due to the Covid-19 restrictions when the project started and also because the team was geographically spread across London, Oxford and Birmingham.

One of the University of Oxford Bodleian librarians (CS) provided training for PPI contributors who were previously unfamiliar with literature review methodology. The sessions were also attended by the PPI Leads from the BRC teams and the senior researcher supporting the work. This training included an overview of the PICO process, developing a search strategy using Boolean logic, reference management guidance, and applied critical appraisal skills. The two lead patient contributors (AB and AV) were also trained on how to use the Critical Appraisal Skills Programme (CASP) tool for assessing the quality and relevance of academic publications [15].

The PPI contributors in this review took lead roles in identifying and specifying the research question, conducting the literature search (including critical appraisal of publications), completing initial qualitative analyses, reviewing the findings, and writing the paper.

Search strategy

Supported by a healthcare librarian, we built our research question using the PICO method. PICO stands for P = Patient/Populations, I = Intervention, C = Comparison, O = Outcomes [16]. The "comparator" part of PICO was not applied as it was not necessary for included studies to be experiments. We aimed only to include papers where the study either focused on PPI with under-served communities, or the participants were part of a study related to PPI. We excluded non-UK projects and publications prior to the introduction of the Equality Act in 2010, which is an important basis of the NIHR Research Inclusion Strategy [17]. We also excluded 'grey' literature. These exclusions also kept the number of publications returned by the search manageable.

In June 2022 we used OVID (Medline) and PubMed to search. (See Table 1 and PICO table Appendix 2).

The two lead PPI contributors (AB and AV) reviewed the titles of the resulting 393 titles. We only included papers where the study either focused on PPI with under-served communities or the participants were part of a study related to a deeper understanding of PPI activities. At this stage, we removed 303 publications. Publications excluded were mostly removed due to ineligibility of geographic location (i.e. not from the UK).

We then reviewed the remaining 90 publications by title and abstract. We divided this task between two lay members of the team (AB and AV). The senior researcher (JLD) and other research experienced team member (AA) conducted a concurrent appraisal of eight papers (a 9% sample) to review the PPI contributor decisions on inclusion. Exclusions at this stage were mostly because publications were focused on including people from under-served communities as consented participants for research rather than involving them in their PPI work.

The team held a meeting to discuss papers which they were not sure should be included. By the end of this stage, which also included a quality assessment using the CASP tool [15], we had excluded another 82 publications.

We divided the remaining eight publications between the team and two members of the team (AB, AV, JLD, RT) each read two papers in full. At this stage we removed four which did not report patient and public involvement work. This left us with four papers which we 'snowballed' by checking references for additional publications that had not been identified through our initial search. This snowballing exercise generated an additional four publications, resulting in eight papers.

Eight publications were included in the original review (see Fig. 1).

Table 1 Table showing final search strategy in OVID

Research question:
What approaches are used to facilitate people from under-served communities getting involved with health research?

#	Query	Results from 19 Feb 2023
1	(Underrepresent* or Minorit* or Under serv* or Under-serv* or seldom heard or hard to research or marginali* or diverse or diversity or bme or bame or disabl*).mp.	863,060
2	(involv* or participa* or engage* or outreach*).mp.	4,195,584
3	(health* adj2 research).mp.	88,382
4	(nhs or uk or england or scotland or ni or northern ireland or wales or britain or london or birmingham or manchester or glasgow or leeds).mp. [mp=title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	491,963
5	1 and 2 and 3 and 4	393

The writing of the paper was delayed due to all team members' workloads and PPI contributors' professional commitments, and personal lives. In May 2024 we checked for new publications. This identified an additional ten papers which were reviewed by one member of the team (RT). All eighteen papers are included in Table 2.

Data extraction and thematic analysis

Two research team members reviewed the original eight papers (each team member reviewed four papers) and provided independent summaries, highlighting key themes and important points. Then each publication was re-read by two different members of the author team to confirm reliability of coding [18]. The full team met to discuss discrepancies.

The senior researcher (JLD) then reviewed all the independent summaries ($n = 16$) and used the principles of reflexive inductive thematic analysis to explore the messages presented though the publications included in this review [19–21]. The reflexive approach acknowledges the personal experiences of the researcher/s which influence their approach and interpretation of the data. In this case it is particularly important that the original publications were reviewed initially by members of under-served communities Findings of the summaries were mapped to a more formal structured thematic analysis. The senior researcher (JLD) followed a standard qualitative approach to data analysis [19] which included initial familiarisation with the data, and created a preliminary coding frame from the data [22].

All PPI contributors (AB, AV, HK, MA) were involved in analysis via group discussion along with the PPI manager (RT) and senior researcher (JLD). At this meeting, the senior researcher (JLD) presented the findings into a visual representation of the coding framework (the one sheet of paper method) [23]. Following the discussion with PPI contributors, the senior researcher (JLD) revised the structure of the findings, forming the basis for the final coding framework and thematic analysis that is outlined below. A further meeting took place where the revised findings were presented to local professionals with PPI-focussed roles and responsibilities (JC, EH, PH). This process provided a valuable 'sense check' on the findings and also guidance on interpretation, particularly in relation to the UK PI Standards [10].

Following this initial data extraction and analysis, the PPI manager reviewed the findings against the NIHR UK Standards for Public Involvement "Inclusive Opportunities" using a spreadsheet to align best practice in

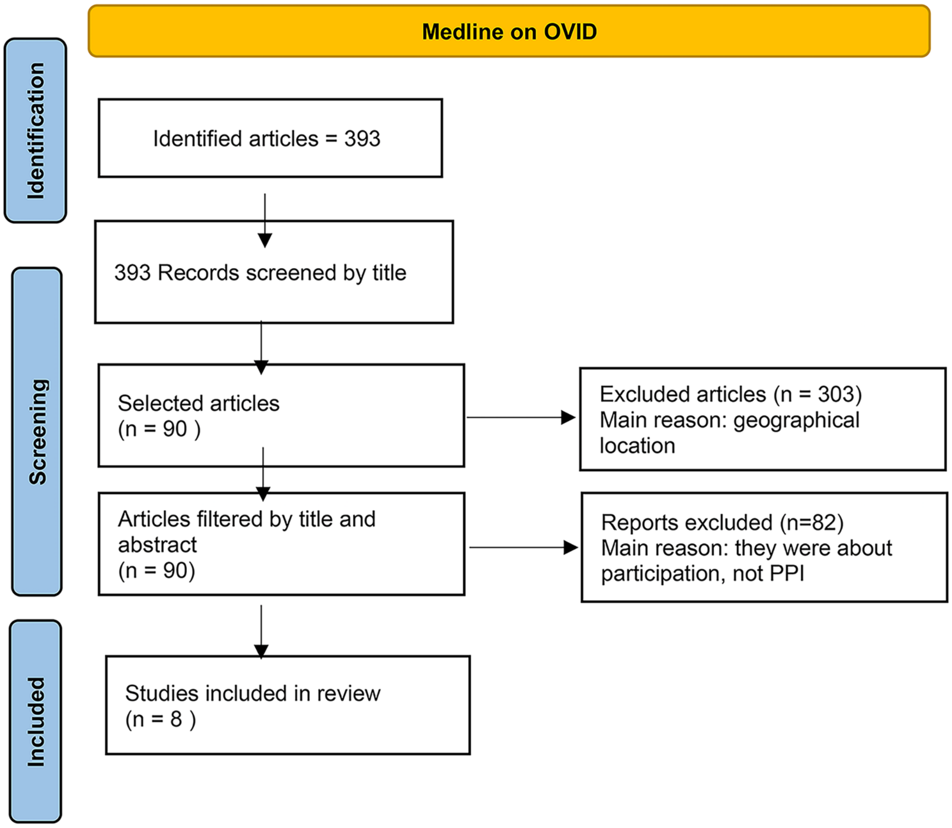

Fig. 1 Prisma flow chart

Table 2 Publications included in the review

Lead Author	Year	Title	Under-served population where relevant (as defined by Equality Act 2010 and/or INCLUDE)	Topic or condition researched	Number and demographics of PPI contributors	Area/s of UK
Brighton et al.	2018	Taking patient and public involvement online: qualitative evaluation of an online forum for palliative care and rehabilitation research	Disability	Palliative care	4 PPI contributors; 5 researchers; demographic information not recorded.	SE London
Dawes et al.	2021	Capturing learning from public involvement with people experiencing homelessness to help shape new physiotherapy research	Homelessness	Physiotherapy research with people experiencing homelessness (PEH)	6 PEH PPI contributors; diverse in age, gender identity and nationality.	London
Dawson et al.	2020	Patient and public involvement in doctoral research: reflections and experiences of the PPI contributors and researcher	Ethnicity	Doctoral research explored the views and experiences of people of South Asian origin on PPI.	5 PPI contributors; With and without PPI experience; all from Black African, Asian or Caribbean communities.	Greater Manchester area
Eccles et al.	2018	Patient and public involvement mobile workshops – convenient involvement for the un-usual suspects	Deprived socio-economic	Online GP booking system in deprived socio-economic areas	26 PPI contributors from existing groups e.g. parent groups, gyms; deprived area; 24/26 White British ethnic backgrounds; ages 21 to 68 years, the average 40 years old; 17/26 were female; 7/26 had a long-term condition; was a broad range of volunteers in terms of their employment; Only a minority (3) had previous experience of research.	Not clear but researcher based in Warwick
Edwards et al.	2018	Consulting parents about the design of a randomized controlled trial of osteopathy for children with cerebral palsy	Disability	Cerebral palsy	20 parents were from a mix of rural and urban locations and included a wide range of child and parental ages and severity of disability of the child.	"Convenience sample" SW England
Grande et al.	2023	Involving carer advisors in evidence synthesis to improve carers' mental health during end-of-life home care: co-production during COVID-19 remote working	Disabiity	Mental Health/ end of life	4 or 5 carers	Manchester
Hedd Jones et al.	2024	Involving older adults and unpaid carers in the research cycle: reflections on implementing the UK national standards for public involvement into practice	Disability	Dementia	Not sure	Cardiff

Table 2 (continued)

Lead Author	Year	Title	Under-served population where relevant (as defined by Equality Act 2010 and/or INCLUDE)	Topic or condition researched	Number and demographics of PPI contributors	Area/s of UK
Johnson et al.	2020	Patient and public involvement in palliative care research: what works and why?	Disability	Palliative care	6 white/1 black; 5 female, 2 male; age 40–60. Length of time involved.	London
Lawton et al.	2023	Strategies for expanding patient and public involvement into under-served head and neck cancer communities	Disability	Head and neck patients	10 PPI representatives	Liverpool
Mitchell et al.	2024	A framework for more equitable, diverse, and inclusive Patient and Public Involvement for palliative care research	Disability	Palliative care	16 PPI members – 10 WB, 4 Asian, 1 Black African and 1 British mixed race.	3 x diverse areas with high deprivation. Sussex, Sheffield London.
Morgan et al.	2016	Combining PPI with qualitative research to engage 'harder-to-reach' populations: service user groups as co-applicants on a platform study for a trial	Age/Deprived socio-economic	Smoking and pregnancy.	21 mothers from mother and baby groups; included younger and less educated women (most likely to smoke); economically disadvantaged areas.	NE Scotland and NW London
Moss et al.	2017	Involving pregnant women, mothers and members of the public to improve the quality of health research	Pregnancy/gender	Pregnancy/women's health	Diverse group of individuals in terms of socio-economic background	London
Parveen et al.	2018	Involving minority ethnic communities and diverse experts by experience in dementia research: The Caregiving HOPE Study	Ethnicity/disability/carers	Dementia	12 PPI contributors; 9 F, 3 M; age 20–80; 5 White British; 1 Myanmar; 1 British Indian; 1 British African Caribbean; 3 were Alzheimer's Society research volunteers.	Bradford
Rayment et al.	2017	Involving seldom-heard groups in a PPI process to inform the design of a proposed trial on the use of probiotics to prevent preterm birth: a case study	Ethnicity/Pregnancy/Socio-economic	Taking prebiotics to prevent pre-term birth.	35 women; aged between 27–43 years; White British, White Other, Indian, Pakistani, East African, West African and Black Caribbean from local authorities in the top 40 most deprived areas in UK.	East London (Hackney, Waltham Forest and Newham)
Smith et al.	2023	Importance of patient and public involvement in doctoral research involving people living with dementia	Disability	Dementia	All had previously engaged with PPI. 3 ppl w dementia; 1 carer; 1 HCP/	Cardiff
Taylor et al.	2018	Engaging seldom heard groups in research and intervention development: offender mental health.	Disability/people in CJS	Mental health	PWLECJS – criminal justice. 8 men 25–56	Bristol/Plymouth
Taylor et al.	2018	Involving young people in Brightlight	Disability	Cancer	CYP 13–24 years old	London

Table 2 (continued)

Lead Author	Year	Title	Under-served population where relevant (as defined by Equality Act 2010 and/or INCLUDE)	Topic or condition researched	Number and demographics of PPI contributors	Area/s of UK
Teodorowski et al.	2022	'To me it's ones and zeros, but in reality, that one is death': A qualitative study exploring researchers' experience of involving and engaging seldom-heard communities in big data research	Researcher experience of working with range of under-served communities	Big data research	12 researchers and facilitators of PPIE projects;	England, Scotland, Belgium and Canada.

Table 3 Summary of PPI groups and research topics

PPI cohort example	Research topic
Carers of people receiving palliative care	Using an online forum for PPI [24]
Carers of people nearing end of life	Carers' mental health [25]
People experiencing homelessness	Physiotherapy [26]
West African women	Probiotics use in pregnancy [27]
Women living in disadvantaged areas	Financial incentives for giving up smoking in pregnancy [28]
Minority ethnic communities	Dementia research [29]
People from Black African, Asian or Caribbean communities	PPI in doctoral research [30]
People with dementia or their carers	Doctoral research involving people living with dementia [31]

the publications with the NIHR guidance. The "Inclusive Opportunities" Standard outlines five questions for researchers to reflect on to help them decide if they have met the Standard. The five questions are in Appendix 3.

The ten publications from the final search in May 2024 were reviewed by one member of the team (RT) and findings were incorporated into the prior analysis.

Results

Table of included publications

Three themes emerged from the analysis of the original eight papers as important for successful PPI with under-served communities. The themes were: Population, Practicalities, and Relationship Building. There is some overlap between the themes – for example, the practical issue of providing timely and easy access to payment and reimbursement also helps to build a good relationship with PPI contributors. Review of the ten papers added in May 2024 did not identify any new themes. We explored where the results showed evidence of the NIHR Standard for Public Involvement Inclusive Opportunities being applied, even if this was not made explicit in the publications.

Population

The theme "population" refers to the PPI contributors involved. We found that the PPI approach taken by researchers across the publications included in this review reflected the UK PI Standard Inclusive Opportunities [10] and the questions:

- "Are people affected by and interested in the research involved from the earliest stages?" and.
- "How is information about opportunities shared, and does it appeal to different communities?".

All the publications identified for this review showed evidence of working with a PPI population that was both under-served and context-specific, meaning it was a population "affected by and interested in" the research topic. Examples of the PPI groups and research topics involved in the publications are offered in Table 3:

Sometimes, the most relevant group of people needed to be quite non-specific in terms of health condition, but diverse socio-economic background of PPI contributors was relevant, for example a project about a GP online booking service [24]. This project involved people attending gymnasiums or working in supermarkets, unemployed people as well as professionals.

The publications demonstrate that reaching relevant under-served communities can be achieved through researchers making contact with people leading or managing existing groups. Working with a third-party intermediary to access under-served populations was highlighted as beneficial and reflects the UK PI Standard Inclusive Opportunities question "How is information about opportunities shared, and does it appeal to different communities?". Example groups from the publications in this review included local community groups or established PPI groups (e.g [25–28]. and were diverse. They included local gyms and supermarkets [24], a charity [27], mother and baby groups [26] and a palliative care PPI group [25]. However sometimes there were challenges. For example, Eccles et al. [24] found that making contact with an "engaged and willing individual" in organisations (e.g. supermarkets) was not always easy. Seven of the research projects described in the publications we reviewed took place in socially and ethnically diverse areas, e.g. Manchester, Sheffield, London.

The relevant people and communities were, in most cases, involved at the "earliest stages" in the research. In one paper, the research was initiated by a carer of someone with dementia [27], others discussed the project with PPI contributors at early stages influencing study/project design [25, 28, 29], while another engaged people as co-applicants early on [26]. Another co-created the project with PPI contributors, having an emphasis on "shared power" [30] and others involved PPI contributors throughout the research cycle [25, 28].

Relationship building

We found evidence of researchers' awareness of the importance of building relationships [28, 29, 31]. The approaches taken by researchers to build relationships reflected the UK PI Standard Inclusive Opportunities questions [10]:

- "Is there choice and flexibility in opportunities offered to the public?"
- "How is information about opportunities shared, and does it appeal to different communities?"

As was noted under the theme "population", in order to access under-served communities, researchers initially built relationships with community organisations and leaders/managers of existing groups. This 'guardian' [29] or 'gatekeeper' [28] role supporting the PPI contributors was beneficial in that they acted as an advocate for the PPI contributors, and facilitated trust and subsequent good working relationships between the PPI contributors and the research team [29]. Practical support was another key benefit of creating links with existing communities, for example organising refreshments and childcare provision [24].

We found evidence that researchers understood the importance of allowing time for PPI contributors to share their experiences [29, 32]. Researchers reported they were mindful of PPI needs and valued their contributions [25, 27], which encouraged the PPI contributors' priorities to be highlighted [27]. Several publications included in this review highlighted that good quality PPI interactions and communications take significantly more time than is generally anticipated [29].

We also identified that PPI with under-served communities might benefit from a diverse research team in addition to a diverse PPI team. Formalised co-production was also noted [33]. The benefits include embedded cultural understanding and the potential for greater rapport with PPI members due to shared backgrounds [28].

Researchers also built relationships through showing flexibility and sensitivity about the type and intensity of PPI involvement. They were aware that it might change over time based on what individuals prefer and feel able to do, particularly when working with carers of people experiencing health conditions that are not stable [27] or where day to day circumstances are uncertain, such as those experiencing homelessness [29]. Researchers reported that they were aware that PPI contributor circumstances meant it was sometimes more convenient to have short sessions, for example when working with people with limited time such as mothers with young children [24]. A key point highlighted across several papers was the need to be flexible to accommodate people's schedules and needs, and to offer a variety of times and locations for meetings, being particularly mindful of who can and can't attend meetings during normal working hours [27].

Several of the papers outlined how research teams had used particular methods to facilitate involvement. For example, one team used Kolb's Experimental Learning Cycle and reported that this ensured the research team had a focus on "listening more, talking less" and undertook reflection and learning across the process [29]. Another paper reported using a person-centred approach which had a focus on personal factors (ability, potential wellbeing, cultural competence and links) which was also noted as being important for ensuring communication was appropriate [27]. Another reported on the importance of reflections of the research team including PPI contributors to learn and improve involvement [28].

Practicalities

We found evidence of researchers being aware of the importance of "practicalities" which related to payment, accessible venues, communication methods and approaches to involvement. The findings reflected the following UK Standards for Public Involvement Inclusive Opportunities [10] questions:

- "Have barriers to involvement, such as payment for time, or accessible locations for meetings been identified and addressed?".
- "Are there fair and transparent processes for involving the public in research, and do they reflect equality and diversity duties?".

Most articles included in this review highlight that research teams were aware of the need to reimburse contributors. A key finding was that payment and expenses processes are somewhat divorced from the realities of daily living, particularly for those in under-served populations. People in under-served populations often have limited financial security, and delays in the payment process can cause difficulties for those expecting payment and expenses reimbursement [31, 33].

Hosting meetings at venues familiar to the PPI contributors (termed their 'own turf and terms' [26]) has value in that the PPI contributors know how to navigate to the venue, and, once there, know they are in a safe space and are more likely to be comfortable sharing information with the research team. To address issues that may be associated with travel to a specific venue, Eccles et al. hosted small group meetings in a variety of easily accessible community locations and a mobile 'outreach' venue as a possible option to be tested in future PPI interactions [24]. However, we also found evidence to suggest that externally hosted sessions are not necessarily straightforward to organise when the host organisation's purpose is more general e.g. a supermarket or community centre [24] or when organisations may have existing relationships with other research groups [34]. We also found evidence of researchers asking PPI contributors to visit their preferred venue which, in some cases, may be a university setting [28] or visiting people in their homes, for example when interviewing parents of children with cerebal palsy [35].

We found that researchers offered multiple ways of communication to enable interactions that are accessible and convenient for a variety of people and circumstances. Some studies reported offering a choice of options for ways of communicating e.g. individual meetings, regular emails, options of where/how to meet, or newsletters [27, 28], or there was an "open-door policy" so that PPI contributors felt fully part of the research team [34]. Regular contact with PPI contributors (especially in their own community) was viewed as a particularly valuable use of time [26, 28, 29]. The need for communications to be engaging and clear was also highlighted with one project using an infographic for visual engagement in the topic, rather than only providing written information [24]. Overall, a blended, flexible approach incorporating both formal and informal communications and contact methods appeared to satisfy both the research teams and PPI contributors.

We found evidence to suggest that projects using 'tried and tested' approaches mainly worked well. These methods included forum group discussion and individual one-to-one conversations, in person and online. Sometimes researchers used a structured approach (for example the Nominal Group Technique [32]) to generate ideas and discussion, finding that a controlled approach supports those less familiar with the research plan, encourages those who are perhaps reluctant to speak, and guides the team to a meaningful conclusion that includes feedback from everyone. Perhaps the best summary of the recommended process for PPI activities in research is presented in Teodorowski et al. as 'one size does not fit all' [34].

Later publications from May 2024 search

We found evidence from the final ten publications to support all three themes that we identified in the original eight (population, relationship building, and practicalities). For example, there was evidence of involving the population relevant to the research, such as carers supporting end of life care [33] and involving people from the earliest stages [36]; relationship building emerged as engaging with existing groups [35] or gatekeepers [7, 37]; and practical issues such as accessible venues [30], payment [38] were cited.

Following discussions with the research team and PPI contributors, below is a summary of key learning and recommendations for researchers. The table is provided to make it accessible to all audiences, something that the DiR Group members thought was particularly important.

Recommendations for researchers

Theme: Population	**Key learning from review**	**Recommendations for researchers**
Involvement of people affected by the research topic	The studies involved people relevant to the research.	Involve people affected by the research topic.
Collection of demographic data relevant to the research topic.	The majority of studies noted demographic age, gender and ethnicity data. Some other data collected was educational background, gender identity, health condition, caring status. Apart from demographic data which was clearly relevant to the research project, there was no consistency on which other demographic data was collected.	Be clear to PPI contributors why demographic information is being collected and how it is relevant to the research project. Understand that some demographic information can feel difficult to disclose and may be more difficult at certain times or in certain settings.
Involvement at earliest stages	Most projects involved PPI contributors from the earliest stages and some involved people throughout the project.	Involving people, even in small numbers, at an early stage builds trust and meaningful involvement.
Area of country that research is undertaken	All studies except one reported that the research had taken place in an ethnically and socially diverse area e.g. Sheffield, SE London, Manchester, Bradford.	If you do not work in diverse area of the country, work with academic partners in areas with diverse populations. Build relationships with community and voluntary organisations to help reach diverse communities in your area.
Researcher cultural awareness and competency	Two studies reported the importance of language and cultural competency amongst researchers and others implied it.	Researcher cultural competency can result in access to communities through existing links, ability to conduct research in appropriate language and ability to challenge assumptions of community gatekeepers.
Relationship Building		
Relationships with gatekeepers of community organisations or existing groups	All studies worked with either advocacy (People Experiencing Homelessness), community (e.g. mother baby and gym), community groups or existing PPI groups (palliative care). The researchers made initial contact with community leaders to find people affected by the research. These relationships helped with practical arrangements and helped build trust between research teams and PPI contributors.	Identify and utilise appropriate existing links. Identify "gatekeepers" who are interested and willing to support. Be clear about the ask and benefits of being involved, both to the individual and to the organisation.
Time	All the studies were mindful of allowing enough time for meaningful PPI.	Allow enough time and negotiate with the groups– allow extra time if needed. Also be aware that sometimes shorter sessions are more convenient.
Awareness of people's needs is important.	Researchers showed awareness and understanding of people's needs is important and how this might vary.	Be aware of PPI contributor needs and be flexible as involvement may change due to personal circumstances.
Approaches	Researchers used different models for involvement that facilitated relationships	Consider using a particular method to facilitate involvement and build trust. E.g. Nominal Group Technique or person-centred approach.
Practicalities		
Venues	The majority of studies used venues that were easy for the PPI group to contact, e.g. at the community centre where the group met or home/coffee shop. Others discussed the venue with contributors who sometimes were happy with a university venue.	Go to where people are already meeting or where they feel most comfortable, giving choice and flexibility. E.g. coffee shop, at home, online etc. Be aware that sometimes existing settings may not be ideal for PPI activities – e.g. toddler groups may be disrupted by children – can childcare support be provided?
Payments and reimbursement	The majority of studies reported that they offered payment and reimbursement. A few only offered refreshments or reimbursed an existing group they were accessing for refreshments.	Always be clear about what payment, reimbursement is being offered. Discuss with community groups on most appropriate renumeration e.g. PEH were provided with vouchers. Make sure payment is made promptly. People do not want to be chasing payment – delays can cause financial difficulties. Where researchers are visiting existing groups and payment is not available, offer to pay the group for refreshments – this helps to build relationships.

Table (continued)

Theme: Population	Key learning from review	Recommendations for researchers
Flexible communication	Researchers often offered different ways of communication e.g. group discussion, one-to-one conversation, online fora, newsletters, emails.	Be flexible and ask PPI contributors what works best for them. Tailor communication approaches to the PPI contributors ensuring a variety in approach is available.
Approaches	"tried and tested' approaches were mainly used and worked well. These methods might include forum group discussion, individual one-to-one conversations.	Be flexible and offer different approaches according to need. Support from group liaisons/leaders is helpful in facilitating the groups.

Discussion

In this PPI contributor led review we found evidence that the UK PI Standard Inclusive Opportunities guidance is being applied, although not explicitly referenced. This indicates that the guidance is intuitive, and is supportive of researchers working with under-served communities. We recommend that all research teams use the guidelines to plan PPI activities that best reflect the advice, and reference this in project reporting. The three key themes identified in this review felt meaningful to the review team of PPI contributors who agreed the themes highlighted were important for successful PPI. The discussion section here includes PPI contributor reflections.

The themes that emerged from this study reflect findings from authors exploring research participation with under-served communities and confirm that the same principles can be applied to successful involvement and engagement activities. For example, the importance of building relationships, trust and cultural competency was highlighted in a 2022 project to develop a toolkit for increasing participation of black, Asian and minority ethnic communities [39]. This study also noted the importance of reciprocal arrangements (e.g. payment and/or training), both for those taking part in research and the organisations supporting the researchers to engage with under-served communities [39]. in a study about British South Asian people with Type 2 Diabetes, Prinjha et al. found that working with local community groups helped build trust and access to groups [40].

A number of papers emerged from the later search in May 2024. This indicates that PPI with under-served communities is increasingly being reported. This may be because of the increasing focus on inclusive research, indicated by the 2020 NIHR INCLUDE guidance [6] and, more recently, the NIHR's requirement for inclusive research as a condition of funding [41]. In addition, we found evidence that PPI is more embedded throughout the research cycle than indicated in a 2018 systematic review of black and ethnic minority involvement [8]. Several studies involved PPI contributors throughout the study (e.g [28]. This change is encouraging, and may be a result of an increasing focus over time on PPI from funders, particularly following publication in 2019 of the UK Standards for Public Involvement [10].

One issue that emerged from this review was the inconsistency of demographic data collected from PPI contributors. To grow the evidence base on which PPI approaches facilitate involvement of specific under-served communities, demographic data needs to be reported. This is because intersectionality within and across the different populations within the under-served communities is relevant. For example, an older PPI contributor from a Black background may have very different needs, motivations, and perspective to a younger Black person. We noted that some protected characteristics, e.g. gender and age were usually reported, but others (for example, sexual orientation) were not, regardless of the relevance to the research topic. This did not surprise the PPI contributors on our research team. Although there is evidence that PPI data collection can be successful [42], we have not had a good response when collecting demographic data collection from PPI contributors. In addition, we have discussed demographic data collection with our PPI contributors (both those on the research team for this review and members of other Oxford and Oxford Health PPI groups). Some members of the groups expressed reluctance to provide this level of information. They have said that they want to know the reason for their data being collected and if it does not seem relevant to the research topic, being asked to provide it can seem like a tick-box exercise. Therefore, researchers in the reviewed publications may have either felt deterred from asking for more detailed demographic information, or the lack of information could be because PPI contributors were asked but did not provide the information. In addition, our PPI contributors have said that some information feels more sensitive to divulge and releasing it is heavily dependent upon the context, how the PPI contributor may be feeling, and the trust between researchers and PPI contributors.

In terms of accessing a diverse population, we noted that nearly all the research took place in large cities which are typically socially and ethnically diverse, potentially indicating that it is easier to access diverse populations when researchers and institutions are co-located in these areas. The implication is that traditionally under-served populations living in less diverse, non-urban areas are likely to have less opportunity for involvement in health research.

The importance of relationship-building and trust for successful PPI with the relevant under-served population has been highlighted in many studies, including those identified in the final search in May 2024 [37, 43, 44]. The guidance provided in the UK PI Standards has been viewed as supportive of "developing mutual trust and respect" [45] and the findings from this study which explored specifically the questions related to the UK PI Standard "Inclusive Opportunities" found that the approaches researchers took, reflected the questions. The studies showed that researchers understand and value building relationships and that this helps research teams to understand the characteristics and interests of those who volunteer for PPI. This personal knowledge of what Dawson et al. termed 'critical friends' helps reduce power dynamics and allows for activities to be better tailored to individuals [28]. However, there is a time investment to create relationships between community groups and the research team, and short-term contracts (which are common in the research community) can have implications on sustaining these relationships.

In terms of practicalities, while the majority of researchers showed they were mindful of addressing "barriers to involvement, such as payment for time or accessible locations for meetings" [10], our PPI contributors reflected that offering and receiving payment and reimbursement is not the only important consideration. They told us that a seamless process without delay is also important, so that PPI contributors are not out of pocket and do not have to chase institutions for payment which can feel embarrassing and put people in difficult financial circumstances. Prompt payment supports the creation of trust [33]. As mentioned in several of the publications we included in this review, the bureaucracy imposed on research affiliated practices by organisations is a significant barrier to widening the diversity of PPI contributors. Our PPI contributors told us that their direct experiences of 'being on the receiving end' of what can often feel like archaic practices regarding payment for time and out of pocket expenses can feel like this part of the wider organisational process of engaging with PPI contributors is sometimes forgotten.

Reflections on the mixed research team

The PPI contributors in this review took lead roles in the process, in that they identified and specified the research question, conducted the literature search, and supported the analysis and writing of the paper. We were surprised we did not identify reports of similar activities in the literature although surmise these activities may be reported under other search terms such as 'co-production', or 'experience-based co-design' which were not part of this specific review question. We have demonstrated that PPI contributors can take a primary role in research activities when given the opportunity and support to do so. PPI contributors involved in this project developed their skills in literature searching, analysis, and writing, as well as a deeper understanding of academic reporting practices.

The four appointed PPI contributors in the reviewing team were from Black African, Asian or Caribbean descent (three British Pakistani, one mixed British Indian), one was a carer for an adult disabled child, another for an elderly mother and three had health conditions. One was a young person, a student, under the age of 25. Two lived in Oxford, one in Birmingham and one in London. All had strong experience in PPI in different settings. One of the PPI authors went on to work for the Oxford BRC. While the research team was diverse, three out of four were women, the two lead PPI contributors both had Master's degrees and another of the other PPI contributors was undertaking a degree. So, while there was more diversity than in some areas, there were aspects of the team that reflected a common demographic of PPI contributors (e.g. female and educated). This point highlights the relevance of intersectionality. Diversity is complex and it can seem reductive to itemise individual characteristics.

Power issues between researchers and PPI contributors were discussed, particularly as the senior researcher (JLD) did the initial thematic analysis before presenting this to the PPI contributors for discussion. However, throughout the project, JLD stressed her belief that the researcher role was accessible to everyone. She was flexible and brought a friendly, encouraging approach that helped everyone feel confident to air views, disagree, and work together to come to a consensus.

Barriers to the mixed research team approach included difficulties with contracts. All PPI contributor members of the team required email addresses for one of the academic affiliated organisations (the Oxford University Hospitals NHS Foundation Trust, or the University of Oxford) to confirm 'eligibility' for training. We are grateful to the Bodleian libraries team who were accommodating in their approach and delivery of bespoke training sessions. We also struggled to meet frequently which likely impacted the timeline. Working with people with busy full-time responsibilities outside of the research environment meant that meetings were generally scheduled for lunchtimes or evenings. The literature searching and critical appraisal was mainly conducted over evenings and weekends, and we are grateful that our PPI contributors were so willing use their time away from their usual jobs, studies, family, or caring responsibilities to complete this work.

Conclusion

In this review, we have identified that the UK recommendations for good quality inclusive PPI are reflected in the included published reports which specifically focused on under-served populations, even when the reports themselves do not directly relate their findings to the NIHR recommendations. This confirms the usefulness and relevance of the recommendations as a guide for PPI activity. On the basis of reported demonstrable benefits identified in this review, and agreement from our own PPI contributors, we recommend that researchers access and reference the UK PI Standards to support their individual PPI activities.

We recognise also that there are complex issues around involving people from under-served communities that are not entirely addressed by the UK PI Standards. Much of this was not identified by our search strategy which was tightly focused. A more detailed exploration of the wider socio-cultural topic would facilitate a more sophisticated examination and encourage discussion across the communities.

We have also demonstrated that it is possible for PPI contributors to take a lead role in research activities and be involved throughout the project when they are supported to do so. This opens the door for a wider scope of involvement and co-production, and the potential for a more creative use of PPI time and resource.

Appendix 1

Advertisement

Literature Review – Outreach Methods - Role description

The NIHR Oxford and Oxford Health Biomedical Research Centres (BRCs) bring together the University of Oxford and Oxford University Hospitals NHS Foundation Trust and Oxford Health NHS Foundation Trust to fund medical research.

We are looking for two people to undertake a literature review exploring outreach methods to increase the diversity of people who are involved with research and health services design and improvement.

While training and support will be provided in literature reviewing methods, we are looking for people who have some experience in this area. We will seek publication in a journal for this work.

***We particularly encourage applications from those who identify as Black, Asian, Minority Ethnic (BAME) or Lesbian, Gay Bisexual Transgender (LGBT+) and young adults (18–30 years). These communities are currently underrepresented in our work.**

Role description

- Work with other PPI contributors and BRC staff to undertake a literature review on outreach methods. This includes training, literature searching, analysis and report writing.
- Collaborate with other PPI contributors and BRC staff on the project.
- Attend meetings with OUH and Oxford University Staff and other PPI contributors (online now).
- Other tasks related to the overall objectives.

Person specification

- Patients, family carers or members of the public with experience and/or interest in health research.
- Some experience of undertaking literature reviews.
- A team player and eager to share ideas and have constructive conversations with a diverse range of people.
- Ability to pick up new information quickly.
- Excellent verbal and written communication skills.
- Willing to undertake training related to the role.
- From an under-represented community or have significant experience of working with under-represented communities (*see above).
- Available for at least 10 days' work.

Appendix 2

PICO

P- Population, patient – (who?).
I - Intervention, exposure – (what are you going to do?).
C - Comparator, control, (if applicable)
O - Outcome - (what you expect to happen?).

Possible search terms

Population	Intervention	Outcome
Patients	involvement	Health research
Service users	Participation	Health care
Survivors	Engagement	Medical research
Carers	Outreach	Increase
Public	Action research	Expand
Underrepresented	Framework	Enlarge
Minorities	Priority setting	Improve
Underserved	Community involvement	Strengthen
Marginalised	Community engagement	Encourage
Seldom Heard	**Intervention**	Grow
Hard to reach	**Training**	Change
Diverse	(Addressing\ tackling, acknowledging) inequality/ inequalities	**Confidence**
Non-tokenistic		**Community**
Non-traditionally engaged		**Diversity**
People		Reduce exclusion
Communities		Increase inclusion
Groups		
BAME		
Demographics		
Discriminated		
Undermined		
Unheard		
Disabled/disability		
Poverty		
Lower education		
Unemployed		
High healthcare burden		
Vulnerable		

Appendix 3

The questions for helping researchers reflect on the NIHR Standard for Public Involvement "Inclusive Opportunities" are below:

Are people affected by and interested in the research involved from the earliest stages?

Have barriers to involvement, such as payment for time or accessible locations for meetings been identified and addressed?

How is information about opportunities shared, and does it appeal to different communities?

Are there fair and transparent processes for involving the public in research, and do they reflect equality and diversity duties?

Is there choice and flexibility in opportunities offered to the public?

Supplementary Information

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Supplementary Material 1

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Author contributions

RT and JLD wrote the main manuscript text. AB and AV conducted the literature search and initial screening. All authors reviewed the manuscript and had opportunities to comment before submission.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethical approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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