



RESEARCH ARTICLE

REVISED

Enablers and barriers to engaging under-served groups in research: Survey of the United Kingdom research professional's views

[version 2; peer review: 2 approved]

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<https://doi.org/10.3310/nihropenres.13434.1>Latest published: 18 Dec 2023, 3:37
<https://doi.org/10.3310/nihropenres.13434.2>

Abstract

Background

There is a known lack of diversity in research participant populations. This impacts on the generalisability of findings and affects clinician prescribing. In the United Kingdom the research community defines those who are underrepresented as under-served. They are commonly those affected by health inequality and disparity. The notion of under-served is complex, with numerous papers identifying multiple factors that contribute to being under-served and in turn suggesting many strategies to improve engagement.

Methods

Research professionals in the UK were invited to complete an online survey. The broad aim was to explore their views on under-served groups. The findings were analysed using statistical and qualitative methods to identify enablers and barriers to engaging the under-served. Descriptive statistics were utilised with associations compared univariately by chi-square test and logistic regression for multivariable analysis.

Results

Open Peer Review

Approval Status

	1	2
version 2 (revision) 18 Dec 2023	 view	 view
version 1 26 Jul 2023	 view	 view

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Any reports and responses or comments on the article can be found at the end of the article.

A total of 945 completed responses were received. Those identified as under-served in this study reflected the previous body of works with a broader descriptor of ethnic and cultural minorities and the addition of adolescents and young adults. Language and literacy skills had the most impact on being under-served. Only 13% of respondents said they felt equipped to meet the needs of the under-served. The main strategy to increase diversity was community engagement and movement of research delivery into the community. The barriers were funding and time. Training needs identified were linked to community engagement, cultural competence and consent processes.

Conclusions

The UK findings from research professionals reflected the previous literature. Adolescents and young people were added to those identified as under-served. Enablers included community outreach and improvement to communication. Barriers were time, funding, organisational processes and lack of focus. Issues were identified with translation and interpretation services. Training requirements focus on methodologies and methods to engage and the consent processes of those from under-served groups.

Plain language summary

Research study participants do not reflect the general population. This means that findings from research cannot be reliably transferred to the general population. The people missing are termed under-served or underrepresented. These people come from groups who have unequal access to health care and have poorer health. There are different reasons why people may not take part in research and many ways to support them to take part.

This project asked the people who work in research who they thought were missing from research studies. It asked, what would make it easier for people to take part and what got in the way. Those who work in research were invited to write their thoughts in an online survey. Answers were then looked at using tests to find out the number of people who said the same or different things. Other answers were looked at to find out their views and opinions.

A total of 945 people filled in the questionnaire. Those who responded thought the biggest group of people who were missing from research populations were from minority social and cultural groups. They also thought teenagers and young adults were missing from research. When asked why people didn't take part the biggest problem was with making research easy to understand. Only 13% of the people who filled in the survey thought they were able to help those who were missing. It was suggested the best way to improve the number of different people taking part in research was to move research from hospitals to the places where the under-served live. The biggest thing that stopped those working in research helping was funding and time.

They also wanted to find out how to carry out research in the community, how to help different cultural groups and aid those with certain medical conditions.

Keywords

Research inclusion, research participation, under-served, underrepresented, enablers, barriers.

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Competing interests: DC, MB, JR, and CW all work in some capacity for NIHR.

Grant information: This work was commissioned by NIHR and funded by NIHR CRN as part of the NIHR infrastructure.

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How to cite this article: Coe D, Bigirumurame T, Burgess M *et al.* **Enablers and barriers to engaging under-served groups in research: Survey of the United Kingdom research professional's views [version 2; peer review: 2 approved]** NIHR Open Research 2023, **3**:37 <https://doi.org/10.3310/nihropenres.13434.2>

First published: 26 Jul 2023, **3**:37 <https://doi.org/10.3310/nihropenres.13434.1>

REVISED Amendments from Version 1

The manuscript has been updated in line with the reviewer's comments.

The abstract has been revised to aid clarity and improve consistency of language. The plain language summary has been reviewed to decrease the complexity of the language used.

Introduction: additional references and updated materials have been added. Rewording has been completed to aid clarity.

Methods: additional information added regarding the literature review and how it aided the project. Typographical and grammar errors have been corrected. PPIE section has been re-positioned as per the reviewer's request.

Results: material added to clarify survey responses. Signposting added to additional information regarding NIHR infrastructure. Conclusions from data revised in terms of causality and associations. Sub-set data has been added in the section on further information and training. An additional figure has been produced to add to the demographic information supplied. Grammatical errors regarding tense addressed. Formatting errors leading to repetition have been corrected. Phrasing reviewed as per the reviewer request (taking consent revised to receiving consent).

Discussion: additions have been made to the limitations of the study. Tense reviewed throughout.

Conclusion: revised to better reflect the setting and findings of the study.

Any further responses from the reviewers can be found at the end of the article

Introduction

There is a lack of diversity in the participants of research studies¹. In the United Kingdom (UK) the groups thought of as underrepresented are termed under-served. They are defined as: 'A group that is less well represented in research than would be desirable from population prevalence and healthcare burden'¹. Commonly these groups are disproportionately affected by ill health, live in poverty and have associated health inequality and health disparity^{2,3}. Their lack of representation reduces the validity and reliability of research findings and inhibits generalisability⁴. This results in interventions and treatments being approved with limited evidence for their use in the under-served populations^{5,6}. The lack of evidence affects the willingness of clinicians to prescribe, limiting treatment options and continuing the cycle of health disparity and inequality⁷. Although many clinical trials collect protected characteristics of study participants this data has not historically been collected in the UK at a National level. This changed in 2019 with pilot data collection of year of birth for study participants and ethnicity data for the COVID-19 vaccine studies. This is particularly pertinent as there is a known imbalance in the degree of impact COVID-19 has on ethnic minority populations and a known absence of this group from clinical trials⁸. Very recently the all-party parliamentary group on medical research published a report on health disparities and why medical research is a crucial tool for change⁹. This report included a section on recruiting a more diverse range of participants to clinical research.

In recent years there has been a move to improve the representation of under-served groups in research. There is a large body of work, mainly from the United States of America¹⁰⁻¹², where the preferred term is 'underrepresented'. In the UK the National Institute for Health and Care Research (NIHR) funds, enables and delivers research; it has funded and completed two major projects aimed at engaging potential research participants^{7,13}. NIHR INCLUDE⁷ specifically focused on those who may be under-served, involving them directly in producing the definition of under-served used in the UK. Prior to this there was no formal definition of what constituted an under-served or underrepresented group, the terms being context specific and used interchangeably.

The lack of a formal definition plus the multifaceted and complex nature of what constitutes being under-served results in many works connecting the terms under-served or underrepresented to one or more of the following identifiers. demographics such as age^{5,14} or ethnicity, (for example 'increasing participation in Black Asian and Minority Ethnic groups')^{15,16}, a specific disease such as cancer^{17,18}, or a strategy aimed at engagement (examples being digital outreach and improved communication)^{19,20}. The focus may be narrower looking at engagement within a named group and a specific disease, for example, 'children with autism' or 'African American women with SLE'^{21,22}. In some cases the focus is even narrower, using named group, named illness and named engagement intervention: an example being, Hispanic and Latino people (named group) with depression (the illness) using a mobile app (the intervention)^{10,23}.

The identified strategies to engage the under-served fall into five main areas: changes to research methods and methodologies^{11,24,25} (such as novel consent approaches and participatory design), organisational initiatives^{7,12,26}, use of technology^{23,27}, (specifically mobile apps) enhancing trust^{28,29} and finally changes to reporting and publication^{30,31}. (aimed at improving the reporting of the make-up of study participant samples.)

While the issues with the lack of diversity in research populations is well covered in the literature there are limited works on the views of research professionals around improving access to research. Two contemporary works, set in the UK, have been identified that explore researchers' views^{30,32}. These works highlight general and specific barriers and facilitators to engagement, including lack of time and funding³² and issues with approvals and consent processes³⁰. They explore the complexity of engagement in these groups and the need for researchers to be proactive. These works have been published very recently and form part of the body of knowledge this work is included in and builds on.

This article forms part of the output from a cross-UK NIHR programme board with specific emphasis on engaging under-served communities in research. It reports on a survey which explored the views of research professionals. The survey covered: who the research professionals felt were under-served,

what factors they thought led to being under-served, what changes promoted inclusivity, what barriers existed for research professionals and what additional training and resources they required to aid engagement activity.

Methods

Ethics and consent

The NIHR under-served programme board agreed that ethical approval was not required for this research, as the survey was deemed service improvement. Participants' consent was presumed by the active choice of clicking the link to the survey and completing the questions. Responses were anonymous. The survey data were stored on password protected devices and only accessed by the research team. Free text comments were reviewed prior to analysis and any identifying information removed or coded.

Survey development

An online survey was designed and delivered in smartsurvey.co.uk³³. It was produced following a focussed review of the literature. The review was completed between July and September 2021 using the terms 'under-served' and 'under-represented'. PubMed database was utilised, and the search was limited to articles produced between 2018 and 2021, where full-text or abstracts were available. All article types were included and the bibliographies of each reviewed. A total of 62 articles were identified and reviewed for relevance. After the initial assessment, 47 articles formed the focussed review. That focussed review produced themes which were used to determine the groups identified as under-served and factors that impacted on being under-served. These were peer reviewed within the study team and formed part of the piloting process to formulate the survey responses.

The subsequent survey was piloted and peer reviewed by six members of the NIHR under-served programme board. Feedback from peers was discussed and acted upon and there was one further round of revisions. A copy of the survey is available³⁴.

Patient and Public Involvement

There was no patient or public involvement in this project as it was aimed at professionals working in research.

Recruitment and data collection

The survey was advertised through an NIHR communications package. It was circulated to all Local Clinical Research Network communications leads and partner organisations with a request to share. It was promoted via regional NIHR newsletters and the Clinical Research Network (CRN) national newsletter. Further promotion appeared on Twitter and LinkedIn. As an example, in the North East and North Cumbria CRN, the request to share was actioned by the communication lead. This led to the direct emailing of research and development managers, speciality groups leads and core team delivery staff which totalled 89 direct emails. The recruitment aim was to reach those working in the public sector of the UK who were involved in research delivery. There was no defined target sample and there were no specific exclusions.

The survey commenced with an introductory statement and link to the [NIHR INCLUDE project](#). It was split into four sections totalling 19 questions. The first section of nine questions collected demographic and role information. This was followed by one question regarding specialism. The next seven questions were titled 'Barriers and enablers' and gathered information on who are the under-served, factors impacting on being under-served and strategies to improve research activity to better engage the under-served. The final two questions allowed respondents to indicate if they wanted to make direct contact with the NIHR under-served programme board and leave their contact details. Question types included closed, open, ranking and four free text response questions. Only complete data for each section was analysed.

Analysis

Statistical analysis was performed using R software³⁵. Descriptive statistics were utilised with associations compared using chi-square test. To test relationships between categorical variables, statistical significance was deemed as p. value of <0.05. Qualitative analysis of the free text responses was completed using a thematic approach³⁶. The analysis followed three steps. Initially the free-text comments were read to familiarise and anonymise. The comments were then coded and descriptive themes generated. The themes were guided by the findings from the focussed literature review. Finally, the descriptive themes were reviewed to generate an overall viewpoint^{36,37}. Analysis was aided by Microsoft Excel, topic models³⁸ and tidytext³⁹ packages.

Reflexivity

The process was verified for trustworthiness by the core team. Reflexivity was demonstrated by acknowledging the prior views and knowledge of the research team. Themes were guided by the previous literature, however differing views and information were explicitly sought out. Data were coded by different individuals and data analysis clinics held to reflect on codes and discuss initial theorising³⁶.

The authors have experience of survey research (DC, CW, JR), statistical (TB) and qualitative analysis (DC). CW was responsible for the original idea, CW, JR and DC formulated the questions and JR built the survey. MSB has expertise in equality and diversity and aided the qualitative analysis with DC. The study is reported in line with CROSS⁴⁰ (Checklist for Reporting Survey Studies), STROBE (STrengthening the Reporting of OBservational studies: [cross-sectional studies](#))⁴¹ and SRQR (Standards for Reporting Qualitative Research)⁴² guidelines.

Results

Demographics

Data was collected from 945 fully completed and submitted survey responses. All respondents confirmed they were happy to complete the survey³⁴. Responses were received from all geographical areas of the UK. The largest number came from the North East and North Cumbria (n=111, 12.4%). The age, sex and ethnicity profiles reflect that of the UK's National Health Service (NHS) with 72% (n=660) identifying as female, 82% (n= 748) white and over 30% (n=275) in the

45–54 years age group⁴³. Respondents self-identified their sex, the options being male, female, prefer not to say and other (please specify). Figure 1 illustrates the demographic profile of the respondents.

All components of the NIHR infrastructure and Clinical Specialties in the NHS were represented. Further information on the NIHR infrastructure and clinical specialties can be found at: <https://www.nihr.ac.uk/explore-nihr/support/research-infrastructure.htm> and <https://www.nihr.ac.uk/explore-nihr/specialties/>. To identify any differences in enablers and barriers across clinical settings, sub-set analysis via specialism was completed. These were: hospital-based specialties (n=323, female 222, male 91), mental health (n=124, female 82, male 38), and primary care (n=118, female 90, male 24), including public health and community. These three sub-sets comprised 60% (n=565) of the total responses.

Place of work and role

The commonest area worked in was secondary care (41%, n=371, female 259, male 102), followed by research higher education institutions (39%, n=355, female 242, male 97). The least cited place of work was the ambulance service (0.3%, n=3). When asked, 75% (n=587, female 290, male 153) of those who responded stated they were involved in identifying participants for research studies, with 69% (n=624, female 442, male

164) saying they had direct contact with research participants and finally 54% (n=491, female 353, male 128) declared they were involved in consenting participants for research studies.

Who are the under-served?

The respondents were asked to identify who they felt were under-served in ‘your area’, ‘your area’ being open to the respondent’s interpretation. Five open text boxes were provided to insert a descriptor. Respondents were not asked to rank the five descriptors. In total 2782 responses were made across the five open text boxes. The responses were collapsed into categories. Table 1 illustrates the top seven categories and the total responses for each. The most cited group was ethnic and cultural minorities, followed by those deemed as having a lower socioeconomic status, then those where a given age was used as an identifier (the old, very old, young adults, adolescents, children and neonates). In the category where age was used as an identifier, ‘adolescents/young adults’ were put forward as a group not previously identified. The ethnic and cultural minority group contained a broader descriptor than found in the literature which focussed on Black and Hispanic groups.

Subset analysis by specialism revealed that the hospital-based group placed ‘condition specific’ (9%, n=76) above ‘mental health’ (6%, n=52), with those specialising in mental health putting ‘mental health’ in second place (18%, n=79) followed

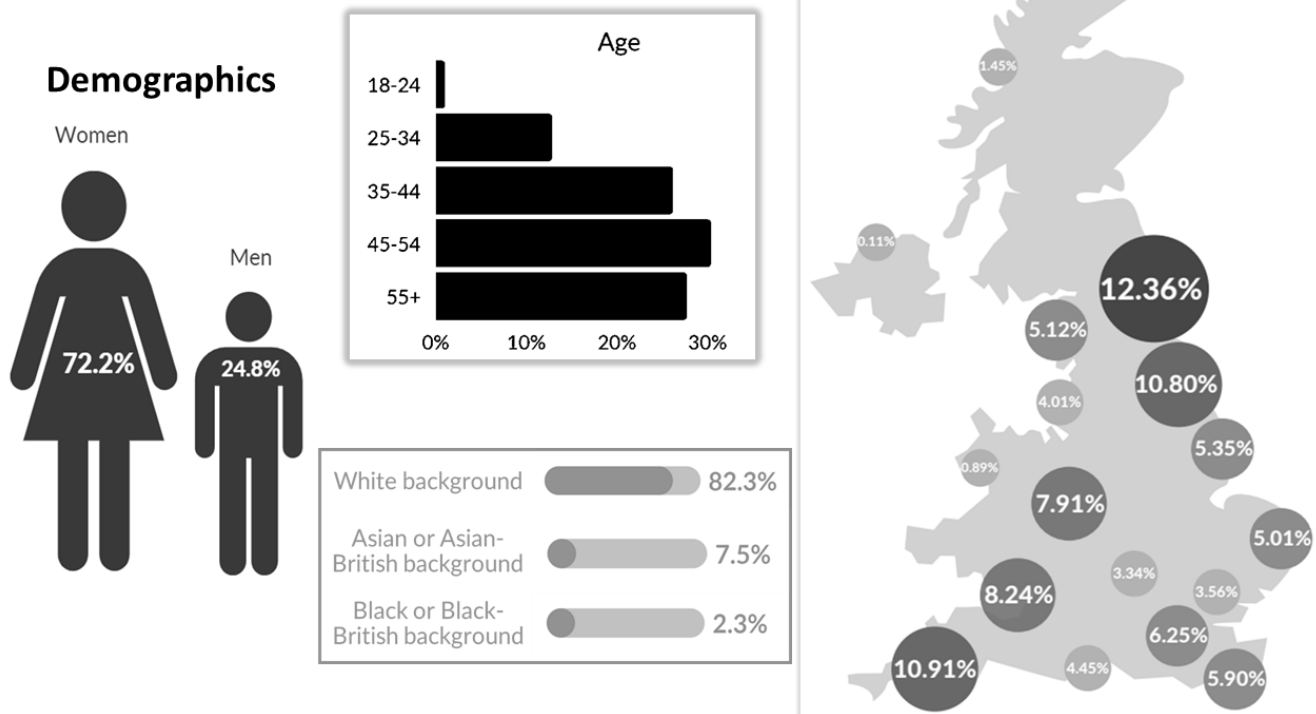


Figure 1. Demographic profile of respondents.

Table 1. Who are the under-served in your area?

Description	Total number across the five open text boxes.	% of total responses (n=2782)	% in hospital-based specialism (n=887)	% in mental health specialism (n=450)	% in primary care specialism (n=415)
Ethnic and cultural minorities.	862	31%	34% (n=305)	26% (n=119)	33% (n=136)
Lower socioeconomic status	514	18%	17% (n=151)	14% (n=62)	22% (n=93)
Age related. (Older, younger, adolescent)	304	11%	10% (n=92)	8% (n=36)	10% (n=42)
Mental health, dementia and neurodegenerative diseases	213	8%	6% (n=52)	18% (n=79)	7% (n=30)
Condition specific (excluding mental health, dementia and neurodegenerative diseases)	143	5%	9% (n=76)	2% (n=10)	3% (n=11)
Learning/intellectual difficulty/disability (including ADHD and autism)	131	5%	4% (n=33)	11% (n=48)	3% (n=13)
Access (rurality, workers, limited mobility, car-less) excludes digital access.	139	5%	4% (n=39)	4% (n=19)	6% (n=24)

by 'lower socioeconomic status' (14%, n=62) 'learning/intellectual difficulty/disability' (11%, n=48) and age related 8% (n=36). The primary care-based specialisms elevated 'access' above 'condition specific' (p=0.038).

What impacts on being under-served?

Respondents ranked 10 factors taken from the literature, in terms of how they impacted on being under-served (the 10 factors can be found in Figure 2). Respondents ranked language and literacy skills as the most impactful, with the least impactful being religious and cultural beliefs. Figure 2 illustrates the ranking of factors.

Sub-set analysis via specialism indicated statistically significant variation in greatest impact. Hospital-based specialisms (32%) and primary care specialists (30%) ranked language and literacy skills as the most impactful when compared to mental health 11% (p<0.0001). Mental health services ranked a lack of focus on the under-served as more significant: mental health 22%, primary care 15% and hospital-based 12% (p=0.04). In addition, significant differences were demonstrated for socio-economic status, with this being ranked as a more significant factor in primary care research: primary care 22%, mental health 11% and hospital-based 10% (p=0.004).

Addressing the needs of the under-served

A total of 824 (610 female, 214 male) responses were received from those who answered question 8 (Are you involved in identifying research participants? Yes/No) and question 15 (How equipped do you feel in dealing with the under-served? Yes/Partially/Not very well/No). Of the 538 (392 female, 146 male) who stated they were involved in identifying research participants,

12.3% (n=66, 44 female, 21 male) suggested they felt equipped to meet the needs of the under-served, with a further 48% stating they were partially equipped (n=258, 179 female, 79 male). Of those not involved directly in identifying research participants (n=286, 218 female, 68 male), 8% (n=22, 18 female, 4 male) said they felt equipped to meet the needs of the under-served (p=0.06). A significant difference was also seen in those who identify research participants who felt partially equipped (n=258, 179 female, 79 male) when compared to those who do not identify research participants (38%, n=108, 81 females and 27 males), p=0.006. As expected, those who identify potential research participants in their role felt more equipped compared to those who do not (p=0.0004), similarly staff receiving consent from research participants felt more equipped than researchers who do not (p=0.0001). Those who receive consent from research participants were more likely to feel partially equipped to address the needs of the under-served compared to those who do not consent (p=0.013), suggesting that face to face contact is associated with increased confidence in engaging the under-served.

Qualitative analysis

Four free-text questions were analysed using a thematic approach. They covered positive innovations, barriers to innovations, challenges to engagement and further training requirements. From these responses enablers and barriers were identified and suggestions for training put forward.

Enablers

Several enablers were recognised with comments suggesting strategies to enhance engagement. However, these were often accompanied by the barriers indicating why they could not be

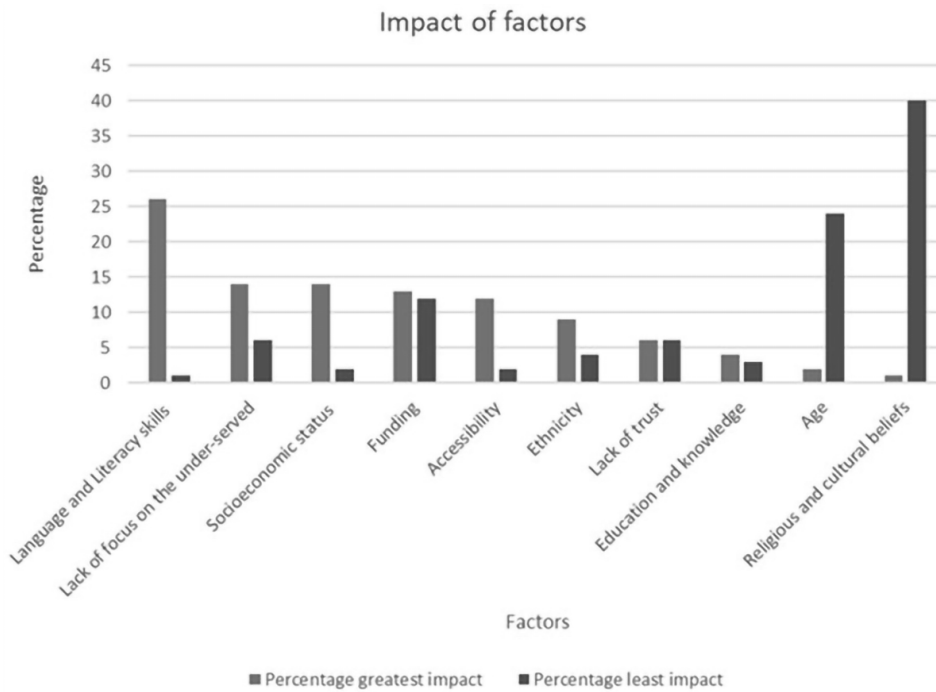


Figure 2. Ranking of 10 factors on degree of impact on being under-served.

implemented. The most cited enabler was community outreach.

Community based research - while not revolutionary - has proved to be highly effective when wanting to involve underserved groups.

Going into the community they live in, engaging at a time most convenient for communities (i.e. in day time in between school hours for young mothers) and in the mid-week evenings at 06:30pm/07:00pm start to allow those who may be working, holding quarterly/6-monthly events on Saturdays (whole day) with necessary support to do out-reach activities such that information can be shared and participations encouraged.

We are never sufficiently funded to do anything innovative. Funding only covers the most basic and efficient of recruitment (e.g., GP search and mailout) and despite our best efforts to make study documents appropriate, engaging and accessible they do not attract groups that we know are underserved.

Community engagement was seen as beginning prior to any notion of conducting research. It included *genuine* participation by the community in setting its own research agenda via collaborative approaches and continued after the completion of any research project.

Genuine engagement - not "involvement" - leading to genuine co-creation of work that meets the needs

*of the community partners *as much* as it meets the needs of the researchers.*

Linking to this was the use of Patient and Public Involvement and Engagement (PPIE) groups. These groups were highlighted as enabling, however there was a degree of scepticism about how representative they were of their group.

Appropriate PPI (i.e. finding the right people to be involved in PPI not just some well-educated, often white person from a professional/semi-professional background). Research organisations should start thinking about recruiting community champions from underserved populations / communities. These should be influential people who can be able to help with ensuring participation of under-served populations. Use of community champions has been an effective approach by community-based organisations (CBO). So where research organisations are not able to directly recruit community champions, development of research partnerships with CBOs can be a very good way forward.

Outreach also included the movement of research from a secondary care setting to the community. It was suggested methods and methodologies should focus on assisting the delivery of research in the community.

Community Ageing Research 75+ cohort study - a national ageing research cohort study funded by (organisation). (They) use an opt-out approach to

consent and have researchers who are proficient in community language skills. The opt-out approach supports engagement with older people with frailty, some of whom find it problematic to actively respond to an invitation to participate in research as they may have mobility problems making it problematic (or simply burdensome) to provide a postal response using an opt-in approach. The approach also supports recruitment of people from minority ethnic groups, some of who speak dialects that do not have a written form, so require a proactive telephone call to discuss participation. Taking this approach, (they) have a recruitment rate of around 40% at all our sites, and 5% of study participants are from the south Asian community (15% in Bradford - consistent with the local demographic).

Need very intensive methods to recruit and then retain under served groups, e.g. provide transport, pay for travel, take research to the community.

Further enablers were identified such as strategies to improve the accessibility of study documentation and the information presented in them. Suggestions were put forward covering multiple different modalities: translation and interpretation services, video, audio, digital platforms, social media, sign language and braille. Again, these suggestions were accompanied by the barriers to implementation.

Using culturally relevant short drama/films to aid raising awareness in communities that do not typically engage with research. Having these in multiple languages to aids those who are not literate in their native language - this is expensive and typically the sector relies on family member to translate but this does not necessarily meet recommended guidelines for consent.

We have asked study teams if they can translate consent forms, information sheets, questionnaires etc. into different languages so that we include non-English speaking participants, however, all study teams have said they did not have enough money/funding to be able to do this and/or to cover the cost of any translators.

Additional enablers to engaging a diverse research population were having a workforce that reflected a varied background and (where possible) the demographic profile of the under-served group. Recruitment via General Practice was thought to better reflect the demographic profile of the area and innovative ways to reimburse participants were also thought to enable engagement.

More active engagement with community groups within diverse communities to support recruitment, developed study materials in formats more accessible to people from diverse communities and with low literacy levels. Trained and paid individuals from diverse communities to support recruitment to studies

and as co-researchers - for example who speak the language or who are known to people in the community. Anything extra that involves more resource as this often isn't possible in the tight funding windows.

The benefits systems mean we can't pay those who we most want to get involved or they are sanctioned. Funders and senior academics want involvement from all but it needs time, commitment, planning- can't be overnight.

At an organisational level it was suggested that study design and approvals processes should reflect those of the urgent public health studies carried out during the COVID-19 pandemic. Highlighted were changes in ethical approval, community engagement, consent processes, data collection methods and feedback of results.

Covid has forced one of our studies to move from face to face follow up to remote follow up. This has lead to a higher recruitment rate as potential recruits are more willing to conduct the follow up at home or in their own time than physically attend a follow up appointment. This has improved accessibility.

Remote data collection (especially promoted by COVID requirements) improves access for some - but need a range of options to be really inclusive.

Electronic consent, (if appropriate). This speeds up the consent process and allows the patient to complete the consent at their own pace at home. This is particularly effective now many clinics are conducted remotely, so paper consenting is not possible.

In Covid research we used a lot of consultee consents for patients who were acutely unwell and we also had lots of ethnically diverse patients inpatients so our recruitment was much more diverse.

Sub-set analysis indicated the most cited enabler from both primary care-based and mental health groups was community outreach, with hospital-based specialties citing changes to research design and methodology.

Barriers

The most cited barrier to engaging under-served groups was time and funding; this was reflected across the whole dataset and the sub-sets of primary care and mental health specialties. The respondents were aware of the strategies to enhance engagement; however, these all required more time and funding, and that time and funding was not planned into project designs. They felt that the current systems and processes around grants/funding applications and ethical approval were obstructive and risk averse. Funding processes did not consider the planning needed to design studies that are co-produced with communities and approvals processes question innovative recruitment strategies and reimbursement of participants. Comments suggest a disconnect between policy and practical application.

Time - it takes significantly longer to take someone whose first language is not English through a study.

The whole ethics process is not set up for considering the needs of this population.

Need NIHR to ensure there is funding to support this and to understand that there is a substantial time and resource commitment to undertaking research that addresses under-served populations.

We are required to develop patient information sheets that go against the advice of our patients and basically, we know that they aren't read but we churn them out because we don't get approval otherwise. If you have a non-English speak/illiterate person and they are faced with some of the approved documentation, it's no wonder they won't even talk to you.... There is no point in trying to be even slightly inventive because you just know the REC (Research Ethics Committee) is going to be a barrier to you actually being able to use it.

Barriers also included issues with communicating research to specific groups who may be under-served. Respondents highlighted problems with translation and interpretation services and how useful they are in the field of research.

Across multiple studies, we have been limited in the number of non-English speakers that we have recruited due to a lack of access to translators. The issues we have faced around translation is a lack of availability of translators and a lack of funding for translation services.

Another issue is being dependent on a translator communicating in the way you want them to - I had experience of a situation where the translator deemed that catheterisation of a little girl meant she was no longer a virgin.

Paying for actual translators not having to rely on family (which can often mis-translate, negate details, or might prevent sensitive topics being explored).

The concerns expressed centred around availability when required, knowledge levels and personal views of the translator or interpreter. Cost of translating written materials and the time taken were also thought to be obstructive. These were the most cited barriers in the hospital-based specialism. There were also comments which suggested that while the use of digital platforms may for some enhance engagement, it conversely disenfranchises some others.

Further information and training

Suggestions about additional information and training to aid researchers were diffuse. They included ways to conduct community engagement including methodologies, methods, inclusive recruitment strategies for both participants and PPIE, funding applications and innovative reimbursement methods.

Further general training was requested in cultural competence, taking in cultural awareness and sensitivity and general equality and diversity. Some specific under-served groups that were mentioned regarding engagement activities were the LGBTQi community, those with disability and the homeless. Finally, requests were made for training in consenting those where English is not their first language or their comprehension of English may be reduced, and those who may lack capacity. Sub-set analysis indicated all three groups wanted information on general awareness of under-served groups and improved ways of communication with these groups. The mental health and hospital-based groups also requested training on research design methods.

Cultural awareness training. I feel this would be helpful to me with regard to those of Pakistani and Roma ethnicity, and for the Deaf Community. Advice regarding how to identify and link up with local community groups, to find PPI contributors from underserved populations. Training in inclusive research study design, sharing best-practice and learning from the successes of other researchers.

Be trained in how to speak to those and consent those who have dementia or other mental problems in their older years...How to work with those whose English isn't their first language.

How best to engage with such communities, build their respect and interest and to understand value of research.

In summary, the findings from the survey generally reflected the literature in this area. Those working in the field of research felt only partially equipped to deal with engaging the under-served and requested additional information, support and training. The responses overall are context specific and focussed around the respondent's area of speciality. The main enabler to engaging the under-served was thought to be community outreach. However, there was a consistent reference to lack of time, funding, capacity and support to develop site and project level interventions to engage the under-served. Respondents were aware of numerous strategies to improve the diversity of research participants and there was a sense of divide between policy rhetoric and ability to practically apply.

Discussion

The findings from the survey were from across the UK, with substantial representation from areas of known deprivation and rurality, both factors associated with being under-served^{2,44}. This may reflect an increased awareness and engagement in these areas and indicate strategies were already being utilised to enhance representation.

The groups identified as being under-served reflect the literature and the previous NIHR work^{7,13}. Whilst the literature from the USA focusses on Black and Hispanic communities as minority ethnic and cultural groups^{6,45} the UK findings suggest a wider descriptor including non-white, non-native English speakers,

migrants, refugees, Roma and traveller communities. These groups plus those termed Black Asian and minority ethnic (BAME) were the largest group deemed under-served. Of note is that during the timespan of the survey the UK government recommended a move away from using BAME as a descriptor of ethnic minority groups⁴⁶. The second largest group identified as under-served were those who live in low socio-economic circumstances, including those who were digitally excluded, those who live in geographical areas known to have high levels of deprivation and those who are unemployed. This group was followed by those with an age descriptor attributed to them, the old, very old, young adults, adolescents, children and neonates. There is limited previous literature to suggest young adults or adolescents are under-served by the research community. This group was identified across numerous research specialities and is a finding worthy of further understanding.

In terms of why groups may be under-served, the impact of factors appeared to be cumulative in nature. Descriptors often cited more than one identifier, for instance an older person living in a care home, or a migrant living in a rural area. Therefore, the possibility of being under-served was increased as descriptors or impactful factors were attributed to a group. This and the differing order of who is felt to be under-served by each speciality group aptly demonstrate the context specific nature of the 'under-served' and the influence of workplace and specialism. When asked to rank the factors that contribute to being under-served, language and literacy skills were thought of as the most impactful. Whilst it was felt ethnic and cultural minority groups were the largest groups under-served, it appears the communication to groups is the most impactful. This ties into the barriers where the participant information sheet, which is required by all approved research studies, was seen as a barrier to inclusivity. It was suggested that the level of English comprehension required to understand research is an issue when trying to engage the under-served. This then links strongly to the suggestion that improvements are needed in communication and information accessibility. These include interpretation and translation, plus information being accessible across multiple different platforms and modalities. Examples were cited from the urgent public health work carried out through COVID-19, where PPIE and community engagement had been very successful^{47,48}. This work was highlighted as community outreach in action and worthy of further study to explore application and impact.

While interpretation and translation were suggested as strategies to increase the diversity of research populations, there were also several issues with this approach, particularly from the hospital-based perspective. These issues were centred on availability of translated study documentation, of individual translators and interpreters when required, their understanding of research and the cultural norms and impartiality of the interpreters. Some of these have previously been reported⁴⁹⁻⁵¹ however, there is limited empirical work in this area with central guidance covering the general health setting only⁵². Translation of written study documentation is put forward as an

inclusion strategy², however there is little information about how often this service is utilised and if it has a positive impact. Conversely it is known anecdotally that research sponsored by academic institutions often cites lack of funding as a barrier to translation. The areas of translation and interpretation requires further investigation into the use of, and levels of satisfaction in these services, from both research professionals and participants perspectives. This may lead to a stronger rationale for their use or suggestions for different approaches.

The strongest enabler was community outreach. Recommendations were made to explore focussing research delivery outside of secondary care. It is known that engaging communities in identifying their own needs and requirements has many positive benefits⁵³. There are innovative strategies that allow interventional studies to be conducted wholly or partially in the community where the under-served are^{25,45}. General practices are seen as providing access to local communities who reflect the demographic profile of the area and are more representative. Community outreach also gives opportunities for health researchers to work in partnership with local government and non-governmental organisations and the potential for 'researchers' to better reflect the local demographic. However, this requires time, funding and planning, needing to be resourced and supported from the outset.

It is discouraging that many of the specific requests for training, such as consent where capacity may be an issue, are already freely available across the health research sphere⁵⁴. This implies more effort is needed to advertise and signpost what training is available. Respondents may simply not have time to search for training, guidelines or toolkits, or it may be that these need to be more specific to a group, illness or setting. Added to this are the low levels of confidence expressed by respondents in their ability to address the needs of the under-served and the call for more information and training on improving the accessibility of study materials, methodologies to promote inclusivity and sharing of best practice. All these areas have previously been put forward to improve representativeness⁷ and were known and highlighted by the respondents of the survey. It is also disappointing, when considering the previous works, that there is still a lack of focus on the under-served, implying more is required from an organisational perspective. This was particularly noted in those working in mental health and may require further investigation.

The qualitative work suggested that those working in the field of research are aware of the issues surrounding under-served populations. However, there was a sense of exasperation that systems and processes thwart ideas and strategies to increase representation. Highlighted were the processes of grant and funding applications and the ethical review process. These barriers linked back to the lack of time and funding to plan research projects, which are specially designed to increase representation. Many stated that work in this area takes considerably longer.

The limitations of this work are primarily around the make-up of the respondents. While this work sought the perceptions

of public sector researchers in the UK working with or in the NHS, it does not include the views of the under-served, large multinational pharmaceutical organisations or private research delivery and monitoring companies. These private sector organisations could be significant in addressing the diversity of research populations. A further limitation is the current climate in the NHS post COVID-19. There was a significant amount of upheaval in the NHS during the pandemic and research activity, outside that of urgent public health, was negatively impacted. That effect is still being felt, with the Department of Health and Social Care setting up a programme of work to increase study numbers to pre-pandemic levels under the banner of the Research Reset programme³⁵. The current funding climate and the push to increase the number of studies being carried out means that those working in the field are under significant pressures.

This work suggests that there needs to be a drive from a strategic level to put at the forefront of research the funding and support to engage the under-served. There is room for mandatory targets in recruitment, improved reporting of study populations and strategies utilised to engage those who are under-served in the current research paradigm.

Conclusion

Lack of inclusivity in research creates problems with the generalisability of findings, adding to health disparity and inequality. This survey explored the views of research professionals working in the UK. These professionals identified ethnic and cultural minorities and those in a lower socio-economic situation as those more likely to be under-served. They recognised the most impactful factors on being under-served as language and literacy skills. These findings largely concur with the wider literature. However, this work suggests a broader description of minority ethnic and cultural minorities and the addition of adolescents and young people as an under-served group. While the concept remains context specific, the barriers to inclusivity included both systemic and local factors. Recommendations are made to engage the under-served prior to the research process, to conduct where possible research in the community and to supply and disseminate information across multiple modalities. Support for researchers to address these recommendations is required in terms of time and funding. A further recommendation is made to explore the use of translation and interpretation in the field of research. There also needs to be a concerted move to address the barriers and support the enablers at an organisational level with additional funding, review of grant application processes, ethical approval and training availability. This work has built on the previous works

commissioned by NIHR in the UK. It has drawn out the enablers and barriers to improving inclusivity and made recommendations to further address under-served populations in research.

Data availability

Underlying data

Discussions have taken place with the Editors of the NIHR Open Research platform. Due to there being small numbers of respondents in some geographical and/or specialist areas, the open data has been limited to the pseudonymised responses from which the enablers and barriers were drawn (see below). This data has been disaggregated from the demographic data to ensure anonymity of respondents. Full anonymised data are available on request to the corresponding author (Caroline.wroe@nhs.net). Applicants must provide a sound rationale for the use of the data and confirm their commitment to confidentiality.

Open Science Framework: Enablers and barriers to engaging under-served groups in research: Survey of the United Kingdom research professional's views. <https://doi.org/10.17605/OSF.IO/F5KNW>³⁴

This project contains the following underlying data:

- Barriers and Enablers raw data.xlsx (Pseudonymised responses from the enablers and barriers section of the questionnaire).

Extended data

Open Science Framework: Enablers and barriers to engaging under-served groups in research: Survey of the United Kingdom research professional's views. <https://doi.org/10.17605/OSF.IO/F5KNW>³⁴

This project contains the following extended data:

- Copy of the survey.pdf

Data are available under the terms of the [Creative Commons Zero "No rights reserved" data waiver](#) (CC0 1.0 Public domain dedication).

Reporting guidelines

Open Science Framework Repository: CROSS checklist for 'Enablers and barriers to engaging under-served groups in research: Survey of the United Kingdom research professional's views. <https://doi.org/10.17605/OSF.IO/F5KNW>

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Open Peer Review

Current Peer Review Status:  

Version 2

Reviewer Report 06 February 2024

<https://doi.org/10.3310/nihropenres.14675.r30927>

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Thank you very much to the authors for their consideration of the review comments and the subsequent revisions to the article. There are strong improvements to the article resulting from the revisions and enhanced clarity and context, particularly for readers outside of the UK. The article is a great contribution to this field of literature and identifies interesting avenues for future research and understanding to improve equity of access. Thank you for the invitation to review this work.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Clinical Research Nursing, Research Participation, Research Delivery, Practice Standards

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 08 January 2024

<https://doi.org/10.3310/nihropenres.14675.r30926>

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 Lesley Smith 

University of Hull, Hull, England, UK

The article has been improved by addressing the comments from peer review and I have no further comments to make.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Survey design and analysis, mixed-methods research, research with underserved groups.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 03 October 2023

<https://doi.org/10.3310/nihropenres.14571.r30388>

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Thank you for the opportunity to review this article, and congratulations to the authors and study team on their work.

The article reports on new research conducted to better understand the gaps in access to clinical research within the UK, from the perspective of research professionals. A well-disseminated online survey has been utilised, with a mixed methods approach to elicit information regarding perceived under-served populations, barriers and enablers to participation in clinical research for these populations.

The article draws on the work within the NIHR INCLUDE program and has strong foundations in recent literature, particularly from within the UK and USA. The article is reported using standard reporting conventions and best practice guides.

The survey reported is a well-designed tool that has captured views of a large number of health

professionals within the NIHR. Overall the article presents an interesting and valuable contribution to this field of knowledge. A number of minor revisions are suggested below to improve flow and readability, as well as to suggest some areas where deeper background or context would further enhance the article.

It's always fantastic to read quality research in this important area, and the interest and passion of the authors clearly comes across, particularly in relation to the barriers that research professionals encounter in implementing innovations and strategies to improve equity of access to research.

The article provides strong evidence that the knowledge and expertise is available to combat many of the barriers to access for under-served groups, however system and resource challenges limit innovation and progress in this space.

Minor revisions suggested:

Style

- Consider tense used throughout document (particularly within abstract) and keep consistent.

Abstract

Background

- Suggest consistent use of the term 'participant', rather than 'subject'.
- Correct 'effects' to 'affects' ('...and affects clinician prescribing').
- Rephrase sentence defining under-served to make the relationship between 'underrepresented' and 'under-served' terms within this study (or within the UK) explicit (i.e. suggest replace 'thought of' with 'defined as').
- Clarify what is meant by 'Works..', i.e. replace with 'Previous literature' or similar.
- Suggest replace 'illness' with 'health'.
- Expand sentence regarding survey aim (expand to include what views were being explored).

Methods

- Word-count dependent – could consider including target audience/dissemination information within first sentence.

Results

- Reference here to previous literature, but it is unclear to the reader whether this refers to one previous study or the general evidence in this field.
- Consider wording carefully here – it is a little confusing on first read, as it reads as though the general population were surveyed to identify the groups and factors related to being under-served, but it is important to articulate that this is a reported perception of who is under-served, based on views of research professionals, not a survey of the general population themselves.

Conclusion

- References confirmation of USA findings, however this previous research isn't referenced

otherwise within the abstract. If this article was building on USA research or replicating work from the USA, this should be described in the background section. As per comment for 'Results', clarification regarding what previous literature is being confirmed would be helpful. If just one previous study is being referenced/validated, this should be explicit. The second sentence also appears to build on findings from a previous study, but these are interesting stand-alone findings (new knowledge) from this study.

- Again, ensure that it is clear that the study reports on views of research professionals, not views of the under-served populations themselves.
- Last sentence needs to be checked – is there a word missing related to consent? Revise to clarify/correct.

Keywords

- These are consistent with the article. Could also use 'clinical research professional', 'clinical research practitioner', or 'clinical research nurse'.

Plain language summary

- In some sentences the explanatory terms used for simple concepts have increased complexity e.g. '...in a questionnaire found on the internet' could be replaced with '...in an online survey', and '13 out of 100' can be replaced with 13%. I would suggest reviewing with lay panel members/consumers, or even utilising AI software that provides 'plain language' outputs, to edit this summary and ensure sentences are simple and concise. Ensure the sentence structure clearly identifies the subject (e.g. 'they' is used extensively, but it is not always clear who this refers to).
- Unclear as to what is meant by carrying out research '...in the community'. Suggest rewording for those unfamiliar with health terminology to be explicit that this means research taking place outside of traditional hospital/research facilities.

Introduction

- The first sentence should be referenced and this section would benefit from elaboration regarding the status quo. The lack of diversity in clinical research is the main premise that underpins the study, so it would be interesting here to see some recent statistics around clinical research participation and perhaps an example or two from recent literature as to the impact of including only a homogenous group of participants.
- Line about NIHR INCLUDE – '...involving them directly in producing the definition above.' Which sentence/definition does this refer to? Reword to clarify meaning and retain flow for the reader.
- Consider expanding reference/information regarding the recent work in this area in the USA, as this work is referred to in both the abstract and conclusion.
- Reference in next paragraph first sentence to '...nature of the concept...' – what concept and which 'terms' does this refer to? Although it will increase repetition, as a reader it would be much easier to be explicit regarding each sentence's subject to help the reader understand meaning and intention. Particularly within this paragraph, but please consider throughout the article. It becomes clearer with second or third read, but is quite confusing on first read.
- When describing how previous works link terms, can you give some examples as well as the

descriptors, again to help the reader follow what you are describing? E.g. 'Many narrow the focus to engagement within a named group and a specific disease, *e.g. females underrepresented in heart disease research...*'

- Last sentence (related to what the survey covered) – 'what barriers exist..', does this refer to barriers for participants or barriers to change?
- The gap in access/involvement for under-served groups is well described, but I would be interested to read a little more within the introduction about any identified gaps in health professional understanding of barriers/enablers that drove this study to investigate their views. I.e. why is understanding health professionals' views important to improve equity of access and diversity in clinical research?

Methods

Patient and Public Involvement

- It may be appropriate to move the information regarding peer review of the survey (within 'Survey Development') to this section, as this constitutes consumer involvement, as meaningful input from the target audience to study design.

Survey development

- It would be helpful to expand upon how the literature review was utilised in the survey design, particularly related to determining the 10 factors that impact being under-served that were used in the survey for ranking.

Recruitment and data collection

- '...local clinical research network...' Needs capitalising?
- Include (CRN) in brackets after 'Clinical Research Network' as CRN acronym is used further within the paragraph.
- I don't think the example provided regarding the North East and North Cumbria CRN is necessary. The dissemination approach is well described and this is a little confusing with the number of email invites listed just for this area. It would be interesting instead to read an estimate of how many research professionals were reached through the network and perhaps an idea of what kind of roles (e.g. research nurse, AHP, etc).
- The questionnaire was described as anonymous, however (optionally) contact details were collected? What was the purpose of the inclusion of contact details and how/what did the study team follow up with for those who provided contact details?

Analysis

- Well described and information provided that would allow replication of methods and analysis.

Results

Demographics

- Did all 945 complete the survey in full? Or was this the total number of completed surveys? Were there many/any who started the survey but did not complete it?
- Could you expand on 'all components of the NIHR infrastructure and Clinical Specialties...' for readers who may not be familiar with the NIHR/NHS structure?

- Demographic data is well covered, but this data would be nicely represented as an infographics summary rather than in-text. Particularly the geographical data, also to aid those outside the UK who may not be familiar with regions.

Place of work and role

- Information is provided on the type of role activities (consenting, identifying participants), but was information also collected on the role of respondents? Or length of time in research role?

Who are the under-served

- ...in their area' – Does this refer to geographical area, CRN, or clinical specialism?
- Reference to previous literature could come within Discussion, as it's not expanded here, so is difficult to know which literature this refers to (a specific study, or the current body of knowledge?).
- Repetition of text within Table 1 descriptor and results text.

What impacts on being under-served

- Repetition of text within Figure 1 descriptor and results text
- Suggest describing the 10 responses to be ranked.

Addressing the needs of the under-served

- Is there a significance of gender to warrant inclusion of that info within the brackets alongside number of respondees? There may be many other sub-group analyses (age, role, region, specialism) that would be relevant to include if this was part of the research question(s), but if there were not specific sub-group analyses done on these questions by gender or any other demographic, I would suggest removing the gender breakdown info to make it easier to read.
- Perhaps consider capitalising the response options to make it easier for the reader to follow which result each sentence is reporting. For example, within the sentence, 'A significant difference is also seen in those who identify research participants who felt partially equipped....', it is not clear on first read that the result being reported in this sentence relates to number of respondees identifying as 'Partially Equipped', rather than reporting on those who identify research participants.
- Correct to 'receiving consent' (rather than 'taking consent'). Again in the following sentence, rephrase to 'receiving consent'.

Qualitative analysis

Enablers and Barriers

- May be helpful to firstly introduce/summarise the main themes found in each sub-section before expanding on each.
- An overview/summary table with the themes identified across Enablers and Barriers could work well?
- There is some cross-over here with content that could easily fit within the Discussion section

or is repeated there.

- For consistency, include sub-group analysis for barriers, to report on most cited barriers for primary care and mental health groups.

Further information and training

- The final paragraph to this section could fit within the Discussion, or even Conclusion, as the findings are nicely summarised here.

Discussion

- Provides a nice summary and delve into the results, with interesting observations drawn and areas for further research identified.
- Do draw the reader back to the context of the study to acknowledge limitations – this study is reporting on perceived factors that impact being under-served from the perspective of research professionals, not based on surveying the general population or under-served populations themselves.

Conclusion

- I would prefer a high level summary of the findings from this study regarding who is under-served and the main factors related to this, rather than the reference back to the USA literature.
- Review phrase ‘...to conduct where possible research in the community...’. Might need a comma or just a tweak.
- Final sentence refers back to ‘underrepresentation’. For consistency, should this be amended to refer to the under-served populations?

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Partly

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Clinical Research Nursing, Research Participation, Research Delivery, Practice

Standards

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 28 Nov 2023

Dorothy Coe

Response: Thank you for the detailed review of our work. We have discussed the comments made and revised in light of our discussions.

Style: Consider tense used throughout document (particularly within abstract) and keep consistent.

Response: Reviewed as requested.

Abstract:

Background

Suggest consistent use of the term 'participant', rather than 'subject'.

Correct 'effects' to 'affects' ('...and affects clinician prescribing').

Rephrase sentence defining under-served to make the relationship between 'underrepresented' and 'under-served' terms within this study (or within the UK) explicit (i.e. suggest replace 'thought of' with 'defined as').

Clarify what is meant by 'Works..', i.e. replace with 'Previous literature' or similar.

Suggest replace 'illness' with 'health'.

Expand sentence regarding survey aim (expand to include what views were being explored).

Methods

Word-count dependent – could consider including target audience/dissemination information within first sentence.

Results

Reference here to previous literature, but it is unclear to the reader whether this refers to one previous study or the general evidence in this field.

Consider wording carefully here – it is a little confusing on first read, as it reads as though the general population were surveyed to identify the groups and factors related to being under-served, but it is important to articulate that this is a reported perception of who is under-served, based on views of research professionals, not a survey of the general population themselves.

Conclusion

References confirmation of USA findings, however this previous research isn't referenced otherwise within the abstract. If this article was building on USA research or replicating work from the USA, this should be described in the background section. As per comment for 'Results', clarification regarding what previous literature is being confirmed would be helpful. If just one previous study is being referenced/validated, this should be explicit. The second sentence also appears to build on findings from a previous study, but these are interesting stand-alone findings (new knowledge) from this study.

Again, ensure that it is clear that the study reports on views of research professionals, not

views of the under-served populations themselves.

Last sentence needs to be checked – is there a word missing related to consent? Revise to clarify/correct.

Response: A new abstract as been produced taking into account the above comments and the allowed word count.

Keywords:

These are consistent with the article. Could also use 'clinical research professional', 'clinical research practitioner', or 'clinical research nurse'.

Response: These terms are not consistent with our work as participants included non-clinical research staff.

Plain language summary:

In some sentences the explanatory terms used for simple concepts have increased complexity e.g. '...in a questionnaire found on the internet' could be replaced with '...in an online survey', and '13 out of 100' can be replaced with 13%. I would suggest reviewing with lay panel members/consumers, or even utilising AI software that provides 'plain language' outputs, to edit this summary and ensure sentences are simple and concise. Ensure the sentence structure clearly identifies the subject (e.g. 'they' is used extensively, but it is not always clear who this refers to).

Unclear as to what is meant by carrying out research '...in the community'. Suggest rewording for those unfamiliar with health terminology to be explicit that this means research taking place outside of traditional hospital/research facilities.

Response: Advice taken as suggested and reviews made in light of comments received.

Introduction:

The first sentence should be referenced and this section would benefit from elaboration regarding the status quo. The lack of diversity in clinical research is the main premise that underpins the study, so it would be interesting here to see some recent statistics around clinical research participation and perhaps an example or two from recent literature as to the impact of including only a homogenous group of participants.

Line about NIHR INCLUDE – '...involving them directly in producing the definition above.'

Which sentence/definition does this refer to? Reword to clarify meaning and retain flow for the reader.

Consider expanding reference/information regarding the recent work in this area in the USA, as this work is referred to in both the abstract and conclusion.

Reference in next paragraph first sentence to '...nature of the concept...' – what concept and which 'terms' does this refer to? Although it will increase repetition, as a reader it would be much easier to be explicit regarding each sentence's subject to help the reader understand meaning and intention. Particularly within this paragraph, but please consider throughout the article. It becomes clearer with second or third read, but is quite confusing on first read. When describing how previous works link terms, can you give some examples as well as the descriptors, again to help the reader follow what you are describing? E.g. 'Many narrow the focus to engagement within a named group and a specific disease, e.g. females

underrepresented in heart disease research...'

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Response: Revised with comments taken into account.

Methods:

Patient and Public Involvement

It may be appropriate to move the information regarding peer review of the survey (within 'Survey Development') to this section, as this constitutes consumer involvement, as meaningful input from the target audience to study design.

Survey development

It would be helpful to expand upon how the literature review was utilised in the survey design, particularly related to determining the 10 factors that impact being under-served that were used in the survey for ranking.

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'...local clinical research network...' Needs capitalising?

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The questionnaire was described as anonymous, however (optionally) contact details were collected? What was the purpose of the inclusion of contact details and how/what did the study team follow up with for those who provided contact details?

Analysis

Well described and information provided that would allow replication of methods and analysis.

Response: PPIE moved as suggested although the Editors may have an alternative suggestion.

The example from the NENC CRN was requested by the editors. Granular information on job type (Nurse AHP etc) was not collected. Thank you for pointing out the inaccuracy regarding anonymity. The survey was anonymous. Respondents were invited to leave their contact details for the NIHR under-served programme board. This was to collect 'best practice' examples and was outside of the research project reported. The study staff were not involved in the collection of email addresses or the production of best practice examples.

Results:

Demographics

Did all 945 complete the survey in full? Or was this the total number of completed surveys?

Were there many/any who started the survey but did not complete it?

Could you expand on 'all components of the NIHR infrastructure and Clinical Specialties...' for readers who may not be familiar with the NIHR/NHS structure?

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Who are the under-served...in their area' – Does this refer to geographical area, CRN, or clinical specialism?

Reference to previous literature could come within Discussion, as it's not expanded here, so is difficult to know which literature this refers to (a specific study, or the current body of knowledge?).

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What impacts on being under-served

Repetition of text within Figure 1 descriptor and results text

Suggest describing the 10 responses to be ranked.

Addressing the needs of the under-served

Is there a significance of gender to warrant inclusion of that info within the brackets alongside number of respondees? There may be many other sub-group analyses (age, role, region, specialism) that would be relevant to include if this was part of the research question(s), but if there were not specific sub-group analyses done on these questions by gender or any other demographic, I would suggest removing the gender breakdown info to make it easier to read.

Perhaps consider capitalising the response options to make it easier for the reader to follow which result each sentence is reporting. For example, within the sentence, 'A significant difference is also seen in those who identify research participants who felt partially equipped...', it is not clear on first read that the result being reported in this sentence relates to number of respondees identifying as 'Partially Equipped', rather than reporting on those who identify research participants.

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Qualitative analysis

Enablers and Barriers

May be helpful to firstly introduce/summarise the main themes found in each sub-section before expanding on each.

An overview/summary table with the themes identified across Enablers and Barriers could

work well?

There is some cross-over here with content that could easily fit within the Discussion section or is repeated there.

For consistency, include sub-group analysis for barriers, to report on most cited barriers for primary care and mental health groups.

Further information and training

The final paragraph to this section could fit within the Discussion, or even Conclusion, as the findings are nicely summarised here.

Response: The respondent interpreted 'in their area'. Repetition, the submission requires tables and figures are discussed within the text, therefore to some extent repetition cannot be avoided. However a formatting error has been corrected which had led to whole paragraphs being repeated. The 10 factors are described within the figure. The inclusion of gender (whether significant or not) was requested by the editors. We feel that additional capitisation detracts from the presentation of the work, but will be guided by the editors. Consent phrasing has be revised as suggested. We feel an overview/summary table in not required and would lead to repetition. Sub-group analysis has been added to the 'further information and training' section. We have chosen to leave the interim conclusions at the end of the results section.

Discussion:

Provides a nice summary and delve into the results, with interesting observations drawn and areas for further research identified.

Do draw the reader back to the context of the study to acknowledge limitations – this study is reporting on perceived factors that impact being under-served from the perspective of research professionals, not based on surveying the general population or under-served populations themselves.

Response: Additions to the limitations section have been added.

Conclusion:

I would prefer a high level summary of the findings from this study regarding who is under-served and the main factors related to this, rather than the reference back to the USA literature.

Review phrase '...to conduct where possible research in the community...'. Might need a comma or just a tweak.

Final sentence refers back to 'underrepresentation'. For consistency, should this be amended to refer to the under-served populations?

Response: A higher level summary has been added as requested. Thank you for pointing out errors in phrasing.

Competing Interests: No competing interests were disclosed.

<https://doi.org/10.3310/nihropenres.14571.r30386>

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Lesley Smith 

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² University of Hull, Hull, England, UK

The research article describes the results of a large survey of research professionals' views of engaging individuals who are under represented in health research studies in the UK. This is an important topic and this manuscript adds value to the existing literature on the topic.

It is well written with a clear structure. The methods are transparent and comprehensively reported with the exception of the qualitative analysis which need expanding. A description of how the barriers and enablers were derived and categorised from the themes would enhance the methods.

The interpretation of the following statement needs more cautious interpretation. "Those who consent research participants were more likely to feel partially equipped to address the needs of the under-served compared to those who do not consent ($p=0.013$), suggesting that face to face contact improves confidence in engaging the under-served."

Causality cannot be inferred about engagement leading to confidence from this cross-sectional survey. Reverse causality cannot be ruled out whereby those that are more confident engage in recruitment more. All you can say is that there was an association, not that it suggests a cause effect relationship.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Survey design and analysis, mixed-methods research, research with underserved groups.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 28 Nov 2023

Dorothy Coe

Thank you. We have drawn back on our conclusion as per your suggestion.

Competing Interests: No competing interests were disclosed.
