NHS

Increasing Diversity in Research Participation:

A good practice guide for engaging with underrepresented groups

Executive Summary

This guide is designed for researchers from a wide and varied audience.

Its purpose is:

- To help researchers understand why research participation might be low in a group
- To provide meaningful insights into working with groups where participation in research is low
- To provide practical suggestions to increase participation in research

This work was undertaken in two phases:

1. A review of the available literature, contemporary media and online insights to explore existing understanding and resources
2. Outreach work with six underrepresented groups to understand challenges and enablers to getting involved in research, and to co-develop practical tips to address these

Insights drawn from both phases of work have underpinned the development of this guide, which has been co-developed with the groups in question.

The first half of this guide provides context, background, and insights into the challenges around recruiting a diverse participant base. The second half outlines practical tips, guidance, and case studies from the underrepresented groups.

This guide is relevant to all research professionals but for brevity throughout the guide we refer to the audience as those working in patient and clinical research.

What do we mean by underrepresented groups in research?

The diversity of research participants should reflect the clinical or care community for whose benefit the research is taking place. When this is not the case, some groups are underrepresented, and we use this term in this guide. The term under-served is also widely used to describe groups for whom healthcare and research provision needs to be improved.

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1.1. What is the purpose of the guide?

National Institute for Health and Care Research (NIHR) data has revealed that **UK geographies with the highest burden of disease also have the lowest number of patients taking part in research**. The postcodes where research recruitment is low also aligns closely to areas where earnings are lowest, and indices of deprivation are highest.

This means that research is often being conducted with healthier individuals who may have different responses to a therapy or experiences of services compared with other members of the public. As part of the **Saving and Improving Lives: The Future of UK Clinical Research Delivery**, NHS England and other organisations have committed to increase public participation in research. This guide supports that ambition, offering insights and practical suggestions to support researchers to engage more diverse research participants.

1.2. Methodology

This guide has been co-created with six groups, who are among those **reported by the National Institute for Care and Excellence (NICE)** as being underrepresented in research. Working directly with these groups through focus groups and follow up discussions has provided valuable, first-hand insight on how to conduct meaningful engagement.

1.2.1. How was this guide created?

Literature review:

The project team reviewed available literature including academic papers, health research studies, toolkits, podcasts, and online content, from the UK, the US and elsewhere, to understand the factors behind underrepresentation of some groups, and to establish any suggested lines of enquiry and/or solutions. This review shaped the development of this guide. A full list of references can be found in the Appendix.

Outreach work with groups:

The project team worked with trusted group advocates to undertake focus groups with six groups between March and July 2022. The focus groups tested findings from the desktop review and explored perspectives of barriers and enablers to getting involved in research. Further interviews took place with each group advocate to understand more about each group and the cultural context behind the insight given in the focus groups. Co-creation activity during summer 2022 ensured that content for the guide was shared with groups and refined through further discussions before arriving at the final version.

1.2.2. Working with groups

The six groups engaged to produce this guidance were:

- Young adults, living in temporary accommodation in an isolated seaside group (Scarborough)
- Roma group, temporarily residing in the UK (West Yorkshire)
- South Asian older adults living with diabetes (Bradford)
- Military veterans (Salisbury)
- Digitally excluded people living in rural groups (Shropshire)
- Black African and Black Caribbean people living with diabetes and dementia (South London)

This sample was chosen to represent a broad range of participants from demographic and non-demographic groups, with an appropriate geographical spread across England.

We also selected groups that do not feature to any great extent in existing guidance on underrepresentation in health research. Experienced social health researchers ('trusted advocates'), who work with these specific groups regularly, were recruited to conduct the focus groups.

1.3. Desktop review findings – Why are some groups underrepresented?

Headline findings from the desktop review include:

The primary reasons given for underrepresentation are:

Language Barriers

Accessibility

Mistrust

Language may be a sub-category of access, but it received a high proportion of comment so is listed separately.

The project team tested these findings with the focus groups. All the findings were confirmed within the discussions to varying degrees from group to group, and these nuances are reflected in the guidance provided in Part Two of this document.

1. Background and Context

Language

Clear communication in written and spoken forms that is easy to understand and lacking in confusing terminology is an underpinning factor to access and trust. Without it, a research study is less likely to achieve representative diversity of research recruitment.

Barriers identified include:

- Participants not speaking English (or speaking English as another language), with no access to good translation services
- Health literacy and the use of jargon/acronyms
- Culturally inappropriate explanations
- Difficulties in consenting for another person
- Communications not being suitable for people with learning differences

Access

Access refers to being able or feeling able to join in a process. There are physical, educational, financial and even psychological barriers to participation:

- Requirement to fill in many forms
- Difficulty for participants in travelling, and needing the support of carers to do so
- Physical distance from a research centre or institution
- Barriers relating to physical disability
- Lack of available trials or poor trial promotion
- Negative financial impact in participating (e.g. requirement to miss work or pay for transport)
- Lack of effective incentives for participation, or lack of clarity around incentives
- Research design that places too big of a burden on trial participants
- Not wishing to allocate valuable family or social time to the process
- Narrow research selection criteria
- Participants suffering anxiety and trauma that they may not want to revisit or exacerbate
- Some research candidates believe researchers wouldn't value their opinions

Trust

Candidates question the motives of the research, its processes and what will happen to their views and opinions.

Barriers relating to trust include:

- Potential participants finding it difficult to adjust to or accept a diagnosis or health condition
- Potential lack of interest in research process and its conclusions from those eligible to take part
- Participants' perception of risk associated with taking part in research
- Specific cultural, religious and belief barriers e.g. a strong belief in their faith and written scriptures
- Specific health fears such as concerns about test and procedures that may be involved
- Poor day-to-day service from the NHS leaving potential participants unwilling to commit time or insight for research
- Previous negative experiences, lack of support during or after some research procedures, or poor communication around research can affect enthusiasm for participating again

There are other reasons why a group may be underrepresented. These are referred to in the National Institute for Health and Care Research **(NIHR) paper on Improving Inclusion of Under-Served Groups in Clinical Trials**. Whilst NIHR's list is not exhaustive, it served as useful context to the study.

Offering payment for research participation is considered good practice and is **recommended by The National Institute for Health and Care Research (NIHR)**. There may be reasons why payment for participation is not suitable in all circumstances. While payment might not be appropriate for every trial, there is also an inconsistency in the application of this practice.

Recommended approach to increasing diversity of participation in research: a summary

Recommendations overview

2.1. Pre-research planning

Learn and develop relationships to support engagement work

- Learning from communities
- Recruitment
- Establishing trust
- Incentives
- Preparation

2.2. During research

Involve and respect differences

- Facilitation
- Active listening
- Inclusion
- Respect
- Check assumptions
- Wellbeing

2.3. Post research

Feedback and amend

- Maintain relationships
- Long-term trust
- Positive legacy

2.1. Pre-research planning: Learn and develop relationships to support engagement work

The first stage in increasing diversity of participation focuses on building relationships. Positive relationships are built on trust, and trust is developed with groups through listening to their experiences and engaging in culturally competent ways. Developing a two-way relationship where a group knows that its insight and expertise will be acted on is important.

Clinicians tell us that people are generally interested and keen to be involved when they know more about the options and the role they can play. This echoes findings from our **Dementia Attitudes Monitor** that found 89% of the public would be willing to take part in clinical research – so we can assume that many people from under-represented groups are motivated to take part, it is down to us to facilitate.

What is cultural competence and how does it link to trust?

Gallegos, Tindell and Gallegos (2008) refer to cultural competence as: The process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors, in a manner that recognises, affirms and values the worth of individuals, families and groups, and preserves the dignity of each.

Cultural competency is not guaranteed by being a member of a particular group. It is as much about non-judgemental attitudes and empathy as it is about knowledge and experience. Training courses are available through the **Centre for Ethnic Health Research** and further background reading is available from Gallegos, Tindell and Gallegos (2008).

2.1.1. Learn about your group of interest

- Ensure the research is of interest and relevant to members of the group. Explain why group involvement is important, ideally using a real, local example. For example, the Black African and Black Caribbean group showed an understanding of the importance of research because of the disproportionate number of deaths in the group from COVID-19
- Involve people with lived experience from inception and design of the research. This will help ensure that the approach meets the inclusion and accessibility needs of the group
- Ensure that engagement is clearly articulated and properly resourced within research proposals, plans and protocols
- Build relationships with groups. Building trust from the outset or building on pre-existing contact with groups is likely to improve outcomes in research accessibility, recruitment and retention
- Gain additional insights from the groups' online environments, such as Facebook groups

2.1.2. Recruiting for research with underrepresented groups

The challenges with recruiting underrepresented groups can be counteracted by spending a proportionally greater amount of time and resource on inclusive study design and recruitment to maximise the opportunity to achieve representative participation.

Identifying and building partnerships with trusted advocates

To begin to build a dialogue and trust within a group, an essential first step is to recruit a 'trusted advocate.'

This guide uses the term 'trusted advocate' in place of 'group champion', as the latter can carry connotations for some underrepresented groups, suggesting that group champions are entitled or permitted to speak on behalf of a group. The term 'trusted advocate' can be more inclusive and better reflect the views and breadth of groups.

- Be prepared to work with several trusted advocates to help you engage with a group. Groups are themselves made up of people with diverse views and experiences. For example, a trusted advocate who can help build engagement with older people might be a different advocate from someone who can reach out to young people
- Complete as much due diligence as possible before making the approach, to ensure the advocate is an appropriate person for the project

- Be transparent about the research brief and the organisations you are working for, or with
- Be prepared to invest significant time and energy in this process and be sensitive to the pressures within the group
- Ensure communications during group engagement are provided or delivered in an accessible format and with suitable language
- Understand that people often belong to more that one underrepresented group. This is called intersectionality, and spending time to explore this with community group can give a better understanding of people's experiences

It may be useful to consider creating a formal role for the trusted advocate(s). In the development of this guide, one trusted advocate said: *"Making this a professional relationship could be the difference between a busy trusted advocate putting up a poster in a group centre and nothing more, to going out of their way to make sure your research succeeds."*

Potential ways to do this include:

- Directly paying a trusted advocate to become part of the research delivery team
- Funding a group organisation that employs trusted advocates who can facilitate the research
- Seeking out group organisations, with trusted advocates, that have aligned goals with the research. Where the group organisation already has funds to support this aim, they may welcome a partnership

Try to find a range of voices from each group

Potential methods or connections to help identify trusted advocates include:

- Charities, group centres and faith organisations. Search for grassroots local charities embedded in the groups of interest; these are more likely to be able to reach an underrepresented audience quickly
- Local **Healthwatch**
- **Patient Recruitment Centres** may have team members with expertise or links with underrepresented groups
- Shop-owners, providers of local services such as hairdressers and pharmacists may be influential routes into groups, as are faith and religious leaders
- Public sector or local authority staff, social services and the police can be a rich source of advice, information and contacts, although may not be appropriate advocates themselves where groups have a mistrust or fear of authority figures

Digital recruitment

The move towards digital recruitment offers an opportunity for greater access for many underrepresented or geographically isolated groups of people. New technology and data-driven research can enable researchers to reach huge numbers of relevant people, quickly. While these advances are powerful in increasing reach and engagement, it is important to consider groups who are likely to be affected by digital exclusion, or mistrust digital approaches, and who will require offline recruitment approaches.

Digital recruitment strategies are much the same as face-to-face approaches. Researchers should continue to follow the principles of researching, learning, and working in partnership with trusted advocates and group organisations.

Three approaches to recruit participants

This guide recommends three key methods for recruiting underrepresented groups, which should be done with the help, support and guidance of the trusted advocate:

01

Recruiting participants by referral:

This is the process of asking existing participants to recommend other participants to the study. Helpful techniques include:

- Asking for recommendations from trusted group advocates
- Asking for peer-to-peer recommendations
- Work with NHS colleagues to spread the word amongst patients within groups of interest, through face-to-face or online meetings and/or written materials
- Approaching existing patient groups or group networks

Recruiting by referral can produce larger numbers of participants both quickly and inexpensively, but this type of referral approach can result in a lack of diversity amongst participants, due to the nature of their networks. It can also risk additional barriers and long-term mistrust if people who have been told about the research and want to take part, do not fit the inclusion criteria. It should be clearly communicated that not all people referred will be eligible to participate.

02

Recruiting participants by invitation:

This is the process of the researcher and the trusted advocate generating a list of participants based on pre-determined knowledge, such as patients attending specific clinics, or patient sign-ups from previous information campaigns. Be aware that this type of recruitment usually needs rigorous understanding of General Data Protection Regulation (GDPR) requirements and usually involves additional partnership involvement and legal arrangements with a clinical team, or local authority, for example.

03

Recruiting participants by advertising:

Possible techniques include:

- Posters or leaflets: Create literature for GP surgeries, hospital waiting rooms, group centres and shopping centres in English and local languages. Consider easy read formats and ensure the information is simple, jargon-free, and contains images
- Social media: Even where the chosen demographic may not be active on social media, those who are can be asked to relay information. Short videos and adverts on social media channels, and posts within NHS or local online groups can be used to leverage ready-made audiences. Where promotion and adverts are sponsored by an organisation, ensure the group does not have an adverse view of the an organisation before proceeding
- Group media: Specialist communications agencies can be helpful, and should be included in project budgets if these activities are planned
- In-person events: Attend group events such as celebrations or festivals, to talk about research and its importance and hand out information. Ensure that the marketing resources are appropriate to the group and deployed in the most effective way by involving trusted advocates in the campaign from the outset

Recruitment hints and tips

- Think about the three main barriers to participation (language, access and trust) and prioritise finding solutions to these
- Find opportunities to listen to, learn from, and build trust with the groups you hope to engage
- Ensure you engage with a number of trusted advocates to reach out to diverse groups
- Be mindful that research should be sensitive to cultural and religious beliefs
- Explain exactly what participation will entail and ensure that there will be no surprises if people agree to participate
- Ensure that consent is obtained in a way appropriate to group needs, for example, orally recorded or translated via written material, make them aware that they are free to withdraw
- Be clear about any incentives that will be offered to those taking part (see the incentives guide opposite)
- Be clear about what confidentiality, anonymity and data recording is in place. Some groups may have concerns about this, so transparency is vital
- During recruitment, be honest about how and when research may benefit the specific group

Use of incentives

Formalising the incentives process can be another way to build trust

The focus groups felt that incentives to take part can have a positive impact on participation in some groups. Different incentives motivate different groups.

Researchers should seek guidance on incentive formats by asking the trusted advocates and the group that they are seeking to work with. For some groups, being able to access an opportunity whilst taking part in research can be motivating. For example, a research project involving families could be held at a local play centre, and once the research activity has taken place, families are given free access to the centre. Or at the end of a day of research activity, the team and participants can mark the occasion with a special meal. Groups may be encouraged to participate if research takes place alongside a group event, such as a carnival or festival.

Financial incentives can make a significant difference to enabling people to get involved. This particularly applies where people may be experiencing financial hardship.

Participants should be encouraged to seek benefits or tax advice before accepting cash payments or vouchers, both of which may be seen as an income by the Department for Work and Pensions (DWP) or His Majesty's Revenue and Customs (HMRC) and may have implications for an individual's financial circumstances. **The Health Research Authority (HRA's) latest guidance** on this topic provides further information. Researchers can work with their trusted advocates to explore alternative options for non-cash alternatives which would act as an incentive with their group members. For example, some groups suggested that access to training courses could be of interest.

Expenses

Researchers must cover all expenses incurred by participants and their carers to ensure they are not left out of pocket. It is best to pay expenses upfront or provide travel tickets in advance, as some participants may not have the means to cover expenses and then claim money back. Where this is not possible, expenses should be paid at the end of each session. Keep a clear, written record of all transactions for auditing purposes.

2.1.3. Practical preparation for workshops and interviews

Fundamental to any session planning is the safety and wellbeing of participants and researchers. **Williamson and Burns (2014)** share some useful insights into the safety of all parties involved in qualitative research, which should be followed.

Logistical considerations

Be prepared for conversations with groups to involve a degree of health discussion and signposting. It is important to make them feel this is a safe space to raise questions and voice opinions. Take details of local GPs and support groups for further contact. Take culturally appropriate refreshments and anything else that may help participants feel at ease. Other guidance includes:

Choosing an appropriate venue: Work with trusted advocates to find a location in the local group where participants will feel at ease. While places of worship may be a comfortable venue for some people within a religious group, others may find religious venues off-putting. Equally, pubs may be inappropriate for groups that abstain from alcohol. Research can increasingly be conducted remotely, which often reduces the need to travel, making it more accessible.

Choosing an appropriate time: Before scheduling workshops or interviews, consider the specific needs of the group or group you are meeting with. Are there any routine constraints that must be worked around such as school runs, prayer times or regular appointments?

Consider hosting an activity at the sessions alongside research work: To encourage participation it may help to position the research conversations in parallel to a more informal activity. The activity can be decided in partnership with your trusted advocate(s) based on the preferences and characteristics of your participants, but examples might include cooking or eating a meal together, carrying out a craft activity, playing a game or going for a walk.

Workshop or interview sessions should be succinct and time-effective.

Language and accessibility of content

It is very important to deliver sessions in a language, format, and using terminology that participants are comfortable with:

- Work with the trusted advocate(s) to understand the group's communication needs in advance. Consider whether you need additional resources such as a handout, audio recording, sign language interpreter, translator, easy read versions or visual aids
- If you are using a translator, have a pre-meeting with them to explain the project and format of the session, desired outcomes, and why the trust of participants is so important. They can help pick up any non-verbal cues displayed. Translators and/or co-researchers could be recruited from the groups being researched
- If facilitating the session in English, avoid any use of jargon and acronyms that could confuse or alienate participants. Deliver everything in accessible terms and do not assume any background knowledge

Official accessibility guidance is **available online**.

2.2. During the sessions: involve and respect differences

Throughout the research:

- Build in time for relationship building before getting into the detail of the research topic
- Be empathetic
- Listen actively
- Respect experiences and stories that are shared by members of the group

2.2.1. Research involving focus groups, workshops or interviews

Good facilitation is critical in creating trust and increasing the likelihood of open and honest conversation and useful insights. Working with a facilitator or co-facilitator who is a trusted advocate or peer of the group can support in building credibility.

- Create a safe space to collaborate: Participants may want to 'offload' initially. They may want to talk about health experiences that have led them to being involved in health research. Be empathetic, build in time for this discussion and offer signposting contacts to other services if appropriate. Facilitators can proactively manage this with the group and set a notional time limit in advance, *"with your permission I will move us on after ten minutes, so that we can also cover other topics."*
- Use icebreakers: A well-chosen icebreaker can be useful to start a session and get people talking. The use of icebreakers should be appropriate to the group **There are lots of examples online**. Two are given below:
  - Make a deflecting statement and go round the room asking people to agree or disagree with it, and give their reasons why, for example; *"I like/don't like getting up early in the morning because..."*
  - Ask for people's thoughts on a simple, uncontroversial issue, such as: *"will you watch Strictly Come Dancing this year?"*

- Don't make any assumptions. Use exploratory questioning approaches to gather a range of viewpoints and clarifications
- Manage conflict: Sometimes participants may be sceptical and suspicious of research, especially if they've had negative interactions with large organisations or NHS services. This may create defensive or even openly aggressive responses, especially in early interactions. If this occurs, it may be appropriate to pause or stop the session. During this time, attempt to reassure the individual. If they are uncomfortable in a group or are affecting the group's dynamics, explore alternative approaches to involve them, e.g. one-to-one interview. They may also choose to stop taking part. Reassure participants that incentives will be paid, no matter how long they have stayed
- Session dropouts can be normal. In these cases, reconvene with the trusted advocate and work together to re-engage participants
- Remind researchers of cultural competence. Being conscious of potential cultural bias, stereotypes and prejudices is fundamental to maintaining trust in underrepresented groups or groups
- Arrange a debrief: These may be challenging or emotional sessions for facilitators. Researchers may wish to discuss the sessions afterwards with colleagues

2.2.2. Research carried out by telephone

Telephone interviews can be a quick and effective way to reach large groups of people. Key elements to consider for underrepresented groups include:

- Is a trusted advocate needed to initiate the conversation and introduce the researcher?
- Is an interpreter required? Working with a family member as an interpreter can bring challenges relating to confidentiality, privacy, dignity and integrity of translated response. Balanced consideration should be taken in advance as to whether this is appropriate
- Group language interpreters should hold a group interpreting qualification at level three and have had **enhanced disclosure and barring service clearance**. **The National Register of Public Service Interpreters (NRPSI)** holds a list of registered interpreters
- **The National Register of Communication Professionals working with Deaf and Deafblind People (NRCPD)** ensures that registered professionals have signed up to its code of conduct, which includes assurances around confidentiality, competence, integrity, impartiality and professional development

2.2.3. Non-synchronous research (without a face-to-face element)

In some cases, researchers will favour questionnaires, either online or offline. These are cost-effective methods and can be simple to administer at scale. There are also significant reach and accessibility benefits; participants can engage even if they are unable to travel or have inflexible work commitments. However, the non-synchronous nature of questionnaires means there is less opportunity to explain study parameters, nuances or respond to any concerns. Surveys can also bring barriers for those with literacy or language needs. If a survey is an important part of the research, instead of interviews or focus groups, consider ways that people could be supported to take part, for example, working with a supporting family member.

Online surveys may not be accessible by those who experience digital exclusion. There are many reasons that people experience digital exclusion, including lack of access to good connectivity, devices, cost of data, confidence using online platforms and literacy levels. To engage with people who are digitally excluded, consider how each of these might be addressed. For example, researchers with available portable devices could go to local group spaces such as city centres, shopping centres, or libraries to seek participants. Taking a device to a place of good online connectivity removes the need for people to use a personal device and data package and can provide some 'human' support if people need this to complete the survey.

As with other types of engagement, work with trusted advocated to explore appropriate survey content and dissemination. Develop and test your content with trusted advocates and if your questionnaire is online consider using video and interactive content to increase accessibility.

Languages and translation

Willis, Isaacs and Khunti (2021) wrote in the Lancet that simply translating a document into a heritage language is unlikely to be an effective solution to increasing diversity in research. They suggest that researchers considering language translation in clinical trials should consider language needs at the trial conceptualisation phase. Robust translation methods should be employed (e.g. forwards and backwards translation with input from multiple translators and clinical reviewers). Where possible, emphasis should be placed on achieving conceptual equivalence, with appropriate readability levels, assessed via end-user testing. Inclusion and access barriers need to be more broadly considered from end-to-end throughout the research.

2.3. Post research: feedback and amend

2.3.1. Providing feedback

Sharing feedback and findings from the sessions and the overall research outcomes with those who attended sessions is fundamental to the research process, and to maintaining trust with underrepresented groups.

- Early in the process, ask which members of the group would like to be kept updated on the research progress and findings. It's likely that not all will say "yes"
- If participants would like to receive this follow-up information, ensure you ask for contact details
- Ask how participants would like to receive feedback; verbal, written, or via the trusted advocate
- When research outputs are written and published, in formats such as journal papers or reports, ensure that these are shared with those who took part in the research process. Consider inviting trusted advocates or key session attendees to be co-authors where they have been involved in designing and guiding research. Ensure the input from public participants is acknowledged
- Explain when this is expected to happen, but also manage expectations so participants understand that research outcomes can be slow

2.3.2. Building a positive legacy

Mark the end point of the research engagement with an appropriate communication with participants. Include your thanks, information about how to receive updates or feedback, and information on how people can find other research opportunities. Where relevant, offer to pass details to other researchers, making personal introductions to other local research teams. Ensure that this is in line with informed consent and **General Data Protection Regulation (GDPR)** guidance. This helps to create a positive legacy, building trust between individuals and public institutions, supporting groups to be research active and potentially helping future health researchers to further address underrepresentation.

3. Conclusion

Increasing diversity of participation in health research will require widespread adoption of well-considered and targeted approaches that actively promote and support access to research for people in underrepresented groups. It will require time spent investing in group relationships, building trust, connections, and credibility. It also requires a focus on cultural competence, appropriate communication, and language.

A researcher cannot hope to solve the range of challenges that society faces. However, researchers can ensure participation is including in funding applications, study design and resource allocations. By making reasonable adjustments to enable broader participation in health research, researchers can ensure a more representative set of voices and inputs in health research, ensuring resulting therapies, practices and policies are better placed to be effective for our population.

4. Challenges and enablers identified for specific underrepresented groups

In addition to what has been identified above, the work undertaken with six diverse groups highlighted several specific considerations that are outlined in the case studies below. It should be noted that the participants were not 'representing' their whole group, nor could they be representative of the breadth of experiences making up diverse and intersectional groups, but were talking from their own experiences.

- Young adults, living in temporary accommodation in an isolated seaside group (Scarborough)
- Roma group, temporarily residing in the UK (West Yorkshire)
- South Asian older adults living with diabetes (Bradford)
- Military veterans (Salisbury)
- Digitally excluded people living in rural groups (Shropshire)
- Black African and Black Caribbean people living with diabetes and dementia (South London)

4.1. Black African and Black Caribbean people living with diabetes and dementia

Participants and group:

Participants in this focus group lived in Brixton, in the Lambeth area of South East London, where there is a highly diverse population. **The health and care needs of its people are complex**. As with other diverse boroughs across the country, South East London saw a high proportion of deaths from COVID-19. In discussing engaging with public bodies, the group felt that mistrust of the state is highly prevalent in this area, which they felt stemmed from poor relations with the police and their controversial use of stop-and-search powers.

Key barriers to participation in research:

Largely sceptical of research as a whole, one participant stated that this specific research is no different to when anyone from ***"the state"*** is seeking information from this group. They explained that experiences have not always been positive and for some people, negative experiences are deep rooted. However, participants recognised that it is important to take part in health research: ***"We have to take part or else our people will be left behind."*** The focus group felt that general awareness of research in the group was low, and one of their main concerns was what the researcher would do with the information that the participants shared. There was also a fear of misinformation, which the group felt was common within the group. Participants gave the example of being in the at-risk group for the COVID-19 vaccination and the discussions surrounding the implications of the vaccine. One participant said: ***"ultimately, it's a matter of personal responsibility, and that's a lot of pressure."*** **The Tuskegee Study** has also left deep-rooted issues of conscious and subconscious responses to mentions of any health research within this group.

Other barriers were noted as:

- The group was unsure if they would be accepted for any sort of research
- They also had a fear of the research itself: ***"Could I be subjecting myself to something that will harm me or kill me?"***
- The researchers don't look like members of this group and there is a concern about how many young people from the Black African and Black Caribbean group have access to careers in this industry
- Lack of understanding or information about what's in it for the participants. One participant said: ***"is it a business transaction?"***
- Lack of understanding or information about how visible/transparent the process will be. One participant said: ***"who is benefiting from this, why am I being asked to do this and what do they want from me?"*** and another commented: ***"I'm too scared to – what if something goes wrong? The people doing the research would have to sit down with me and explain what they are going to do, so that I can understand before making up my mind."***

Key enablers to engagement and participation:

Important points to consider with this group when breaking down barriers to participation are:

- Spending time with groups to understand what is important to them
- Conducting research in places familiar to participants, where they will feel comfortable and safe
- Research material, posters, flyers to contain visuals that represents groups and that they can relate to

"Ultimately, it's a matter of personal responsibility, and that's a lot of pressure."

"I'm too scared to – what if something goes wrong? The people doing the research would have to sit down with me and explain what they are going to do, so that I can understand before making up my mind."

"We have to take part or else our people will be left behind."

4.2. South Asian group living with diabetes

Participants and group:

This focus group took place in Girlington, in the Toller ward of Bradford. **Deprivation because of poor health and disability is common in this area**.

80% of the participants in these well attended focus groups session were women over 50 and were second-generation British Asians. A majority self-identified as religious and regular attenders at Mosque. More than 70% could speak and understand English proficiently, however, the participants reported that they felt more comfortable, and researchers felt they gained more insight when questions were set and answered in Urdu. These women not only look after and make decisions about their own health and treatment but that of their extended family.

Key barriers to participation in research:

Most participants did not have any experience or understanding of research. Almost everyone agreed by the end of the focus group that research was important and that it would be beneficial for members of the group to partake, to help others. But, they would need to have confidence that the research was confidential and anonymous. Participants trusted their GP if it was NHS research, but the researchers had to be trusted before people could speak openly. They overwhelmingly wanted to have researchers to be known to them or to have someone known to them involved in supporting the researchers' sessions. Participants also commented that there is a lot of ***"fake news"*** out there about diabetes. From ***"treatments"*** available on the internet and stories from friends to people selling herbal medicines and claiming ***"cures"*** in lots of different ways. Participants said the main place to get trusted information was from the doctor or the nurse at the GP practice.

4. Challenges and enablers identified for specific underrepresented groups

Key enablers to engagement and participation:

Important points to consider with this group when breaking down barriers to participation are:

- Participants said they would prefer accessing information, whether about diabetes or about research, in group languages and from people they knew and trusted. Getting information from their children was seen to be an important means of accessing information, and participants discussed being able to sense check information with their adult children. Almost everyone in the group said it was of benefit to them to have peer led support to learn about health conditions
- Trust is particularly low in this group and the trusted advocate has a vital role to play
- Being 'like' the participants isn't enough. Researchers from this group with a comparable lived experience are more likely to be trusted
- The focus group facilitator used Urdu to facilitate the session. However, he was able to pick up on small cues to demonstrate that participants hadn't quite understood the questions, so he repeated himself in Punjabi. This highlights the importance of multilingual facilitators in this group

Further, **specific resources aimed at working with this group** are available online.

4.3. Young people who have experienced homelessness

Participants and group:

All participants in the group had been homeless and were either in (or had passed through) short term hostel accommodation provided by the **Inspire North** charity in Scarborough. Our trusted advocate was the hostel manager, who attended the meetings. The ten men and seven women who attended have all been referred to the re-homing service and many have lived difficult and complex lives, leading to them living in a hostel or sheltered environments. Some shared that they had a diagnosis of mental health illness, predominantly for anxiety.

All participants were between the ages of 17 and 24 years. This group felt that there is a general mistrust of society and its intentions amongst. Even the basic societal touch points (family, NHS etc.) had little ***"trust"*** associated. Friendship groups were small and relationships fleeting. Trust and positive experience of authority or government was not expressed without facing challenge from other group members. There was deep cynicism and distrust of authority and government.

Key barriers to engagement and participation:

Access and trust are the key barriers to participation with this group. Physical access to trials and research hampers participation. Scarborough attracts young homeless people from across the country. It is 30 miles from the closest active health research cluster in York and 50 miles from Leeds, the closest large research cluster. There are poor transport links with return trains to Leeds costing more than a weekly personal allowance (universal benefit) and taking between one and half to two hours depending on connections.

The group is digitally excluded too, due to financial restraints. Phone data costs money, so most participants indicated that they would access the internet in known free wi-fi hotspots. Their priority for time online was not research or enquiry but catching up with friends and formal processes such as checking email and job opportunities.

4. Challenges and enablers identified for specific underrepresented groups

The concept of ***"clinical research"*** was a complete unknown to the group. Participants found it difficult to identify the purpose that health research and or its benefit. A small but influential number of participants openly questioned the motivation of scientists. The group in general did not draw a clear line between scientific advance and this being of help to society, their friends or indeed, themselves.

Key enablers to engagement and participation:

Important points to consider with this group when breaking down barriers to participation are:

- Analogue materials such as posters and leaflets as well as word of mouth work well in raising awareness
- The group was easily convened (by the trusted advocate) when it became clear that a cash incentive would be paid
- Confidence and trust flow from the presence of the trusted advocate in the room
- Confidence and trust are gained most readily from friends/other group members being positive about the process and its possible outcome
- Smaller groups (no larger than five participants) empowered meaningful contributions and participation
- A formal setting (market research style focus group) is not as effective as semi structured discussion and interactions over an active task
- Longer term studies may consider the supply of equipment and mobile phone data to increase access as part of the study design
- Financial incentives were welcomed by the group

Key recommendations:

Groups of people who have experienced social exclusion and with complex lifestyles can prefer less formalised ways of working.

This group demonstrated a need to feel they were in control of the situation and had agency – and to demonstrate this to peers. Self-deprecating humour, helped defuse the tension, but could be highly disruptive especially in a larger group of young people. Out of this group, over 50% said they would take part in clinical or health research if they were asked as long as they were offered some form of control over the process, namely being able to walk away if it wasn't working for them.

4.4. Military veterans

Participants and group:

All participants were male and had previously served either in the army or navy. Their experiences varied from serving in World War II, The Falklands and most recently in Afghanistan, and Libya. All nine participants received support from the health services due to injuries incurred whilst serving or support due to trauma based on their experiences as serving personnel. By working with Salisbury Hospital and local charities, we were able to bring these veterans together.

11% of British Armed Forces today are female. No accurate data exists but one can reasonably expect that fewer than 11% of UK's military veterans are female. Despite our efforts to encourage women to attend and participate in our focus group none took up our offer. This demonstrates how difficult it is to construct an accurate sample even with excellent access to an established group.

Key barriers to engagement and participation:

Most of the participants had very little knowledge of health research or clinical trials. They felt quite strongly that the NHS has no real understanding of the needs of veterans and is not proactive in engaging and involving veterans in general health and care developments. There were two participants who had previously been involved in clinical trials for a significant period, however they were asked to leave the clinical trials once they reached the age of 70 years.

The participants had a very strong view about clinical research. They felt that the NHS and Ministry of Defence need to work collaboratively in supporting military veterans to get the basics right when accessing and receiving care and treatment, before they commit to giving something back to the NHS with their time, expertise and insight. Participants clearly articulated their frustration in the lack of awareness and understanding by health care practitioners of the needs and experiences of veterans. They were clear that building trust is important. One participant said: ***"the researcher needs to make the effort to know our group and our experiences. There must be something in it for me too, to make it worth my time."***

Key enablers to engagement and participation:

Important points to consider with this group when breaking down barriers to participation are:

- Take time to get to know veterans as a group of interest – this cannot be achieved by a single engagement session
- Be mindful that dependent on age range veterans' experiences will be different. Do not make assumptions that veterans have the same experiences
- Use the charities associated with veterans as one of the vehicles for engaging and involving veterans
- Be mindful that veterans may have witnessed some horrific incidents, and a trauma informed approach to research would be beneficial

4.5. Digitally excluded groups

Participants and group:

Participants were predominantly from farming groups in Shropshire, **where 57% of the population live in rural areas**, with limited access to digital platforms and technology. **Healthy life expectancy (the age at which health starts to be impacted due to a long-term condition) for males in Shropshire is 64.6 compared with West Midlands 61.5 and England 63.2**. The fact that Shropshire is a relatively affluent county masks **pockets of high deprivation**, growing food poverty and rural isolation.

The participants in this group were all male, aged between 35 and 65 years. Recruiting the participants was relatively straight forward as the conduit to the groups was through local voluntary organisations. This group of interest is time-poor, given the nature of its day to day lives, as working farmers.

Attracting farmers, agricultural labourers and their families to take part in our research was exceptionally difficult. Our research team believe that with more time and a change in method (going individually to recruit and interview participants) we might have reached more isolated and digitally excluded farmers and recruited more women to take part in this study.

4. Challenges and enablers identified for specific underrepresented groups

Key barriers to engagement and participation:

Limited awareness of research was expressed by the group; however, the participants referenced their understanding of the importance of research. The participants described how researchers, and health services in general, need to understand the needs and day-to-day lives of people who live in rural groups. Participants described involvement in research as a ***"business contract"*** therefore their time and contributions to the research or clinical trials should be remunerated.

- One of the participants shared their experience of being involved in a clinical trial, responding to a flyer seeking participants. The information on the flier was not specific, and there was very little feedback from researchers during or after the trials
- Like our military veteran's group of interest, this participant group described the importance of researchers "***doing their homework***"
- Participants believed that many health and care professionals have preconceived ideas about rural groups that are often inaccurate. One participant stated, ***"I don't have access to all these fancy gadgets, smart phones or the internet, but good old fashion face-to-face meeting over a cup of coffee can go a long way to building up trust and an effective relationship with us."***, ***"We don't all spend our days in the fields. We are real people with different experiences that health professionals need to make the time to understand"***
- Participants noted the importance of payment: ***"We are like everyone else, research is like a service, so payment for taking part is important."***

Key enablers to engagement and participation:

Important points to consider with this group when breaking down barriers to participation are:

- Make sufficient time to get to know the groups you wish to engage in research
- Engagement should not be a one-off exercise
- Leave any preconceptions or biases at the door
- Meeting with people in their own environments is very powerful and often more comfortable for individuals as they are on ***"home ground"***
- Payment for participating is an important factor for individuals

4.6. Roma group

Participants and group:

Twelve people of Roma heritage took part in the focus group, which took place in a group centre in Bradford. The participants were of a cohort of mixed ages, with the youngest in her twenties and the oldest in her late sixties. Three of the participants were male and nine were female. All except one struggled with English, so an interpreter who was known to them and trusted by the wider group supported the session.

The Roma group is a relatively recent arrival to the UK. **Many members of the group experience high social and economic deprivation in the inner-city localities of Bradford**. Poor health is exacerbated by conditions associated with poorer housing, such as living in back-to-back houses with rented accommodation. Social constructs relating to health and engagement in research were reported by the attendees as very different to how services are accessed in Slovakia. They shared that access to health is more difficult in Slovakia compared to the UK, whilst involvement in research was non-existent for all the people who took part in the focus group.

The discrimination against the Roma group in Slovakia has impacted the confidence and trust of the group in larger organisation. All participants felt they had come across negative stereotyping in their interactions with health and care.

Key barriers to engagement and participation:

There was a significant lack of awareness of research within this group. None of the participants had taken part in any previous research. After explaining what research and engagement with NHS could do to support patients and develop services, participants stated they would need to trust the researchers asking them the questions. Not having someone known to the group to act as interpreter or facilitator meant this group would be even less likely to take part in any research.

Language was a significant barrier. Almost all the participants said they would need to have research conducted in their first language, to fully understand what was being asked and be able to convey full and complete responses. The language barrier was perceived to be a cause for being treated less favourably, with the absence of spoken English being perceived as associated with broadly poorer engagement with (and treatment by) services.

4. Challenges and enablers identified for specific underrepresented groups

Key enablers to engagement and participation:

Involvement in research was not seen to be something this group would necessarily avoid, but knowing about it before making an informed choice was the obstacle.

Their comments consisted of:

- A trusted advocate to facilitate the sessions, in a trusted location, is essential
- Slovakian speakers or translators must be involved
- Participants need to understand what the research is about before getting involved
- Spoken information through trusted sources is more acceptable than information from unknown individuals or sources such as the internet
- Remuneration for participation is seen as a key factor

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