

Equality, Diversity and Inclusion (EDI) Toolkit

 <p>Historical Context and Structural Inequality</p> <ul style="list-style-type: none"> • Has previous research excluded certain populations? • What historic and structural issues might affect research participation or involvement? • How will you navigate these issues? 	 <p>Data Collection</p> <ul style="list-style-type: none"> • How equitable is your data collection strategy? • Do your methods address participants' protected characteristics, circumstances and needs? • What steps will you take to include 'seldom heard' groups?
 <p>PPI</p> <ul style="list-style-type: none"> • How aware are you of EDI issues in PPI? • How will your PPI strategy enable you to recruit and retain diverse public contributors? • How will you support and empower your diverse PPI group? 	 <p>Data Analysis</p> <ul style="list-style-type: none"> • How will you report on protected characteristics? • What intersections of characteristics will you analyse? • Has diverse PPI been incorporated to support the interpretation of results?
 <p>Research Team</p> <ul style="list-style-type: none"> • How diverse is your research team? • How culturally competent is your team? • How has incorporating diverse perspectives and lived experiences affected your research design? 	 <p>Data Presentation</p> <ul style="list-style-type: none"> • How will you describe participants' protected characteristics? • How will you preserve the anonymity of people from minority groups?
 <p>Selection of Participants, Sites and Samples</p> <ul style="list-style-type: none"> • How generalisable is your sample? • Has geographical need informed your choice of site(s)? • Are you excluding anyone, if so is this justified? • How is data on EDI collected? 	 <p>Dissemination and Implementation</p> <ul style="list-style-type: none"> • Will findings be disseminated via accessible and inclusive formats? • How will this research be taken forward to benefit all patients/service users? • Does the research/intervention work across all settings? E.g. rural/urban

Welcome to the pilot version of the RDS EDI toolkit. This has been developed as part of the RDS's national priority work on EDI, led by RDS East Midlands. We invite you to use this toolkit as a resource to support your clients to respond to the NIHR's new (as of May 2020) requirements to address EDI considerations in funding applications (<https://www.nihr.ac.uk/documents/strengthening-our-commitment-to-equality-diversity-inclusion-and-patient-and-public-involvement-and-engagement-ppie/24697>).

We will be seeking your feedback on this draft toolkit in the summer, prior to revising it and making it available for advisers and researchers across the RDS in Autumn 2021. For now, we would request that this toolkit only circulated internally, but please feel free to share any of the references and weblinks with clients. Later in the year, the toolkit will be expanded to include an EDI glossary, case studies of good practice and lessons learned, and video interviews.

If you have any questions or would like to offer any feedback about the toolkit or experiences of using it in your advising, please email Dr Rebecca Barnes rb358@le.ac.uk or Dr Chris Newby Christopher.newby@nottingham.ac.uk

Historical Context and Structural Inequality

- **Has previous research excluded certain populations?**
- **What historic and structural issues might affect how under-represented groups feel about research participation or involvement?**
- **How will you navigate these issues?**

Because health and social care researchers have only more recently become aware of the importance of capturing diversity within their studies, much of the literature that informs our proposed research is based on designs and sampling strategies that have traditionally yielded predominantly white, male, well-educated samples. Indeed, many studies do not report on the ethnicity, socio-economic status and other characteristics of their samples ([Vyas et al. 2018](#); [Furler et al. 2012](#)). Of 1518 COVID-19 trials registered on ClinicalTrials.gov, only six have collected data about ethnicity – despite the disproportionately severe impacts of Covid-19 on Black and South Asian people ([Treweek et al. 2020](#)).

The needs and perspectives of under-served groups remain invisible when they are either not participants in research or are not disaggregated in the analysis ([Petkovic et al. 2020](#); [Phillips and Hamberg 2016](#)). This prevents us from knowing whether an intervention is safe and/or effective for all population groups, and yet interventions are commonly implemented for the whole population based on this partial evidence. With equality, diversity and inclusion now recognised as integral to *all* research, we need to critically reflect on the implications of knowledge gaps about the most under-served groups and demonstrate how we will avoid reproducing these limitations ([Witham et al. 2020](#)).

Historic and enduring experiences of oppression and exploitation can lead to mistrust in medical, social care and research professionals. Infamous examples of grossly unethical research exist, such as the Tuskegee Study (1932-1972), conducted by the United States Public Health Service. Hundreds of African American men with syphilis were recruited into a study where they were told that they were receiving medical treatment ‘for bad blood’. In reality, the researchers’ intention was to observe the natural progression of untreated syphilis, and the participants were not given any useful treatment. Even when penicillin became routinely available as a treatment for syphilis in the 1940s, the researchers made every effort to deny participants this treatment, even ordering doctors not to offer medication. This led to the unnecessary suffering and premature death of many participants, as well as transmission to their wives and children.

In contemporary times, statistics from the ONS about uptake of the Covid-19 vaccine indicate that amongst the over 70s, 91.3% of White British people had received their first dose by 11th March 2021, compared to just 58.8% of Black African ethnicity and 68.7% of people of Black Caribbean ethnicity ([ONS, 2021](#)). Prior qualitative research conducted by [ARC East Midlands \(2020\)](#) revealed the concerns which different minority and/or marginalised groups have about participating in vaccine trials. African and African-Caribbean communities were most suspicious about the vaccine and questioned whether efforts to recruit Black people reflected a hidden agenda, such as using Black people as ‘guinea pigs’, or even seeking to eradicate them.

Such suspicions need to be understood in the context of ethical atrocities and long-standing health inequalities which signal that Black people’s lives have less worth. For example, Black women have more than a four-fold risk of dying during childbirth ([Knight et al. 2020](#)) and Black people are over four times more likely than white people to be sectioned under the *Mental Health Act* ([NHS 2020](#)).

Comparable concerns exist amongst people with learning disabilities who have been subject to forced sterilisation or 'do not resuscitate' orders. Another example concerns lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) people who have been pathologised or stigmatised within health and social care services, and may have been refused care or forcibly subjected to harmful and demeaning treatments ([Vincent, 2018](#); [Smith et al. 2004](#)).

Researchers need to understand that structural inequality and injustices lead to mistrust and fear of the medical and social care professions, and of researchers. This is further compounded by under-served communities having limited understanding of research, because they are seldom offered opportunities to participate. Sensitive and committed outreach, relationship-building and public involvement will be required to build trust and encourage participation ([Prinjha et al. 2020](#); [Hussain-Gambles 2004](#)). Keeping to your promises is particularly important when working with groups that have been repeatedly exploited and disrespected, as well as being clear and realistic about what the benefits of research participation will be.

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Patient and public involvement (PPI)

- **How aware are you of EDI issues in PPI?**
- **How will your PPI strategy enable you to recruit and retain diverse public contributors?**
- **How will you support and empower your diverse PPI group?**

To develop this guidance, we collaborated with our public contributors to find out what they thought that researchers needed to know about the role of equality, diversity and inclusion (EDI) within patient and public involvement (PPI). Their perspectives are informed by their lived experience, different identities and experiences of working with researchers.

The first question, **'How aware are you of EDI issues in PPI?'** encompasses various sub-questions, such as:

- How are you addressing your own training needs with respect to EDI?
- How have you allocated time and space to address equality, diversity and equity in PPI?
- How aware are you of how and why some communities/groups have been historically marginalised from research by virtue of socio-economic status, language, disability, age, health literacy and intersections of these?
- Why do you think some groups or populations continue not to engage in research?
- How aware are you about the different strengths and weaknesses of a range of PPI engagement methods (e.g. consultation, collaboration or participatory/user-led approaches)? Which approach suits your research aims and population(s) of interest?

These questions show that public contributors need to be assured that you have taken time to educate yourself both on EDI and on the previous experiences of their communities/groups in research. If you have not yet done so, examine the existing literature to see who has and has not been included in previous research relevant to your proposal, either as research participants or, where reported, public contributors. Take time to understand how marginalisation, lack of knowledge about research and practical barriers have prevented some communities/groups – often those most under-served – from being involved in research. Diving straight in can result in causing harm to already under-served and poorly understood communities ([Vincent 2018](#)). This could have negative psychological impacts and further diminish their trust in researchers, and possibly by association, the health and social care professions. It could also make it much harder to gain access and support for your research.

You may already be familiar with different models of PPI; consultation, collaboration and participatory or user-led approaches. These are characterised by varying levels of involvement: consultation offers the least opportunity for traditional power relations in the research process to be disrupted, whereas co-produced, participatory or user-led approaches are potentially the most empowering models of PPI (see [NIHR \(2021a\) public involvement briefing note 7](#); [NIHR \(2021b\) co-production guidance](#); [Ocloo and Matthews 2015](#)). Your chosen approach needs to suit your research aims and objectives, but EDI is highly relevant too. If you hope to include populations that have historically been marginalised and 'done to', a participatory or user-led approach may be more empowering and would share power more equitably (see NIHR (2021c) co-production in action [case studies](#) and RDS South

East's and NIHR Centre for Engagement and Dissemination's ['That Co-Production Podcast!'](#)). When considering participatory approaches, do not under-estimate how much time will be involved in developing relationships and shared vision, mutual learning and training, communication and making decisions democratically. This needs to be factored into your timelines and budget.

Once you are ready to start planning your PPI activities, the second question, **'How will your PPI strategy enable you to recruit and retain diverse public contributors?'**, requires you to consider:

- How will your PPI recruitment strategy enable you to engage with a range of public contributors, beyond the 'usual suspects'? If you're already working with public contributors, which communities/groups are absent and how could you include them?
- What are the benefits and drawbacks of contacting community leaders or 'gatekeepers' to access particular communities or groups?
- How will you build relationships with the most relevant people/organisations that can support you to develop your understanding and access the most appropriate public contributors?
- Do you need an experienced PPI lead/co-applicant to organise PPI activities?
- How will you support public contributors to understand what is expected of them?
- What benefits are public contributors likely to gain from engaging with your study?
- How honest and transparent will you be about the potential benefits of this proposed research, both to them personally and their wider communities?

Just as you would usually seek a diverse research sample, perhaps recruiting patients or service users from multiple sites, so too should this be embedded in how you recruit your public contributors. The public contributors who are most accessible – perhaps those who belong to an existing patient/user involvement group – may lack diversity. A range of lived experience is required to draw out varied perspectives ([Ekezie et al. 2021](#)). In relying on who volunteers to be involved, absent groups such as Black young men, older Muslim women, traveller communities and people from very deprived areas may be labelled 'hard-to-reach'. It is more appropriate to describe them as 'seldom-heard', however, and to scrutinise how we can make PPI more visible and accessible to them.

A range of different recruitment strategies will be needed to recruit a diverse PPI group, such as attending community events, developing links with places of worship and giving talks on local radio ([Centre for BME Health 2018](#)). Often, the most fruitful relationships develop out of sustained community engagement. This is not a quick approach: it takes time to identify the most appropriate contacts, build trust and mutual understanding, and learn about the dynamics, values, and power relations within a particular community or group ([Cowan 2020](#)). It is not reasonable to expect one individual to speak for their community; rather, they are sharing *their* lived experience. Caution should be applied in situations where a community member tries to position themselves as a spokesperson.

To recruit and successfully retain public contributors, you need to be clear about the nature of the proposed involvement. Many individuals will not know the difference between public involvement and research participation. What tasks will they be asked to take part in? What is the time commitment? What is the purpose of it?

It is important to value people's lived experience and to reward their involvement financially or in other ways (see [NIHR \(2021d\) payments guidance](#)). However, there are other benefits that you could

offer community groups and public contributors to encourage a more reciprocal relationship. This could include training to develop their skills and enhance their CVs, community education sessions to boost knowledge and understanding of their health condition, or access to university facilities.

Being honest about the likely impacts of the research guards against disappointment further down the line. Your research is unlikely to be world-changing, certainly not in the short-term, and there is no guarantee that your public contributors or their families will personally experience improvement in the health or social care that they receive. You can explain that you are building an evidence base, but that translating findings ‘from bench to bedside’ is a gradual process. You can assure them that PPI improves the chances of this research being relevant and meeting patients’ or service users’ needs.

Depending on your background and prior experience, developing skills for PPI and community engagement takes time. To facilitate this work and build your skills, you could include an experienced PPI lead as a co-applicant. This is a requirement for most NIHR grant funding. It would be advantageous to choose a PPI lead who has experience (ideally lived experience) of the communities or groups who will be involved in the research, as well as skills in coordinating PPI activities.

The third question, ‘**How will you support and empower your diverse PPI group?**’, focuses on how to work effectively and equitably with your diverse PPI group. Questions to consider here are:

- How will public contributors know what is expected of them at each stage of the research process, and what they can expect from you?
- How will you ensure that your communication and interactions with your diverse public contributors are based on respect, humanity and empathy?
- How can you ensure that power is distributed equitably and fairly throughout the PPI process?
- How will you ensure equitable access for your public contributors?
- What training and support will public contributors receive to equip and empower them to engage meaningfully in PPI and research processes?
- How will EDI be embedded in your ongoing evaluation of the PPI process?

Successful PPI requires transparency, regular dialogue, and actively empowering public contributors to have a meaningful role in your research. It is important to clarify, not only at the outset, but throughout, what is expected of public contributors, particularly if these expectations change. The research team also needs to set out what public contributors can expect from them, for example, frequency of contact, availability of training and support, and promptness of payments. Opportunities for sustaining relationships with public contributors beyond the lifetime of the project should be sought ([Jinks et al., 2016](#)), but manage public contributors’ expectations so that they do not feel ‘dropped’ or forgotten when a project ends.

Building relationships with public contributors is crucial. Incorporate opportunities for the research team and public contributors to get to know one another more informally and to see each other as individuals. This will help to break down barriers of ‘them and us’ and fosters empathy and humanity. Getting to know your public contributors will mitigate against making prejudgements about their identities, experiences or capabilities. Avoid seeing public contributors as fulfilling a quota because they belong to a particular ethnic group, have a specific health condition, or fall into a given age

bracket. The diversity which they bring will be a product of their overlapping identities and range of lived experience, beyond what is immediately visible.

A key challenge in PPI concerns power relations. Public contributors may be intimidated by researchers' qualifications, titles and long lists of publications. There may also be power differentials between public contributors, for example, resulting from different levels of experience of PPI, or structural factors such as gender, ethnicity and age. Power imbalances are likely to inhibit public contributors from being heard or feeling able to engage. Some simple steps which can make a difference include not using titles, holding meetings in community venues and not in a boardroom format, ensuring that everyone has the opportunity to speak, and ensuring that public contributors are not heavily outnumbered by research team members. Ground rules such as not interrupting and offering any criticism constructively are helpful to collaboratively agree too. [Cowan's \(2020\)](#) report on learning from the Reaching Out projects encourages researchers to relinquish power and be prepared to take themselves out of their comfort zones.

Be careful to distinguish between 'focus groups' as a qualitative research method and PPI discussions. PPI discussions should be freer than focus groups typically are and should not simply reflect the researchers' agenda. Power dynamics will operate differently when comparing a focus group that is steered by a researcher and is relatively restricted in scope, and less hierarchical PPI discussions which can stimulate researchers to think about their research in different ways, throughout its whole cycle.

Your ability to recruit and, importantly, retain a diverse PPI group will depend on how inclusive your PPI activities and processes are. Find out about public contributors' circumstances and needs so that any language and communication needs (e.g. the need for a sign language interpreter) or access requirements can be met. Schedule PPI activities and meetings around public contributors' work, care, religious or health commitments. Many working-age public contributors cannot take time off work, or will lose earnings if they do. Financial support with travel and childcare costs will help to widen participation, as well as varying meeting days and times. Only meeting online will exclude some older people or those with low socio-economic status who have no internet access or limited mobile data. Try to be flexible about how public contributors can be reimbursed: cash is preferred by many, though not all. If gift vouchers have to be used, offer a choice to avoid giving something that will be redundant.

Critical reflection upon, and evaluation of, your PPI activities will help you to identify any aspects how you can improve public contributors' experiences of involvement in your project and maximise the value and relevance of their contributions (see [Gibson et al. 2017](#); [Kok 2018](#)). Include EDI considerations within this reflection and evaluation: are some voices not being heard, and if so, why, and what can you do to empower them? Might EDI issues account for some public contributors having more or less positive experiences of your PPI activities than others? How is PPI impacting your research, and are you being sufficiently open to all perspectives, particularly those which challenge your own expectations or experiences?

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Research team

- **How diverse is your research team?**
- **How culturally competent is your research team?**
- **What difference has incorporating diverse perspectives and lived experiences made to your research design?**

There are various reasons why a diverse research team is a stronger team. Often, people with similar characteristics are drawn to one another. However, idea generation and creativity flourishes when teams include individuals with a mix of life experiences, values and characteristics ([Powell 2018](#); [Rock et al. 2016](#)). Research teams which do not represent a range of protected characteristics, professional roles, lived experiences and geographies are less likely to conceive of, design and conduct research which will meet the needs of a diverse population. This tends to disadvantage under-represented groups. The result has been countless examples of devices being designed to suit men's bodies rather than women's bodies ([Fidler 2020](#); [Hutchison 2019](#)); drugs being less effective for, or having serious side effects on, female patients or patients from particular ethnic groups ([Mak et al. 2018](#); [Parekh et al. 2011](#)); and barriers to research participation for people with low socio-economic status or those living in rural locations being overlooked ([Mbuagbaw et al. 2017](#); [Sharrocks et al. 2014](#)).

When researching populations who have a protected characteristic which is often under-represented in research, it is good practice to ensure that there is a senior researcher on your team who shares that characteristic. This signals to public contributors and prospective participants that a protected characteristic which they share is valued and understood, strengthening your team's credibility. This does not mean that only women can conduct research about women, or only Black people can research Black people's health. Rather, it suggests that it is problematic to research women's health, or Black people's health, without a woman or a Black person on your research team. A rallying call from marginalised groups is "nothing about us without us". Populations with a long history of being oppressed (for example, women, minority ethnic groups, lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) people and people with disabilities) may be suspicious of researchers and are more likely to participate in studies where the researcher shares their protected characteristic(s) ([Vincent 2018](#)).

However, the under-representation of researchers from these groups means that it will not always be possible for your team to reflect the population(s) studied. This relies on wider work to break down structural barriers to the career development of under-represented researchers and clinicians ([Rollock 2019](#); [Kilne 2014](#)). Further, it should not be assumed that because someone identifies as belonging to a particular group or community, they will automatically have a nuanced understanding of the perspectives and barriers within that community, or will be able to build relationships across that community. For example, some LGBTQI+ people know very little about the historic oppression that their predecessors have faced, or may have little understanding of the intersecting challenges facing LGBTQI+ people of colour, of faith, or those who have physical disabilities. They may have prejudiced attitudes towards other groups within the LGBTQI+ umbrella, or may have no knowledge at all.

Regardless of how diverse the team appears to be, all research teams need sufficient cultural competence to engage effectively and respectfully with the populations which they study ([Vickers et al. 2012](#)). Your proposal will be stronger if you can demonstrate how your knowledge of structural

oppression, health inequalities, cultural differences, communication needs and key gatekeepers informs your research design.

There are different ways of maximising how well-placed your team is to design research that is relevant, sensitive and accessible to the communities that you seek to include. First, try to ensure that your team includes at least one investigator who shares the same protected or other characteristic(s) of your participants, and who has appropriate cultural and linguistic competence in relation to the study population. This is relevant whether the population of interest comprises Bangladeshi people, men who have sex with men, Deaf people or another minority group. Another option is to employ and train one or more community development workers or community researchers who can be a bridge between the research team and the community ([Prinjha et al. 2020](#)). In all cases, diverse patient and public involvement and collaboration with relevant community stakeholders is critical ([Vickers et al. 2012](#)).

Whichever approach you adopt, it is critical to ensure that this diversity makes a difference. Having a diverse group of people around the table is meaningless and merely tokenistic unless there is a willingness to listen to different points of view, learn from the lived experiences of others – particularly those with less structural power – and be open to your research design, data collection and dissemination decisions being transformed through such dialogue.

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Selection of Participants, Sites and Samples

- **How generalisable is your sample?**
- **Has geographical need informed your choice of site(s)?**
- **Are you excluding anyone, if so is this justified?**
- **How is data on EDI collected?**

Sometimes in research you might want to carry out your study on a very homogeneous sample that will show less variation or 'noise' to improve the chance of seeing a difference in your analysis. Although this makes sense numerically, and in the realm of personalised medicine where you tailor a drug to a person's genotype or phenotype it may be justified ([Vogenberg et al. 2010](#)), the purpose of most studies is to improve the health and social care of *all* groups of people within the population being studied.

Researchers need to consider how well their study samples reflect the population to which the results will be applied and eventually if successful implemented on. If this population is heterogenous in terms of protected characteristics, then your sample should reflect this, if not you could be contributing to health inequalities. Your sample should be relevant to the population and not have too many possibly unnecessary exclusion criteria. These exclusion criteria sometimes have deep-rooted assumptions such as not including older people in research on digital interventions due to assumptions about digital literacy. If exclusions are made, then these need to be justified and supported by compelling evidence.

In some disease areas, exclusion based on personal characteristics is required. For example, for asthma diagnosis children less than 5 years old are often excluded due to difficulty in gaining objective tests ([NICE 2021](#)). However, looking at ethnicity as a characteristic, we find that although asthma has the same prevalence amongst British South Asian people as compared to British white people in the UK, they have a disproportionately high rate of A&E attendances for asthma attacks ([Griffiths et al. 2001](#)). This suggests that they may have different needs or require adjusted logic models when creating an asthma intervention. Without this diversity the intervention could fail in this part of the population. It is important not only to match your sample to the study population but to fully defend any exclusions and inclusions.

In some research it may be justified to use oversampling in order to get an adequate sample of a minority group in your research and there are several methods to do this ([Vickers et al. 2012](#); [Kalton 2009](#)). In other studies research is carried out in geographical areas where disease burden is small compared to the areas that would greatly benefit from such research ([Bower et al. 2020](#)) and rural areas are neglected ([Smith et al. 2016](#)). NIHR is increasingly keen to see that research is being conducted where the need is, and not only in large cities or leading university hospital trusts.

When collecting demographics and characteristics from your participants it is important to collect data about protected characteristics such as sex, ethnicity and disability. These can be used later to carry out sub-group analysis to determine if certain characteristics affect results such as prevalence of diseases, differences in primary outcomes, or adherence to treatments. Although these statistics are likely to be underpowered if characteristics reflect a minority, the statistics can still be compared to

determine if they are at least similar to the majority of the sample. If differences are seen, these should be justified/accounted for or used to inform qualitative work in the project.

If this data capture is carried out in feasibility or pilot work there is still a chance to tailor the study to accommodate a greater diversity of characteristics which would make the intervention and its findings more generalisable. In the [NEON trial](#), a mental health trial consisting of an intervention accessing recovery narratives, it was found in feasibility data that participants from minority ethnic groups had less connection to narrators of narratives and that participants who had the same broad definitions of ethnicity then that of narrators rated narratives more favourably. As a result, more diverse narratives have been added to the intervention library of mental health narratives (paper in preparation). If the feasibility sample had lacked ethnic diversity, the final intervention would not have brought equal benefits to participants from a range of ethnic groups.

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Data collection

- **How equitable is your data collection strategy?**
- **Do your methods address participants' protected characteristics, circumstances and needs?**
- **What additional steps will you take to be inclusive of 'seldom heard' or marginalised groups?**

Embedding EDI at the design stage will maximise the accessibility and inclusivity of your research. This will increase the likelihood of your study recruiting sufficient participants, achieving diverse participation and keeping to its timelines. It also signals to prospective participants that you are considerate of their needs and preferences. This is particularly important when trying to recruit and include groups of the population that are under-represented in research studies and that might be termed 'hard to reach', or alternatively, 'seldom heard' or 'easy to ignore'. It is common to see grant applicants making statements about their intentions to recruit a diverse sample, but a reviewer may ask, 'Which measures will be taken to make the research inclusive, and what expertise does the team already have in conducting research with diverse and under-represented populations?'

Many studies have examined barriers to the participation of under-represented and minority groups in applied health and social care research. The greatest focus is on how to more effectively include Black, Asian and minority ethnic communities ([Prinija et al. 2020](#); [Ahmed et al. 2019](#); [Lloyd et al. 2008](#); [Hussain-Gambles et al. 2004](#)). A growing literature has also shared learning and recommendations regarding, not exhaustively:

- Gypsy, Roma and Traveller communities ([Condon et al. 2019](#))
- People with physical disabilities ([Rios et al. 2016](#); [Young and Hunt 2011](#))
- People with intellectual disabilities ([Frankena et al. 2019](#); [Bigby et al. 2014](#))
- Transgender people ([Vincent 2018](#); [Owen-Smith et al. 2016](#))
- Socio-economically deprived populations ([Bonevski et al. 2014](#); [McMillan et al. 2009](#))
- Older people ([McMurdo et al. 2011](#); [Zermansky et al. 2007](#))

Useful resources include the Centre for BME Health's (2018) [toolkit](#) for increasing the participation of Black, Asian and minority ethnic communities in health and social care research and the [INCLUDE Ethnicity Framework](#). These resources highlight the importance of tailoring approaches to including different communities, through being aware of different linguistic, communication and practical needs, and differing levels of health literacy and awareness of health and social care research. They also emphasise the importance of building trust, developing reciprocal relationships, and developing strong links with relevant gatekeepers and community organisations.

Language and communication are key issues. There are significant scientific limitations as well as health equity issues if you exclude prospective participants who cannot give informed consent in English. Often, therefore, it will be necessary to allow sufficient budget and time for translation of written materials and/or for the use of interpreters. There are various issues to consider with translation and the use of interpreters, whether for translating outcome measures, seeking informed consent or conducting qualitative interviews via an interpreter ([Patel et al. 2016](#); [Vickers et al. 2012](#);

[Lloyd et al. 2008](#); [Squires 2008](#)). Many terms cannot be directly translated, and it should not be assumed that all prospective participants will be literate. Also, some communities will respond more positively to different recruitment strategies, such as being verbally briefed through a more personal approach, rather than being sent a written invitation.

Barriers related to communication are not unique to minority ethnic communities. Wider questions need to be asked about how accessible your research is to those with poor literacy, and those who do not have easy or any access to the internet. If prospective participants need to have an email address in order to be recruited, whose voices and experiences will be omitted? Can opportunities to participate be communicated in other ways?

Researchers need to have good cultural awareness and knowledge e.g. being familiar with common foods that are eaten within different ethnic communities in research that asks questions about diet, as [Prinjha et al. \(2020\)](#) advise. Some research topics or questions might be culturally, religiously or politically sensitive amongst different communities. Medical conditions, treatments, social care needs and healthcare experiences that researchers may feel very at ease with discussing may be very controversial or offensive to tackle without first building sufficient trust and understanding (e.g. [Culley et al. 2007](#) in relation to South Asian communities and infertility). Other issues to consider are whether participants would prefer to engage with researchers who are either from inside or outside of their communities ([Vickers et al. 2012](#)), and for data collection activities to be differentiated by sex, age or faith ([Centre for BME Health 2018](#)). Early patient and public involvement is essential to guide your decisions.

Physical accessibility also requires consideration. How far will participants have to travel to take part in the study, and what support is being given to those to who live in rural areas, who have disabilities, or who are carers? Is it possible for some testing or follow-up monitoring to take place in general practices or other community facilities or remotely, rather than in hospitals? Are participants able to choose from a range of times to attend appointments for either the intervention or data collection to fit around work, care commitments and the availability of informal carers? Thinking through these issues at the design stage is critical because they may have budgetary implications.

Alternatively, it might be necessary to consider whether conventional methods are going to be most effective for the population(s) that you are studying. When trying to reach a community that feels disempowered, under-valued or misrepresented by health and social care professionals and researchers, a participatory approaches such as participatory action research may help to redress power imbalances and share knowledge and skills ([Baum et al. 2006](#); [Cargo and Mercer 2008](#)). Conventional methods such as questionnaires, interviews and focus groups may not be very accessible to those with poor literacy, social anxiety or cognitive impairment ([Fearon 2019](#); [Phillipson and Hammond 2018](#)). More novel approaches such as photovoice ([Drainoni et al. 2019](#); [Cluley 2017](#)), photo elicitation interviews ([Fearon 2019](#)) or arts-based methods ([Bird 2017](#); [Coemans and Hannes 2017](#)) may be more appealing, can offer multi-sensory insights, and may be a less threatening means of exploring sensitive topics.

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Data Analysis

- **How will you report on protected characteristics?**
- **What intersections of characteristics will you analyse?**
- **Has diverse PPI been incorporated to support the interpretation of results?**

In any research project you will have a main analysis which will be carried out on your research sample. Statistics on participant characteristics (demographics) are obtained from your sample to describe your target population e.g. age, gender and ethnicity. Your research sample should reflect the population that you want to implement the research findings on. This might not necessarily reflect the whole of the UK e.g. your disease area or social care need might be more common in older people such as Chronic Obstructive Pulmonary Disease (COPD) or Parkinson's Disease.

Within your sample there may be effects that are dependent on demographics that can be examined. We can test these formally through interaction effects in statistical analysis, but these are often underpowered due to not being statistically considered for such analysis. This means that minority groups typically become indistinguishable from the majority in statistical analysis, and the experiences, attitudes and/or results of majority groups conceal the nuances between groups. This often occurs in relation to sexuality, as has been illustrated in relation to research on domestic violence ([Donovan and Barnes 2019](#)) and differences in outcomes of donor intrauterine insemination and assisted reproductive technology treatments ([Tarin et al. 2015](#)).

We can however examine the results through a sensitivity analysis within each demographic group, whatever the amount of people in them, to see if it is similar to the whole sample without any formal testing to see if any heterogeneity between groups of characteristics can be seen or implied all be it non significantly for low amounts of groups. This sensitivity analysis can be applied to any research, either quantitative or qualitative, and should routinely be carried out to determine how the whole population respond to interventions or themes so that research can be adapted for different groups of people with similar characteristics.

If we take clinical trials, for example, a study showed that the most commonly used drugs have been tested on samples that under-represented minority ethnic groups ([Hussain-Gambles 2003](#)), leading to repercussions regarding the safety and the efficacy of the drug use in minority ethnic groups. This highlights how important it is to increase diversity in trials ([Clark 2019](#)).

The NIHR have now made it compulsory to include reporting on protected characteristics in your application ([NIHR 2020](#)), but best practice would be to extend this to analyse intersections between protected characteristics. Differences within groups can be starker than differences between groups, and intersectionality ([Crenshaw 2016](#)) draws our attention to how being, for example, Black African and gay, or Pakistani, older and female, may lead to very different experiences of health and social care compared to studying those identities in isolation.

With qualitative data analysis, it is important to reflect on your codes and themes as they emerge, and consider whether these resonate with the different groups in your sample, or whether some speak more to particular groups than others. Acknowledging negative cases which contradict dominant findings is a key aspect of robust qualitative data analysis and writing up ([Patton 1999](#)), but it is also important interrogate whether there are any patterns in the data that are pertinent to EDI. For

example, it might be that most participants spoke positively about their experiences of a new health or social care service, but what about those who were negative or ambivalent? Did they have any protected or other characteristics that need to be acknowledged and that might highlight an intervention that is not sufficiently inclusive, or the need for further research about a sub-group's needs? Particularly with thematic analysis, it is important not to be so focused on specific themes that you become detached from wider contextual factors such as participants' age, gender, ethnicity or disabilities and their related experiences of structural and health inequalities. It is also valuable to ensure not only that more than one person is involved in the coding and generation of themes, but also that these researchers occupy different social positions and therefore will look at the data from a range of vantage points. Practising reflexivity (Probst 2015) is key to recognising how your own identity, lived experience and values might affect your analytical decisions and interpretations.

Related to the need to incorporate a breadth of perspectives and experience, it is vital to involve your PPI members, who should bring diversity of experiences and identities (INVOLVE 2012), in your data analysis. In some studies, PPI members could be involved in the analysis – for example, identifying themes and coding qualitative interviews. At the very least, results should be presented to your PPI members in order to make sure that the conclusions gathered are not influenced by the research team's unconscious bias, but reflect the data being seen.

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Data Presentation

- **How will you describe participants' protected characteristics?**
- **How will you preserve the anonymity of people from minority groups?**

People often describe other people in relation to themselves, and this can result in people who are often the objects of research being described in ways which may not accurately reflect their identities and experiences. When reporting participants' protected characteristics, what language will you use? Who came up with these names/categories? Did the people you're describing have a say in what they are called?

Terms to describe people's identities are constantly evolving, meaning that terms which may at one point have been acceptable or analytically convenient may now be considered offensive. The term BAME, standing for Black, Asian or Minority Ethnic is increasingly being rejected by those to whom it is applied ([Fakim et al. 2020](#)), ([Inc Arts UK. 2020](#)), with criticism being directed to its tendency to clump together people who were considered to be or identify as non-white. This is sometimes done in order to gain statistical power by merging existing smaller groups into one big group or to summarise results more concisely. However, the communities which 'BAME' refers to are far from homogeneous and sub-categories of characteristics should not be clumped together where possible.

We should ask ourselves what are we hoping to determine when presenting data on protected characteristics or differences between protected characteristics? Data on protected characteristics might be used to highlight:

- Differences in social determinants of health e.g. institutional racism's effect on health outcomes
- Genetic differences contributing to health differences e.g. impact of different genes to blood pressure (although genetic differences are usually higher within race categories rather than between them ([Egede 2006](#)), so it might be better to use actual genetic information rather than race categories).
- Physiological differences that have different risk factors for diseases e.g. relationship between skin colour and skin cancer.
- Different attitudes to health care, e.g. some religious attitudes to divine protection from disease, or fatalism.
- Different behaviours that could lead to different health outcomes, e.g. different sexual practices within protected characteristics and risk of HIV infection.

You should check with a diverse group of people with the characteristics being researched to determine how to name categories, whether it be ethnicity, gender, sexuality, disability, or living with a health condition. However, you should also be prepared for challenges in arriving at a consensus: views among populations who share a protected characteristic can be varied and what may be acceptable to some individuals may be considered offensive by others (e.g. [Vincent, 2018](#) in relation to transgender and non-binary gender identities).

When reporting statistics, creating graphs or presenting interview excerpts for people from minority groups, it is important that participants cannot be identified. These risks are amplified when we report

participants' intersecting identities. For example, if we quote from an interview with someone who identifies as a Black woman with a physical disability, this might only describe one or two participants in the sample. Recognising intersectionality is important as different intersections of characteristics have different experiences ([Crenshaw 2016, TEDTalk](#)), but it is clear to see that if this data were made public, it could identify people in the data. This also applies to intersectional statistics. A good rule of thumb is if a table entry has less than five people in it then state ≤ 5 for the number and not the actual count. For a list of possible identifying variables see ([Hrynaszkiewicz et al. 2010](#)). For good practice in sharing data see the [UKRI guidance on best practice in the management of research data](#).

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Dissemination and Implementation

- Will findings be disseminated via accessible and inclusive formats and channels?
- How will this research be taken forward to benefit all patients/service users?
- Does the research/intervention work across all settings? E.g. rural/urban

The [NIHR Mission](#) is to improve the health and wealth of the nation through research. To achieve this at scale, clear plans need to be in place to share the findings and outputs of the research as widely as possible, through **dissemination**. Secondly, there is a need to map out the steps to upscaling an intervention or translating knowledge and practical guidance into practice, through **implementation**.

Dissemination is needed to communicate the key messages of the research to as wide an audience as possible. This can include academic papers to an academic audience, but also executive summaries, lay summaries, infographics, videos and blogs. By using varied formats and media and budgeting for translation into different languages, your results can reach further and influence people who have either been disillusioned with research or have had little opportunity to engage with it.

It is particularly important that you explain in your proposal how you will take the research findings back to the communities who have been involved, as public contributors or participants, and outline the next steps to them. This is key to sustaining relationships and ensuring that under-served communities are not left feeling shut out of the outcomes of the research and that their trust and good will has been exploited. Depending on who has been involved in your research, you may need to consider:

- easy read formats for people with learning disabilities (for example, [NIHR 2021](#))
- accessible formats for people with visual impairments (see [AbilityNet](#) guidance)
- audio/video formats for people with poor literacy
- more engaging and innovative outputs for children and young people (see [Egli et al. 2019](#); [example animation](#) developed with young people from the NIHR Blood and Transplant Research Unit, UCL; the use of theatre in the NIHR-funded [BRIGHTLIGHT project](#))

Making plans for implementation, and research about implementation, is key to ensuring that your study has a credible and prompt pathway to benefits for patients, service users and/or NHS or social care services. Often, research is carried out to extract how effective an intervention is and is often carried out on a small, homogeneous sample. If successful, the implementation stage will see this intervention being applied to a much bigger population that is heterogeneous and this population might not reflect the original research sample.

Implementation studies will usually have outcomes which measure both effectiveness of the research/intervention/tool and effectiveness of the implementation ([Proctor et al. 2010](#)). Some form the implementation studies as having two primary outcomes; one effectiveness and the other, implementation. Researchers often concentrate on the effectiveness of the intervention and delay considering implementation until much later, by which time the population that the intervention has been tested on could be quite narrow. This then jeopardises the likelihood of the intervention improving the health and wealth of all of the nation. For example, if up until this point the research

has only been conducted with English-speaking participants, or only at urban sites with good hospital/university links ([Smith et al 2016](#)) or with people under 65 ([Bourgeois et al. 2017](#)), then the research could be contributing to health inequalities and not addressing where the need is most. A good example of an implementation study is IMP2ART ([Pinnock and Taylor 2018](#)) which stands for Implementing Improved Asthma self-management as Routine. It involves both implementation across diverse general practices as well as patients' asthma action plans being made available in multiple languages, allowing non-English speakers to engage with the implementation.

By not including a diverse group of people in the research from the beginning of the application, we can encounter significant and sometimes insurmountable problems in implementation later on. This can diminish the impact of the research and can even increase health inequalities. Diverse voices through either PPI or the research team need to be heard and acted upon in order to make research the most effective for everyone when it comes to implementation. The [INCLUDE](#) guidance is an informative guide as to which stages these conversations could take place to create more inclusive health research from early on in application development.

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