



Improving inclusion in health and care research:

reflections and next steps

Report co-developed by steering group members from:




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1 Introduction

Research has a vital role to play in addressing the stark health inequalities that are evident across the health and care system.^{1,2} But research has its own problems of exclusion, bias and discrimination that need to be addressed.

Last year, Health Services Research UK (HSR UK) came together with the Health Foundation, the Nuffield Trust and The King's Fund to develop a series of online events that would open up a discussion about inclusion in health and care research. The events were free to participants and were funded by the Health Foundation.

Through these events we aimed to showcase people, projects and organisations using inclusive and innovative approaches, and share ways we can move existing practice forward. We also sought to highlight the barriers to inclusion and consider how they can be tackled within research projects, organisations (particularly funding

organisations) and at a system level. By bringing together a wide range of people, including those with lived experience, we hoped to better understand the actions needed to bring about meaningful improvements for everyone involved in and affected by health and care research.

In this report we share some of the key issues that were raised during the events, by presenters and participants. We also reflect on what we've learned from holding them, and what we might do differently next time. It's aimed at anyone with an interest in making research more inclusive, including patients, service users, and the public, researchers, and research funders.

¹Race and Health Observatory (2022), Ethnic Inequalities in Healthcare: A Rapid Evidence Review: www.nhsrho.org/publications/ethnic-inequalities-in-healthcare-a-rapid-evidence-review

²Institute of Health Equity, Health Equity in England (2020): The Marmot Review 10 Years On: www.health.org.uk/publications/reports/the-marmot-review-10-years-on

1.1 Background

The project was sponsored by the Health Foundation, and the team at HSR UK led its delivery. A steering group, made up of representatives from each of the four organisations and two members of the Health Foundation's Inclusion Panel³, gave input and made decisions about the focus and format of the events, including how to make them as inclusive as possible. A list of steering group members can be found in annex A.

In Autumn 2021 we held three online events of around 90 minutes each:



We promoted the events widely, including on Twitter (#InclusionHCR) and to the HSR UK mailing list, as well as through other networks and organisations, such as National Voices.

Around 50 people attended each event, which included presentations from invited speakers and either one or two breakout sessions to allow discussion in small groups. We ended each event by bringing points made in individual breakout rooms to the wider group of attendees and speakers for comment and reflection.

³Further details about the Inclusion Panel are available at:
www.health.org.uk/about-the-health-foundation/inclusion-panel

2 What does a more inclusive research system look like?

In our first event, Dr Ghazala Mir (University of Leeds) spoke about the importance of addressing social exclusion at the different levels in which it is created and maintained, for example the macro (socio-political or economic), meso (institutional or practice) and micro level (individual).

Yet in reality, she pointed out, they are not easily separated, with dynamics at each level reinforcing the others. Similarly, our events each had a different scope but we heard how the same challenges reverberate from the funding system down to individual projects.

Here are some of the key points made by speakers and participants about how we can challenge barriers to accessing, conducting and participating in research and foster a research system that is genuinely inclusive. It is not an attempt to represent the entirety of the discussions or opinions expressed which, as you would expect, were nuanced and not always in agreement. They also only reflect the views of those who were in the room during each event – mainly researchers and others in related roles, and predominantly people from majority groups. Links to speakers' presentations are listed in annex B and we encourage you to watch them back to hear them in their own words.

1. Community involvement, from start to finish

- Patients, services users, and the communities affected by research should have opportunities for involvement at every stage; from setting priorities and questions to data collection, analysis and dissemination. They should also get to find out what difference the research made.
- Radoš Keravica (University of Leeds) spoke about working with a Youth Research Advisory Board of young disabled people from different countries. The group helped to refine the research questions, methodology and data collection tools, and interpret data, for a project about how disabled children participate in decisions related to their health.
- Linking up with community partners, faith groups and others can be a good way of ensuring reach and meaningful participation. But these groups are often underfunded and researchers need to be mindful when using them as gatekeepers.
- Dr Darren Miguel Sharpe (UEL) highlighted the ethical importance of joining up evidence and mapping what other research is taking place within the community to avoid saturation, duplication and repetition.

2. A secure, valued and diverse research workforce

- Diversity in research teams can help to increase the range of research topics that organisations address and strengthen awareness of issues related to inclusion/exclusion in research, as well as improve interpretation of findings and engender trust between researchers and those taking part in research. Committing to developing diverse research teams can also help to address inequalities that exist within the research workforce.
- There is a paucity of senior Black researchers in the UK². Research careers should be promoted to Black heritage young people in secondary schools and Further Education colleges. Having existing role models who may have similar life experiences could help Black students to see research as an attainable career for them.
- Dr Addy Adelaine (**Ladders4Action**) spoke about the invisibility of marginalised academics, even within projects on diversity, equity and inclusion, and the need for us to recognise and draw on the large body of academic and community led research that already exists in this area (e.g. #CiteBlackWomen).
- She also highlighted the harmful impact of casualised labour and the majority of Black and minority ethnic academics on zero hours contracts, which inhibits people from applying for funding.

3. Recognition that lived experience doesn't exist 'out there'

- Lived experience and scholarship are both valuable – but, as Dr Adelaine pointed out, they are not mutually exclusive and we often talk about them as if they are.
- Researchers with lived experience bring valuable insights to their work.
- Dr Lilian Hunt (**EDIS**) described the research system as a web with experience expertise and research expertise overlapping and interconnected. We should focus on who's doing the research, who's involved in the research and who's benefiting from the research at the same time. Paying attention to these aspects of our research design and delivery can also make us aware of who is not in the room but should be.

4. Different ways to take part, on- and offline

- Online participation can make it easier for some people to take part but those without easy access to devices or the internet can become excluded. It's best to offer a choice.
- Oli Jones (**McPin Foundation**) spoke about engaging young people in mental health research, and the importance of being flexible and adaptable. For example, WhatsApp, voice notes and Mentimeter can be used alongside 'old school' ways of engaging people like postcards and newsletters.
- Shahid Muhammad (Coventry University) provided perspectives on behalf of the **Renal Patient Support Group (RPSG)**, which has an established online space and links across several social media platforms to offer nephrology clinicians, allied health professionals, patients and carers a way to share experiences and integrate between chronic kidney disease (CKD) awareness and research.

⁴Leading Routes (2019), The Broken Pipeline: Barriers to Black PhD students accessing research council funding: <https://leadingroutes.org/the-broken-pipeline>

2. What does a more inclusive research system look like?

5. Support for researchers and patients and public contributors

- Many of the researchers who attended said they would like ongoing training and skills in inclusive research – and time and space to reflect on their practice.
- There should be two-way learning, for researchers and communities to meet in the middle.
- Checklists and equality impact assessments (such as the ARC East Midlands EIA, discussed by Professor Niro Siriwardena) provide a way to systematically think through how your project could be more inclusive. But some cautioned against turning patient and public involvement into a 'tick box' method.
- There is a lack of understanding of what co-production is, but the principles and core values that underpin it can and should be used across the research system, said Niccola Hutchinson-Pascal (**Co-Production Collective**). Co-production is not a way of doing, but a way of being.
- Patient and service-user researchers will also need help and support, as Lynn Laidlaw (Patient Co-Investigator) experienced with the project **COVID Shielding Voices**.
- Research teams should find ways of valuing the input of patient researchers - for instance as named contributors on publications - while recognising the responsibilities of the team to assure the scientific integrity of outputs.

6. Diligent collection and use of ethnicity data

- As Dr Rohini Mathur (LSHTM) explained, ethnicity data can be a lens to understand who is and isn't included in research (with systematic biases in those who don't attend services or don't complete records, such as the homeless or asylum seekers), the needs and priorities of different groups, and disparities in outcomes – but there are important considerations for researchers.
- Dr Sarah Scobie (Nuffield Trust) highlighted the varying quality and completeness of different English health service data sets. Researchers should use the most granular data available and be aware of how gaps and biases in ethnic coding might affect analysis – and consider methods to redress this.
- Consistent data collection at source by NHS-funded organisations, using census 2021 categories, is needed.⁵

7. Organisational buy-in and visibility

- Senior buy in and oversight is essential to model the importance of inclusive research and recognise the efforts needed to make it happen- but culture change is hard.
- Dr Sharpe, who co-designed and co-delivered the Young Commissioners model in Newham, gave examples of how it's possible to work with the system, to bend it to your needs. Linking your project to an organisation's strategy and metrics can help improve sustainability, governance and visibility, and build support for your project.
- Training for the people in the system (like commissioners and health professionals) is also essential to build capacity (see www.arc-nt.nihr.ac.uk/media/st2psodj/how-to-guide-young-commissioners.pdf for guidance on the Young Commissioners model).

⁵The Nuffield Trust (2021) Ethnicity coding in English health service datasets: www.nuffieldtrust.org.uk/research/ethnicity-coding-in-english-health-service-datasets#key-points

8. Organisations taking responsibility for what they can change

- Dr Hunt described the different levers that organisations can pull depending on where they are in the system. Cross-sector collaboration is essential to create system-wide change.
- Funders have enormous leverage and influence. Dr Neha Issar-Brown (**Versus Arthritis**) shared her charity's pledge that it 'will not fund research [...] which is not informed by the needs of people with arthritis and/or does not involve them meaningfully, across all stages of research'.⁶

9. Redistribution of power

- Dr Adelaine spoke about how discrimination and inequity comes from imbalances of power, which can manifest in ways that may be overt, hidden or invisible. For example, overt distortions of power are evident in the research system when you look at who does/ does not get research council funding. While 15% of academic staff come from ethnic minorities, according to UKRI's detailed ethnicity data just 1% of Principal Investigators identified as Black.
- As Lynn Laidlaw concluded, those with power need to be willing to share and cede it. We need to be better at having conversations about who holds power, who doesn't and how can we address it in a hierarchical system.

10. Fair and transparent funding

- Funding applications are time consuming, and often not designed with non-academic applicants in mind.
- Funders should collect (and publish) detailed data about who and what projects get funded. The publication in December 2021 by NIHR of its first year of auditing diversity of applicants, successful awards and funding committees was a welcome move in this direction.⁷
- Some participants questioned whether community and patient-researcher led projects are truly valued by funders. Dorothy Gould (Lived Experience Researcher) shared varying experiences of conducting user-led research including the positive (e.g., the **Keeping Control project** exploring mental health service users' experience of targeted and violent abuse in social care) to the painful and demoralising, with funders calling a project's quality into question when findings were unexpected and challenging. Researchers without user experience are also shaped by their life experiences, including professional training, and are just as subject to bias.
- Professor Judith Smith (NIHR Health & Social Care Delivery Research Programme) gave examples of how the HSDR programme is being more attentive to inclusion and equity– such as increasing the diversity of committees, conducting regular analysis of who bids and is funded, topics funded, where research is carried out, and methods proposed and used. She also gave examples of priority setting with patients, users of social care, and health and care staff, through deliberative processes.

⁶Versus Arthritis (2022), Better Lives Today, Better Lives Tomorrow: Research Strategy p.44: www.flipsnack.com/BC857F5BDC9/j0923-researchstrategy-flipsnack/full-view.html

⁷NIHR Diversity Data Report 2020/21: www.nihr.ac.uk/documents/diversity-data-report-202021/29410

2. What does a more inclusive research system look like?

11. Fully resourced patient and public involvement

- Patient, carer and public involvement needs to be fully resourced and funded from the start, before bids are approved, allowing for relationships to be built over time and paying attention to under-served populations or groups. Research timeframes and funder expectations are often incompatible with this.
- Patient and public contributors must be fairly paid and rewarded otherwise only those who can afford it will be able to take part, as Lynn Laidlaw pointed out.
- Costs may not just cover the time of those directly undertaking the research. For the COVID Shielding Voices project, the team funded interpreters and a patient advisory group to bring in more patients' points of view.

12. Proportionate and flexible research governance and ethics processes

- Rigid, bureaucratic systems can be intimidating and inaccessible.
- Research governance and ethics systems can discourage incremental, co-produced research, for example, small tweaks to materials requiring sign off, or patient information sheets and other resources for ethical approval needing to be produced in advance, meaning they are unlikely to have been co-designed with public partners.
- There's a need for great flexibility and proportionality - HSR UK's **Making Research Work Better** report explores this more fully.

3

Some reflections

Planning and delivering this series of events has highlighted how much more we need to learn and do, as individuals and as part of larger organisations, to improve inclusion within our practices and systems. Actions range from the projects we develop to improving organisational cultures. Below we share some reflections from our experience that may be applicable to others hoping to develop more equitable and inclusive practices within their part of the health services research system:

- As a steering group we didn't dedicate enough time getting to know one another as people, not just the organisations we represent, all with our own perspectives and experiences. Knowing each other better in this way would have helped everyone feel more comfortable to be honest and challenging and understand where we're each coming from a bit better. This links through to the wider themes in the workshops about lived experience not being 'out there' and also rebalancing power.
- It was invaluable to have patient, carer and public representatives on the steering group. They advocated for patients and the public to be considered in all aspects of the event including the topics presented and discussed, the language we used, speakers we invited, and how attendees participated. They also encouraged greater diversity of speakers including Black academics and young people.
- We decided not to directly explore inclusion in research careers as we felt we couldn't do this justice in the time available, but it was difficult to separate out from the other issues being discussed, and it's an area worthy of further exploration.
- In feedback, people said they valued hearing and learning from others, and being able to talk openly. But we are all at different stages in this journey and some are still quite new to these conversations.
- At the same time, it is difficult for those with more advanced understanding of inclusive theory and practice, who have been speaking out on these issues for years to re-tread old ground without addressing deeper rooted causes of injustice, racism, ableism, etc.

3. Some reflections

- As organisations we are still developing our understanding of these issues yet we hold considerable power to influence and change things. In recognition of this, we invited a co-chair with a patient perspective for the final event on research funding.

- The mix of participants was only as diverse as our reach - we made an effort to promote the events to patients, care users and public groups, and to marginalised academics, but the make up of the audience reflected that our main audience is predominantly researchers and others employed by institutions and funders.

- At times there was conflation of inclusive research and user-led research – there are interesting and overlapping debates on these topics but some of the issues probably need to remain distinct.

- It was useful to adapt a framework for working together (see annex C) that set out our expectations for participation– and some speakers asked about these measures before agreeing to attend.

- When using job and academic titles in events it's best to ask what people want - don't assume that by not using them it will mean greater inclusion. Using academic titles can be a way for us to acknowledge expertise and rebalance power.

- We allowed for different levels of participant contribution - some want to speak, others want to listen and not be put on the spot – we discussed this carefully with breakout session facilitators (members of the steering group) to help participants feel comfortable, and it seemed to work well.

- For each event, we felt it was important to include a range of speakers' perspectives as well as in-depth breakout discussions. We also wanted to make them short enough that people would have time to attend and not have to spend too long looking at a screen. Around 90 minutes felt right for these events but it meant that speakers had only a short slot to give their presentations, and there was a limited time for discussion in plenary.

3.1 What we would do differently

- Start as we mean to go on and make time to get to know each other on a personal and professional level, to highlight the different perspectives we brought and where there were gaps.

- Develop the timeline to reflect the additional time needed to achieve this and to address any uneven power dynamics within the group as a way to embed an ethos of inclusion and equity in our practices from the start.

- Acknowledge people's different levels of knowledge and experience with these issues and involve experts in EDI in developing the events.

- Include experts by experience on the Steering Group from the outset (it took a couple of months to bring on board representatives from the Inclusion Panel, so they missed out on early conversations and had to 'catch up').

- Intentionally include academics from marginalised communities in the steering group- this would have brought in valuable perspectives

- Be more explicit with participants and attendees about the areas we were and weren't focussing on.

- Include co-chairs with lived experience in all events so that conversations were not led by the host organisations.

- Create reading lists and signpost resources to acknowledge existing work on improving inclusion in research from academics, non-academics and those that straddle this boundary as scholar-activists. This would have helped to ground our activities in the literature and would also have provided important background for participants.

- Let participants know in advance that there will be breakout, give people time to prepare so they are able to participate fully. We only began to do this after the first event following feedback from a participant. Moving forward we would make this standard practice.

- Do more to encourage a wider and more diverse audience, through existing networks and proactive outreach, particularly to marginalised groups whose voices are integral for improving inclusion.

- Develop a more comprehensive plan around evaluation. Although we did share evaluation forms at the end of each event, more could have been done to ensure higher uptake and consideration given to how we could meaningfully use feedback given in future events.

- Take more time to discuss the framework for working together at the beginning of each event- think about who is responsible for holding participants to account, and how they will do this. It should not fall to the minority individuals in the room.

4 What next



plans to focus on supporting people from marginalised groups in health services research careers through an annual mentoring programme and other initiatives. We will also be recognising inclusive health services research presented at our annual conference, with a new award.



have used learning from these events, as well as other activities, to develop an improving inclusion strategy for the research they fund

Mandy Rudczenko said
"Reflecting on my involvement with the steering group, my main recommendation for improving inclusion in health and care research is for all stakeholders to begin any project by asking: who are we leaving out?"

Gilly Anglin-Jarrett adds to this
"and why?"



has begun to enhance its project planning process by asking explicit questions such as:

- Who are the stakeholders for this project and what is their interest or focus?
- who will benefit from the research;
- who should be involved;
- whose views do we need to hear;

when designing research projects, with a specific intention of addressing the interests and needs of marginalised groups. There is more we need to do to make our strategic thinking more inclusive, and the learning from these events will be invaluable in this and in helping us think about our approach to recruiting and developing researchers.



will use the learning from the improving inclusion events to support our commitment to ensuring that our work and the voices we feature represent the communities we serve and the wider world around us. We will share the learning from the events and the principles identified with staff, and we will use it to design training for all members of staff whose roles involve planning and carrying out research.

5 Annex

A. Steering group members

Hardeep Aiden (The Health Foundation)
Gilly Anglin-Jarrett (Inclusion Panel member)
Rokia Ballo – she/her (Project Officer, HSR UK; Co-chair, Science London)
Helen Buckingham (The Nuffield Trust)
Deborah Fenney (The King’s Fund)
Tara Lamont (HSR UK)
Helen Mthiyane – she/her (Executive Officer, HSR UK)
Diane Redfern-Tofts (The Health Foundation)
Mandy Rudczenko (Inclusion Panel member)
Helen Snooks (HSR UK)

B. Speakers and links to recorded presentations

Event one, 14 September 2021, The Project Level:
Oli Jones, Peer Researcher and Public Involvement in Research Officer, McPin Foundation
Radoš Keravica, Doctoral Candidate, Centre for Disability Studies, University of Leeds
Ms Lynn Laidlaw, Patient Co investigator, COVID Shielding Voices; Centre for Epidemiology Versus Arthritis, The University of Manchester
Dr Rohini Mathur, Associate Professor of Epidemiology, London School of Hygiene and Tropical Medicine
Dr Ghazala Mir, Associate Professor and Chair of the Inequalities Research Network, University of Leeds
Professor Niro Siriwardena, Professor of Primary & Pre-Hospital Health Care and Director of the Community and Health Research Unit, University of Lincoln
Event two, 5 October 2021, The System Level:
Dr Lilian Hunt (they/them), Equality Diversity and Inclusion in Science and Health (EDIS) Lead, Wellcome Trust
Ms Niccola Hutchinson-Pascal, Co-Production Collective
Mr Shahid Muhammad, Academic and Scientist for the Renal Patient Support Group (RPSG)
Dr Sarah Scobie, Deputy Director of Research, The Nuffield Trust
Dr Darren Miguel Sharpe, Senior Research Fellow and Deputy Director at the Institute for Connected Communities, UEL
Event three, 2 November 2021, Inclusion in Research Funding:
Dr Addy Adelaine, CEO, Ladders4Action
Ms Dorothy Gould, Lived Experience Researcher
Dr Neha Issar-Brown, Head of Research, Versus Arthritis
Professor Judith Smith, Deputy Director, Health Services and Delivery Research (HS&DR) Programme, NIHR (pre-recorded and edited by HSR UK to fit the time allowed, due to Professor Smith being ill on the day of the event)
Thanks also to the Co-Chair for this session, Sandra Jayacodi, Public Contributor and Lay Chair, Imperial Biomedical Research Centre

C. Framework for working together

This framework for working together has been developed by the project steering group as a reflection of our values. Our hope is that if we all agree to follow these suggestions, the event will provide a welcoming space for open and productive discussion.

- All attendees, speakers and organisers have the right to feel comfortable and safe whilst taking part - discriminatory language or harassment will not be tolerated.
- Treat each other's names respectfully. If you are unsure how to pronounce someone's name, please ask.
- Everyone is encouraged to include their pronouns in their Zoom name, unless they are unable or do not feel comfortable doing so. Respect the pronouns of other attendees and do not take it personally if you are corrected.
- Be aware of the space you occupy and power imbalances– this means letting others speak and not interrupting.
- Listen with empathy, give feedback with care and challenge constructively.
- Feel free to take breaks throughout the session outside of the one provided to take care of your needs. We understand that home working comes with interruptions and many people are living with dependents.
- We welcome your engagement on Twitter during and after the event (#InclusionHCR), but please do not share any personal experiences or comments that could be attributed to an attendee, without their permission.

Good to know

Speakers' talks will be recorded and shared publicly after the event but other discussions, including in the breakout rooms will not be recorded. Automated closed captions will be available during the event and slides are available in advance. Participation in the breakout discussions is optional - you are welcome to listen only, if you prefer.

If there is anything else we could do to make the event more accessible or inclusive, please let us know. We are learning ourselves and we appreciate your help in making improvements.

Contact

If an issue arises during the event relating to either this framework, or any other inclusion or accessibility issue please contact Helen Mthiyane or Rokia Ballo at HSR UK by email (info@hsruk.org), or through the Chat function, and we will respond as soon as possible.

This framework has been adapted from a document developed by Science London.



is a self-supporting membership organisation dedicated to the promotion of health services research in policy and practice. The collective voice of UK health services research, we connect researchers with health service leaders, managers and clinicians to drive improvement and innovation in the NHS and care system.



is an independent charity committed to bringing about better health and health care for people in the UK.

In 2020 we set up an Inclusion Panel so that people whose views and experiences are not considered enough in planning, delivering and supporting health and social care research have opportunities to influence these processes and the outcomes of the research. Panel members come from all parts of the UK and have a wide range of lived expertise, knowledge and skills. The panel encourages staff and grant holders to address inequality and inclusion issues in their work better by:

- advising on the right questions to ask
- helping them interpret their results
- advising on how to share results with diverse stakeholders to better create change
- identifying areas for research.

nuffieldtrust

is an independent health think tank. We aim to improve the quality of health care in the UK by providing evidence-based research and policy analysis and informing and generating debate.

TheKingsFund

is an independent charitable organisation working to improve health and care in England. Our vision is that the best possible health and care is available to all.

**Thank you to everyone
who attended these
events and contributed
so fully, in particular the
participants, speakers,
and our co-chair
for the final event**



The voice of UK
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Research

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