


Implementing the NIHR Oxford Health BRC's Equality, Diversity and Inclusion Strategy

A mapping and scoping project

April 2024





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Cite as: Public Mental Health Implementation Centre. Implementing the NIHR Oxford Health BRC's Equality, Diversity and Inclusion Strategy: A mapping and scoping project. London: Public Mental Health Implementation Centre; 2024.

List of abbreviations

Abbreviation	Description
Athena SWAN	Athena Scientific Women's Academic Network
BRC	Biomedical Research Centre
EDI	Equality, diversity and inclusion
GDPR	General Data Protection Regulation
HE	Higher education
INCLUDE	Innovations in Clinical Trial Design and Delivery for the Under-served
MHSDS	Mental Health Services Data Set
LGBTQIA+	Lesbian, gay, bisexual, trans, queer, questioning, intersex, asexual plus
NCCMH	National Collaborating Centre for Mental Health
NIHR	National Institute for Health and Care Research
PCREF	Patient and Carer Race Equality Framework
PMHIC	Public Mental Health Implementation Centre
PPIEP	Patient and public involvement, engagement and participation
SPB	Strategic Partnerships Board
WDES	Workforce Disability Equality Standard

Executive summary

Background

The National Institute for Health and Care Research (NIHR) Oxford Health Biomedical Research Centre (BRC) published its first equality, diversity and inclusion (EDI) strategy in 2023. This 5-year strategy aims to establish and enhance the evidence base for EDI, including data collection processes to enhance the diversity of research participants and the workforce.

The NIHR has started to collect protected characteristics data from applicants for research funding. Although the collection of the data is optional, it could become mandatory in the future.

At the Public Mental Health Implementation Centre (PMHIC), we undertook a mapping and scoping project to provide Oxford Health BRC partners with insights into data collection for EDI purposes at the local level and identify any challenges and opportunities. This report also proposes solutions to overcoming possible ethical dilemmas, as well as enablers and barriers to implementing the BRC's EDI strategy.

Methods

We conducted semi-structured interviews with 12 representatives across ten associate partner sites of Oxford Health BRC. Interviews focused on topics including perceived barriers and enablers to implementing EDI strategies, how protected characteristics data are collected in local systems and perceptions of mandating the collection of this type of data.

Potential interviewees were identified by Oxford Health BRC's Strategic Partnership Board (SPB) members, and introduced to the PMHIC research team by the BRC. Interviews were conducted online between February and March 2024. All participants provided informed consent to take part.

Transcripts were generated using in-built Microsoft Teams software with transcripts checked for accuracy. Transcripts were analysed by thematic analysis.

Findings

Collaboration, adequate resourcing and communication were identified as enablers to implementing EDI strategies. Interviewees felt that EDI strategies must feel joined up and a shared responsibility across the whole workforce. Interviewees also shared how having dedicated resources for EDI (including staff, time and guidance) can encourage engagement among staff. This can include specific EDI training and support through mentoring and networking initiatives.

Communication on how EDI strategies are being implemented (for example, progress, challenges and achievements) was also seen as important. This could be through various communication channels, including among peers as well as 'top-down' approaches.

Communication was an important consideration when collecting data on protected characteristics; specifically, what the data is being collected for, who will have access to it and how it will be used. Co-production was found to be a vital part of implementing EDI strategies and collecting data on protected characteristics.

Recommendations

We recommend several next steps for NIHR, Oxford Health BRC and the partner organisations involved in the future implementation of the BRC's EDI strategy:

The NIHR

- Explain clearly why protected characteristics data must be collected and commission further research on the feasibility and acceptability of mandating this.

Oxford Health BRC

- Continue to strengthen the collaboration with associate partners.
- Share the findings of this mapping and scoping project and expand it to gather insights from patient and public partners and wider staff (at an appropriate time in the BRC tenure).

Partner organisations

- Encourage teams to attend networking initiatives and future workshops to address EDI and patient and public involvement, engagement and participation (PPIEP) strategies, and to build networks, learning circles and mentoring opportunities (if these are not already available).
- Engage more fully with the Oxford Health BRC at quarterly meetings of the Strategic Partnership Board, to collaborate more consistently across organisations.

The full list of recommendations can be found in the **Next steps** section.

Conclusions

Bringing together associate partners to provide clarity on Oxford Health BRC's EDI strategy and to align EDI efforts is crucial. Associate partners are still disconnected and would benefit from sharing opportunities, challenges and solutions with one another.

Collecting or accessing data on protected characteristics is a challenging and complex area, due to data protection regulations and differences in the systems and structures of organisations and sectors. There are also relational or behavioural responses that need to be considered if data collection becomes mandatory. For example, making sure information about decisions to share information is accessible and having a trusted relationship with those collecting the data. A co-production approach is therefore essential, particularly for building trust with marginalised communities who may have had harmful experiences in the past that may be related to sharing data.

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Introduction

The PMHIC^a was commissioned by the NIHR Oxford Health BRC to conduct a mapping and scoping project with key stakeholders, including partner and associate partner organisations. The project aimed to gather views on the implementation of Oxford Health BRC's EDI strategy, and to address specific issues including collecting or accessing data on protected characteristics.

This work is important as the NIHR has already started to collect applicant data on protected characteristics in their research funding systems. While this is not mandatory, it may become so in the future. Therefore, this project should give partners valuable insight into their local data collection for EDI purposes and identify enablers, barriers and solutions to any ethical dilemmas raised.

Equality, diversity and inclusion

EDI is a growing area of importance in research and organisational culture across sectors. EDI initiatives are developed to support people with a range of protected characteristics^b in the workplace and beyond. This may include making research opportunities more inclusive, highlighting equity gaps in open research and addressing barriers for participation, engagement and involvement in research.^{1,2}

Example of an EDI initiative: the Athena SWAN

The Athena Scientific Women's Academic Network (SWAN) Charter is an example of a global framework for a gender equality initiative in higher education (HE) and research. Athena SWAN aims to encourage and recognise the advancement of women's careers.³ In 2011, academic departments had to hold an Athena SWAN silver award to apply for funding from the NIHR (although this requirement was removed in 2020).⁴

Research has identified both positive and negative outcomes of mandating such initiatives.^{3,5} Henderson et al³ identified a positive reflection of creating a 'catalyst for change'; however, some viewed Athena SWAN as a 'box-ticking' exercise that required strong commitment by senior leadership to result in any sustainable change. Another study⁶ found respondents (nearly all male) suggesting that linking NIHR research funding to Athena SWAN status led to positive discrimination or a perceived unfair advantage towards women above men. There were also reflections that staff and students in more junior positions had benefited less than tenured academic staff.⁶

Collecting data on protected characteristics

One important way to measure success and develop improvements in EDI is by measuring and collecting data on protected characteristics. There are varied opinions

^a The PMHIC is hosted by the National Collaborating Centre for Mental Health (NCCMH), based at the Royal College of Psychiatrists.

^b See the **Glossary** for a definition of the Equality Act 2010 and a list of the protected characteristics.

on the monitoring and benchmarking of such data. Challenges related to gender equity and equality data include how to assign gender to data (for example, assuming gender incorrectly based on their name), issues whereby metrics are not routinely monitored and the importance of intersectionality of gender with other aspects of identity.³ Suggested recommendations include monitoring gender equity metrics at an organisational level to avoid identifying individuals, and monitoring BRC recruitment and retention by gender (for example, seniority of staff and gender).³

For research purposes

Data collection on how inclusive research studies are (for example, UK cancer trials) is challenging because it involves collecting protected characteristics data.⁴ The collection of data must comply with legal requirements including the General Data Protection Regulation (GDPR).^c According to GDPR,⁵ data subjects have the right:

- to be informed
- of access
- to rectification
- to erasure
- to restrict processing
- to data portability
- to object.

Using data to monitor EDI is also important in the broader research landscape including peer review processes and publishing.⁶

^c See the **Glossary** for a definition of GDPR.

For patient and public involvement, engagement and participation

Similar findings have been reported from studies looking at monitoring diversity in PPIEP.⁷ There are no set processes or requirements for capturing protected characteristics data in public involvement activities in the UK.⁸ However, there is increasing recognition of the importance of developing strategies to collect this data from the public.⁸

Keane and colleagues⁷ developed a form to record protected characteristics data from patient and public contributors. The form was reviewed by a steering group, to ensure its alignment with data protection regulations and the Equality and Human Rights Commission, and for accessibility purposes. The authors⁷ indicated a potential to use this data to create new projects and opportunities to meet unmet needs of local communities. The study emphasised the importance of partnership working, transparency and engagement, and of having clear regulatory and governance structures in place with processes continuously reviewed.⁷

In healthcare settings

Studies looking at broader public opinion on sharing sociodemographic data in healthcare settings have shown mixed results. A sample from Ontario, Canada, (1,306 surveyed; 34 interviews) felt more comfortable with sharing data about language and less comfortable with sharing data about socioeconomic position (for example, household income and educational background) and sexual orientation.⁹ These differences were due to fear of potential discrimination, judgement, pity or the misuse of their information.⁹ Participants suggested acceptable ways to collect information, which were face-to-face with a family doctor and an educational campaign to explain why this information was being collected and used.⁹

A similar study in Canada reported that managers and care providers could understand why knowing the sociodemographic profile of service users could support service improvement planning and advocacy for funding to ensure local communities' needs were met.¹⁰ However, this conflicted with the potential of raising expectations that could not be met due to resource constraints.¹⁰ Leadership engagement, support and commitment to collecting such data were also considered to be essential, as was an organisation's readiness for change, staff buy-in and training to collect the data.¹⁰

Wider barriers to collecting EDI data relate to difficulties in definitions and terminology, and in practical or methodological issues.¹¹ Also, marginalised populations (for example, migrants) may be fearful of the consequences of sharing data more broadly.¹² This may be linked to the wider sociopolitical environment.

In the UK, more NHS services are starting to collect information on protected characteristics to help them address inequalities in patient experience and outcomes. For example, NHS England developed guidance¹³ for improving data quality in the Mental Health Services Data Set (MHSDS) and NHS Talking Therapies for anxiety and depression^d data set. Improvements to how data are collected and the quality of the data are linked to the Advancing Mental Health Equalities strategy¹⁴ and a need to improve the evidence base on health inequalities.¹³ The key principles of collecting data on protected characteristics outlined in the guidance¹³ are:

1. to enable self-reporting
2. not to make assumptions about individuals' identities and circumstances
3. to provide trauma-informed care that 'makes patients feel safe and empowered to share personal information'
4. to routinely review and feedback on the data collected and value in using this to advance equalities.

Other important principles include respecting patient consent and choice, and reminding patients that their information will be kept confidential.¹⁵ It is also important to choose an appropriate time to ask for this information, once trusted relationships are built or when patients are discharged from crisis care to a community team.¹⁵

Project rationale

The NIHR's first EDI strategy was released in 2022.¹⁶ It outlines a 5-year vision to transform practices in research, research and organisational culture and systems (including recruitment, research funding and participation) to be more inclusive. The strategy focuses on everyone from the NIHR workforce to research staff, research participants and the general public.¹⁶ The NIHR also incorporates groups identified by the Innovations in Clinical Trial Design and Delivery for the Under-served (INCLUDE) project in their focus on the diversity of research participants.^{4,17} The strategy¹⁶ refers to both Equality Act 2010¹⁸ and intersectionality as being fundamental to its development and delivery. For example, the NIHR commits to using intersectionality to address diversity among research participants and patient/public involvement contributors.¹⁶

The NIHR does not mandate the collection of, or access to, data on the nine protected characteristics (under the Equality Act) of researchers and research participants in all BRC partner organisations. However, this may change in the future because the EDI Strategy 2022–27 Action Plan¹⁹ includes an action to 'expand the data collection approach to include all protected characteristics'. The NIHR has shared guidance for diversity data questions, which has been informed by multiple sources. The guidance covers suggested wording and categories to collect data across the nine protected characteristics and socioeconomic status.^{4,20–23}

^d Formerly named IAPT (Improving Access to Psychological Therapies).

The NIHR EDI strategy 2022–27 also refers to targeted initiatives for effectively monitoring and evaluating the impact. The initiatives could include data collected on research participants and those involved in shaping the research.¹⁶ This may also include setting 'appropriate targets to diversify participation in our research and systems'.¹⁶ The collection of diversity monitoring information by the NIHR meets the conditions of the GDPR, that collecting the information is in the public interest and has a basis in law relating to the Equality Act.²⁴

As part of their funding contracts to 2027, all 20 BRCs in England needed to submit a formal EDI strategy that was acceptable to the NIHR and dependent on the level of maturity of the BRC. Oxford Health BRC's EDI strategy²⁵ reflected a new BRC, which was established from December 2022 and set up as a network of centres of excellence across England. The vision of the Oxford Health BRC's EDI strategy is to 'work with partners to establish, and enhance, the evidence-base for EDI'.²⁵ The strategy includes a commitment to 'focus on relevant data collection processes that will enhance the diversity of our research participants and workforce, including at senior levels'.²⁵

This report focuses on identifying barriers and enablers to implementing the 5-year strategy, particularly related to collecting data on protected characteristics.

Methods

Research question, aim and objectives

Research question

What are the perceived barriers and enablers to implementing Oxford Health BRC's EDI strategy among partner and associate partner organisations?

Aim

To understand the context, enablers and barriers to implementing the Oxford Health BRC EDI strategy, including possible solutions to anticipated challenges.

Objectives

1. To explore perceptions and experiences of implementing the EDI strategy among partner and associate partner organisations
2. To identify the factors that may enable, or act as barriers to, effective implementation of the EDI strategy, including ethical considerations (for example, collecting data on protected characteristics)
3. To gather views on possible solutions to overcoming issues relating to the implementation of the EDI strategy.

Study design

To answer the research question, we conducted semi-structured interviews (online via Microsoft Teams). We interviewed partners and associate partners of the BRC (see [Appendix A](#) for a list of the partner organisations).

Interviewees were recruited using convenience sampling due to time constraints. Oxford Health BRC asked members of its SPB^e to name suitable interviewees. SPB members are those in senior roles in the partner and associate partner organisations and it was assumed that they would be able to find the appropriate individual to represent each partner in the survey.

Potential interviewees were contacted by Oxford Health BRC with a general introduction to the BRC and the proposed project. A follow-up email was sent from the research team. Interviews were conducted between February and March 2024.

^e The SPB includes one member from all formal BRC partners. The Board is Chaired by the BRC Director and meets quarterly to identify joint strategic goals and support partnership initiatives that focus on the BRC and other emerging national initiatives in mental and brain health.

We aimed to speak to at least one person from each site, including people involved in the implementation of the strategy (for example, EDI leads) and people involved in developing strategy (for example, senior leaders). All participants received an information sheet by email that explained the purpose of the study and what to expect from taking part.

The topic guide (see [Appendix B](#)) was reviewed by a BRC staff member and was refined as the study progressed. The interviews covered topics including:

- awareness of Oxford Health BRC
- knowledge of the BRC's EDI strategy, their local EDI strategy and their role in implementing either strategy
- perceived barriers and enablers of implementing EDI strategies
- how protected characteristics data are collected in their local system
- perceptions of mandating the collection of protected characteristics data.

Interviews were transcribed using in-built Microsoft Teams software and checked for accuracy. Transcripts were managed using NVivo and analysed by thematic analysis by two independent researchers. A codebook was developed by the research team, with an agreed finalised set of themes and sub-themes (see [Appendix C](#)).

Ethical approval was not needed for this work as it is a service evaluation. We did, however, seek informed consent from all interviewees using Microsoft Forms. We also collected some demographic information to ensure we had spoken to a diverse group of stakeholders.

All data are stored securely on Royal College of Psychiatrists' computers. The only staff with access to the data are project team staff.

Findings

Study characteristics

We interviewed 12 representatives from ten associate partners (three men and nine women) of Oxford Health BRC. Three people did not respond to multiple invitations for interviews, so the following organisations were not surveyed: Oxford University Hospital NHS Foundation Trust, Birmingham Women's and Children's NHS Foundation Trust,^f and the University of Sheffield.

Interviewees included staff based at universities and NHS trusts. The organisations represented were:

- Berkshire Healthcare NHS Foundation Trust (n=1)
- Birmingham Biomedical Research Centre (n=1)
- Oxford Brookes University (n=1)
- Oxford Health NHS Foundation Trust (n=1)
- Sheffield Health and Social Care NHS Foundation Trust (n=2)
- University of Birmingham (n=1)
- University of Liverpool (with connections to Mersey Care NHS Foundation Trust) (n=2)
- University of Oxford (n=1)
- University of Reading (n=1)
- University of Surrey (n=1).

Three associate partner organisations officially joined the network in March 2024, and so were not surveyed. These were Birmingham and Solihull Mental Health NHS Foundation Trust, Sussex Partnership NHS Foundation Trust and the University of York.

Interviewees were from a range of roles and included EDI leads (n=7), researchers (n=3), clinicians (n=1) and PPIEP leads (n=1), although some held more than one of these positions in their setting. Length of employment ranged from 6 months to over 10 years.

Interviews took between 30 and 57 minutes (average 44 minutes).

Our findings from the thematic analysis are structured based on the topics covered in the interview topic guide (see [Appendix B](#)) and are summarised in the following sections. Quotes from the interviews are used to illustrate certain points.

^f Other University of Birmingham representatives did respond.

Awareness of Oxford Health BRC

Interviewees were mostly unaware of the relationship between their own institution and the BRC. One-third (n=4, 33.3%) said that the email inviting them to be interviewed was the first time they had heard of the BRC. As described above, interviewees were identified by senior members of each organisation who sit on the BRC SPB, and it was assumed that they would know of the BRC.

Other interviewees who were newer in their EDI role reported that their involvement with the BRC was still to be decided and developed.

Implementation of EDI strategies

Implementation was described as the process of transforming data to recommendations to improve practice. Interviewees acknowledged the importance of values, behaviours and beliefs during the implementation of EDI strategies.

Enablers and barriers

We asked interviewees what 'good' EDI strategies looked like and the challenges that may arise when implementing them. The enablers and barriers to implementation are outlined in **Table 1**.

Table 1: Examples of enablers and barriers to implementing EDI strategies shared by interviewees

Enabler	Barrier
Accountability, oversight and governance by leadership team to ensure EDI work is delivered (for example, action leads reporting to a board)	Lack of leadership and relying on a few people to drive the agenda forward
Awareness and commitment to a shared vision and aligned goal for EDI	Negative attitudes towards or lack of understanding of EDI. This may also relate to a lack of experience and confidence
Celebrating successes to keep morale and awareness high	Failure can be demoralising
Clear actions and process for achieving them with shared ownership across all staff levels through a collaborative approach	Lack of planning and complex organisational systems and structures

Dedicated resources including training and staffing	Finite resources including staff capacity
Embedding EDI and system-level change	Strategy may not lead to any real change
Having an iterative approach	Lack of flexibility in implementation
Monitoring progress as the strategy is implemented	Lack of measurement and monitoring of EDI
PPIEP that shifts towards a 'bottom-up approach'	Not co-producing work and being 'top-heavy' in approach
Solution focused and specific time-limited actions that are tailored, bespoke and place-based	Prioritising quantitative over qualitative measures
Having enough time for reflection and to monitor progress and change	Time commitment is required to drive change, which may conflict with workload; change is not immediately seen and may take several years

Overall, enablers and barriers to implementing EDI strategies focused on leadership and collaboration efforts, and logistics and resources.

Leadership

Leadership was described as being able to ensure the visibility of and commitment to the delivery of EDI initiatives. This was seen as an important part of a team working together as a system to deliver change; for example, Action Leads driving the implementation and people with lived experience holding organisations accountable.

'There will always have to be a leader that needs to coordinate and facilitate all of this, but it doesn't necessarily mean that they are the whole entity of this enterprise.'

Collaboration

Discussions around collaboration centred on making EDI strategies feel like a joint effort and sharing responsibility across all levels of the workforce. The importance of PPIEP was also raised as well as people being kept updated on progress, challenges and achievements. Co-production⁹ was an approach raised by several interviewees as being integral to EDI initiatives.

'Communication, horizontal communication, vertical communication across the board. Top-down and from peer-to-peer, as well, are important. Also, regularly having updates. Not necessary meetings, but a few bullet point updates to keep people in the loop and to be open and honest about some of the challenges that people may be facing.'

Logistics and resources

Logistics and resources focused on the time available to implement EDI strategies and having dedicated staff available to implement change and monitor progress. Resources may also include the delivery of EDI training and support through mentoring and networking initiatives.

'I think in our context, having dedicated EDI resource is an enabler, so my role is new. And I've got an expanded team that's been in place for a year. So, just having a bit more dedicated resource to put into developing support guidance, making it easier for colleagues to engage.'

Oxford Health BRC's EDI strategy

Interviewees shared their views on the Oxford Health BRC's EDI strategy after receiving a summary, despite initial unfamiliarity.

Most were unsure or unclear of their role in implementing the strategy. A few described having given their input to the strategy before it was published. Others discussed how they felt they could support its implementation, for example by providing guidance and information to colleagues. One person felt they did not have a role to play in implementing Oxford Health BRC's strategy.

The areas of the strategy described as being closely aligned with local EDI strategies were:

- ethical considerations for collecting data on protected characteristics
- developing EDI research resources for inclusive research design
- equitable opportunities including mentoring, support networks and leadership.

⁹ See the **Glossary** for a definition of co-production.

'...to develop a positive culture, these open and transparent conversations need to be had. And I think that can be done through mentoring and networking.'

Local EDI strategy

Most interviewees were familiar with the EDI strategy of their institution and drew comparisons with Oxford Health BRC's strategy. Preparing research resources for inclusive research design, inclusive recruitment to studies and training offers were mentioned. Additionally, the role of leadership and management in the process and how progress could be monitored was discussed.

Interviewees also spoke of how their strategies compared with other EDI initiatives and strategies in the wider landscape including the:

- Advance HE Race Equality Charter²⁶
- Athena SWAN Charter²⁷
- Equality Act
- LGBT Foundation/NHS England LGBTQIA+ Positive Practice Guidance (not yet published)
- NHS England Patient and Carer Race Equality Framework (PCREF)²⁸
- NHS Workforce Disability Equality Standard (WDES)²⁹
- NHS Workforce Race Equality Standard.³⁰

'...we have a lot of things to comply with, I suppose, and a lot of things that we aspire to beyond the compliance. And this [Oxford Health BRC EDI strategy] will be another strand of that.'

Interviewees spoke of the complexity of implementing EDI strategies across multiple settings (for example in research and clinical settings, and in higher education).

Collecting data on protected characteristics

Interviewees referred to data protection regulations including the GDPR. They spoke of collecting data across healthcare, research and higher education settings. They shared their opinions on how some protected characteristics may be more challenging to collect than others, for example, gender and sexual orientation. This may relate to felt stigma (internalised or self-stigmatisation), perceived or experienced stigma.

'When you're getting to protected characteristics that people may not feel comfortable disclosing because there's potential bias, potential stigma. So, around sexual orientation...'

Stigma may then result in discrimination, which can be direct or indirect, or manifest as harassment or victimisation. These forms of discrimination are outlined in the

Equality Act. Examples shared by those interviewed included interactions between healthcare practitioners and patients.

'I've lost count of the number of times I've heard it, but they're [patients] worried their practitioner won't understand their sexuality or their gender identity. Or they have accessed services and their practitioner's been quite dismissive, hasn't understood, or [been] outright discriminatory, and that's well-documented in quite a few NHS sources.'

It may also be necessary to gather some protected characteristics data more regularly. For example, maternity or pregnancy status may need to be collected annually. However, this could also be emotionally challenging for some people to share.

'I would have concerns about directly asking people questions about pregnancy and maternity. Just for ethical reasons.... If you're potentially asking somebody who's experienced miscarriage and the like to touch on something that's very personal and upsetting to them. And also, just because of the frequency with which you'd need to ask that question, you'd essentially need to go back and ask it on an annual basis to know that your data's current.'

Interviewees spoke of data being collected for equality monitoring purposes for staff, students and PPIEP. They spoke of the importance of monitoring data to reflect on the progress of a strategy and whether goals are being met, and to inform local decision-making. However, it was felt that data on protected characteristics should only be collected for research purposes when essential to the study's question, design or target population.

I can see how... certainly for the kind of research I do, that could create problems. Just from an ethical approval perspective, I would be expected to say why I need each piece of protected characteristic data... And if it's not relevant for my research question, I'd find that really difficult to justify.

Enablers and barriers

The enablers and barriers to collecting data on protected characteristics are outlined in **Table 2**. Solutions to overcoming barriers to collecting protected characteristics data are outlined on **page 24**.

Table 2: Examples of enablers and barriers to collecting data on protected characteristics shared by interviewees

Enabler	Barrier
Campaigns and training for staff including support networks to raise awareness and increase knowledge and understanding	Lack of confidence when asking questions related to protected characteristics
Communications to promote collecting data	<p>People need convincing why data sharing is important</p> <p>Lack of time and inappropriate timings for data collection (for example, in a crisis setting)</p>
Managing expectations on how long it may take to see change	People may find it difficult to share sensitive data due to difficult past experiences including perceived, felt and experienced stigma and discrimination
Proactive and supportive approach to create a positive learning culture among staff	Poor collection methods or language barriers (for example, badly worded forms and questions)
Providing a template or script to help people ask questions	Lack of understanding about a question about a protected characteristic
Removing 'Other' category and having a choice to self-describe	Use of 'Other' category makes comparison difficult, and categorisation of individuals may result in 'othering'
Systems and technology to support data collection and monitor progress	Different systems and organisations for collecting data make comparison difficult and data-sharing agreements complex
Trust for data collector	Poor relationship with person collecting data and lack of trust in research and data collection
Use of AI (artificial intelligence to support data collection	Challenges keeping data up-to-date and complete

Purposes of collecting protected characteristics data

Overall, it was acknowledged that collecting data on protected characteristics can be helpful for informing decisions and for monitoring purposes (for example, progress of EDI initiatives and strategies) to inform practice and decision-making.

'I see that [collecting data] as the crucial part because without that data, you don't have the foundations to think about levels of representation, or specific metrics are very hard to define. What you'd be looking for is shifts on those metrics in what direction and by how much.'

Interviewees shared that monitoring protected characteristics data can help to illuminate areas of unmet need in service delivery. Therefore, this insight could be used to inform service development.

'So, there's pockets of work going on, and I guess that's part of the rationale for my role, is to sort of try and pull it all together a bit more formally. So, we can then use that to understand what that means, whether there are gaps of particular population groups in certain services or in across the whole [NHS] trust.'

Ethical considerations

Ethical considerations that were raised focused on the risks of sharing personal data (for example, prejudice, discrimination and unconscious bias) and the potential for people being identifiable if multiple characteristics data are collected.

'Looking at themes within Oxford Health BRC, and then you're looking at gender, and then you're looking at role, and then you're looking at ethnicity. You're piling up all your characteristics. There's then one person who this could possibly be.'

Mandatory data collection

Interviewees had mixed views on mandatory data collection. Overall, it was felt that the purpose of mandatory data collection and any associated benefits would need to be explicitly stated. However, there were concerns that mandatory data collection may still not have the desired outcomes.

'I don't think mandatory is the way to go... it often isn't. It's a bit like when people say, "Let's send people on mandatory training." You can physically be there, but mentally you might not be. So, is it actually having the desired effect?'

Interviewees felt that people having a choice about the data they wanted to share was crucial. There was a difference between people 'refusing' to provide data compared with choosing not to share it.

'I think it's really difficult to say that data equality monitoring data should be mandatory because everybody has a choice, even if for the very right reasons we collect it, it's difficult because people still have agency in choice, I suppose, to introduce something that people feel might be considered.'

It was also thought that mandating the collection of protected characteristics data may be at odds with GDPR, for which the explicit need, purpose, relevancy and transparency for collecting the data are required.³¹

'The whole purpose of the GDPR process is to be able to vocalise what it is you're asking for and why, and that's all you can do, but you also have to be really clear. I mean, and this depends on the kind of the lawful basis you're collecting this information, which I expect will be consent because it's not legitimate interest.'

Minimising concerns about mandatory data collection

Interviewees suggested solutions to minimise concerns for mandatory data collection which included:

- 1. Openness to learning and development:** Examples included providing EDI training, using an active listening approach and providing advice on how to respond to concerns and questions.
- 2. Support to collect data and set up systems:** Examples included guidance, briefings and support meetings.
- 3. Transparency about how data are used and why data are being collected:** Examples included providing a flow chart or information sheets on how data is processed, used and managed, as well as retention policies. Information sheets could be provided in multiple languages and formats.

'Why is it mandatory to start with, what's the reason, the rationale behind that? And then once you've got it, what you do with it? Because if you're just collecting it because it's mandatory but not doing anything with it, then ... why collect it? So I think like a process of rationale, reason, actions, so people can almost see that flow of where their information or data goes.'

- 4. Giving people notice ahead of time and enough time to decide whether to share their data.**
- 5. Seeking advice from local systems of governance:** Examples included the Information Compliance Office in universities.
- 6. Sharing positive practice examples where data sharing has led to advancements or progress in achieving equitable outcomes.**
- 7. Establishing task and finish groups or working groups to encourage conversations among staff and public partners to ease concerns.**

Discussion

Key findings

We found that awareness of the relationship between Oxford Health BRC and associate partners was generally low, as was knowledge of the details of the BRC's EDI strategy. However, interviewees did share their insights on how EDI strategies are implemented in their local setting as well as their perceived involvement with the BRC's EDI strategy. This included the responsibilities held by EDI teams, researchers and clinical staff. Also, the structure of governance and accountability of EDI strategies were discussed by several of the interviewees. Overall, interviewees shared a complex narrative for how EDI strategies are formulated, implemented and monitored across their organisations. Collecting data on protected characteristics revealed an even more complex situation.

Leadership, collaboration and resources were the main enablers and barriers to implementing EDI strategies. Interviewees acknowledged challenges in implementing EDI strategies that cut across multiple sectors, including higher education and research (universities), and healthcare (NHS trusts). This is particularly relevant to Oxford Health BRC, which is made up of multiple associate partners that are geographically spread and are based in both clinical and academic settings. Each associate partner will have its own local EDI strategy, and regulatory and governance procedures, which adds to that complexity.

Views on collecting data on protected characteristics were also mixed. Interviewees recognised the potential advantages for ensuring suitable services are provided and for informed decision-making. However, ethical considerations were also raised on the risks of sharing this data including relationships with the data collector which may lead to feelings of perceived stigma.

Mandating the collection of protected characteristics raised similar concerns. Proposed solutions to minimise these concerns included transparent communications, sharing positive examples, and encouraging the learning and development of EDI staff who may be responsible for delivering this work if it is taken forward.

Implications

The limited awareness of Oxford Health BRC's EDI strategy is likely having an impact on the implementation of the strategy. The development and implementation of local EDI strategies could lead to duplicated efforts, causing potential confusion or conflicting initiatives in the future. Therefore, work to bring the associate partners together to provide clarity, be kept updated on the strategy and align EDI efforts is crucial. Additionally, collecting or accessing data on protected characteristics is still a challenging area for EDI work and research.

In practical terms, collecting data on protected characteristics is complex due to the different systems, structures and regulatory processes in place across organisations and sectors. Data is often recorded in different formats, using various categories, and managed in diverse ways. Some characteristics may be more sensitive to collect than others (for example, gender, sexual orientation and pregnancy), which has been demonstrated in the literature.^{9,10} There also needs to be explicit and sufficient reasons why the data is required to meet GDPR regulations.³¹ If the NIHR mandate collecting protected characteristics, an assurance must be made that data protection principles and data subjects' rights meet GDPR requirements.^{5,31}

In relational terms, people may not feel comfortable sharing sensitive personal data with the data collector. Building trust and a good rapport with the person gathering or recording the data can reassure those providing data that it will be managed and protected responsibly. Having a good relationship with the data collector can also help with identifying accessibility requirements (for example, language barriers), which can then be mitigated. Developing resources and tools can help support this process. For example, the NHS South East Clinical Delivery and Networks mental health team have developed materials for both patients and carers (a leaflet, easy read leaflet and video) and staff (a poster and webinar) to promote the collection of protected characteristics data.³² A trusting relationship and supportive social environment can encourage marginalised communities to share sensitive data, despite previous experiences of discrimination or the fear of being judged.

Identifying effective strategies to support marginalised communities in making knowledgeable choices about data sharing is essential. Tailoring these strategies to fit various contexts, environments and communities is crucial. These will also need to consider past experiences with research and healthcare. Therefore, a meaningful, co-production approach is vital.

Next steps

We identified several next steps for NIHR, Oxford Health BRC and partner organisations that involved in the future implementation of the BRC's EDI strategy.

For NIHR:

- Provide clarity on why protected characteristics data must be collected (if mandated) and aligning this with GDPR and local data protection regulations.
- Commission research on feasibility and acceptability of mandating the collection of protected characteristics data from perspective of researchers, patients, carers, the public and clinicians.

For Oxford Health BRC:

- Bring together associate partners (and leads involved in implementing the EDI strategy) to provide clarity, update on the strategy and its progress and align EDI efforts and share learning across the BRC (where possible). It is suggested that the BRC SPB is used to drive this.
- Present findings to the PPIEP groups within the BRC to understand whether patients and research participants agree with the findings and proposed solutions.
- Conduct a similar project with members of PPIEP groups to gather their insights and suggested solutions.
- Consider an appropriate time in the BRC tenure to conduct a survey to collect more opinions on this project from staff across associate partner organisations.

For partner organisations:

- Encourage all staff (EDI and research staff, and clinicians) involved in implementing their EDI strategy to complete a future survey by Oxford Health BRC on their perceptions of the strategy.
- Encourage BRC teams to attend workshops and other networking initiatives to address the EDI and PPIEP strategies^h
- Establish networks, learning circles and mentoring opportunities for EDI work (if not already in place).
- Engage with Oxford Health BRC and use the quarterly meetings of the SPB to provide updates on challenges, opportunities and lessons learned in the local EDI context.
- Engage with the Oxford BRC Communications Team to highlight EDI initiatives worth disseminating to other BRC partners.

^h For example, a joint EDI/PPIEP workshop that was held on inclusive research and exclusion criteria for studies on 26 March 2024.

Conclusions

Our research found that the Oxford Health BRC's EDI strategy aligns with the local EDI strategy of associate partners. However, an opportunity exists to foster shared learning among associate partners, to align EDI efforts and provide clarity on the BRC's strategy.

Our project showed that views on collecting or accessing protected characteristics data remains a complex ethical and practical issue. In the context of the BRC, it is further complicated by variations in the systems, structures and processes of organisations involved. Meaningful collaboration, effective communication and adequate resourcing were all found to be enablers of implementing Oxford Health BRC's EDI strategy and for collecting data on protected characteristics. Co-production would help with alleviating concerns among marginalised communities.

Glossary

This glossary has explanations of terms used in this project. Many of these definitions have been well defined elsewhere and are quoted from cited sources.

Term	Definitions and explanations
Co-production	'An approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. The assumption is that those affected by research are best placed to design and deliver it and have skills and knowledge of equal importance'. ³³
Equality Act 2010	<p>The Equality Act legally protects people from facing discrimination because of the following protected characteristics:</p> <ul style="list-style-type: none"> • age • gender reassignment • being married or in a civil partnership • being pregnant or on maternity leave • disability • race including colour, nationality, ethnic or national origin • religion or belief • sex • sexual orientation. <p>The Act protects people from discrimination in a range of settings including at work and in education.</p>
General Data Protection Regulation (GDPR)	<p>GDPR is a legal framework outlining the guidelines for collecting, processing and managing personal data from individuals within and outside of the European Union.</p> <p>The UK GDPR operates alongside an amended version of the Data Protection Act 2018 and applies to organisations within and outside of the UK that offer goods and services to individuals in the UK.³⁴</p> <p>The principles of GDPR³¹ include:</p> <ul style="list-style-type: none"> • lawfulness • fairness and transparency • purpose limitation • data minimisation; accuracy • storage limitation • integrity and confidentiality (security) • accountability.

Implementation (in research)	'Implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice'. ³⁵
Intersectionality	'A framework that acknowledges that all people have unique experiences of discrimination and disadvantage exacerbated by the overlap of multiple social identities'. ³⁵
Themes	Themes are areas of discussion that came up repeatedly in the interviews. They were found through our analysis of the interviews by coding transcripts during thematic analysis. Codes were then categorised with themes generated to encompass these categories.

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Acknowledgements

The authors would like to thank everyone who took part in the interviews for their insightful contributions, which have shaped this work.

The authors would also like to thank the following for their contributions to this work:

- **Professor Kam Bhui**, Oxford Health BRC
- **Dr Pamela Reid**, Oxford Health BRC

Conflicts of interest

No conflicts of interest were declared.

Appendices

Appendix A: Oxford Health BRC Partners

Oxford Health NHS Foundation Trust has the following partners and associate partners as part of Oxford Health BRC:

Partners:

- University of Oxford

Associate Partners:

- Berkshire Healthcare NHS Foundation Trust
- Birmingham Women's and Children's NHS Foundation Trust
- Birmingham and Solihull Mental Health NHS Foundation Trust
- Oxford Brookes University
- Oxford University Hospitals NHS Foundation Trust
- Sheffield Health and Social Care NHS Foundation Trust
- Sussex Partnership NHS Foundation Trust
- University of Birmingham
- University of Liverpool (with connections to Mersey Care NHS Foundation Trust)
- University of Reading
- University of Sheffield
- University of Surrey
- University of York

Appendix B: Interview topic guide

Thank you for taking the time to speak to me today. My name is [name], I am a [job role] based at the Royal College of Psychiatrists.

The interview will focus on the equality, diversity and inclusion strategy of Oxford Health BRC. The aim of the project is to support the implementation of the BRC's EDI strategy and identify and address any potential issues, for example, relating to ethical considerations.

I have a few things I need to run through before we begin if that's okay.

The interview will take around 30–45 mins, does that still work for you?

We can stop and take breaks as and when you would like and if you would prefer not to answer a question, please just let me know. I will also be taking notes so if I am not looking at the screen, I am listening but trying to capture everything you are saying.

All your information will be stored confidentially on RCPsych computers. We also will anonymise all transcripts and remove any identifiable information.

Finally, I will be recording the conversation to help with transcription – is this okay with you?

Do you have any questions before we get started either about the interview itself or relating to the information you received beforehand?

[START RECORDING]

BACKGROUND

1. Can you please tell me a bit about yourself – what is your current position and involvement with Oxford Health BRC?
2. How are you/would you be involved in implementing the EDI strategy?

EDI STRATEGY

3. Could you tell me about your knowledge of the EDI strategy as it stands?

Prompt: Objectives look at creating equitable opportunities, build leadership networks, develop EDI resources, and ensure patient and public communities have equitable opportunities to participate in research.

Full objectives:

- *Focus on creating equitable opportunities within the BRC facilitated by mentoring, developing support networks, and a commitment to embed EDI within a positive culture.*
- *Build leadership networks within the BRC to advocate for progressive EDI and to challenge resistant systems.*

- *Develop EDI resources and implement them with the production of further relevant materials for better research design.*
- *Ensure that the patient and public communities served by our partner network locally and nationally have the opportunity to participate in our research in accordance with INCLUDE guidance.*

IMPLEMENTATION

4. How would you describe what implementation is, and what 'good' implementation should look like?

Prompt: the process, what and who is involved?

5. What is the Oxford Health BRC already doing in terms of implementation? For example, support/guidance to assist implementation?
6. What do you believe are the key challenges/barriers and enablers to implementing the strategy? Why?

Prompt: type of barriers/enablers (e.g. structural, institutional, psychological, social, etc.)

Prompt: insights into culture change that could aid successful implementation?

PROTECTED CHARACTERISTICS

7. How do you currently collect data on protected characteristics according to the Equality Act 2010 in your local system?

Prompt: Has this always been the way or has this changed over time?

The nine protected characteristics are: age, gender reassignment, being married/civil partnership, being pregnant/maternity leave, disability, race (including colour, nationality, ethnic or national origin), religion or belief, sex and sexual orientation.

8. As you may know, the NIHR has already started to collect applicant data on the nine protected characteristics as part of the systems used to apply for funding. The requirements to collect the nine protected characteristics (plus socioeconomic background) on researchers and research participants are not currently mandatory but the NIHR may change this in the future. What is your view on this? Why?

Prompt: challenges e.g., ethical dilemmas

Prompt: facilitators e.g., better understanding of local assets and areas of missed opportunities

Prompt: best practice for collecting this data e.g., clear data use, storage and sharing statements; clear communications for collecting data and how it will be used.

Further information if required: The NIHR have begun to share guidance for diversity data questions including suggested text for questions and responses for collecting data across the nine protected characteristics and socio-economic status. This guidance has been informed by various sources including 2021 Census, the EDIS [Equality, Diversity and Inclusion in Science and Health] [DAISY \[Diversity and Inclusion Survey\] guidance](#), [AdvanceHE guidance](#) and the draft [Race Disparity Unit's Standards for ethnicity data](#).

The data NIHR suggest be collected are age (year of birth), disability (physical/mental health including longer than 12 months), national identify, ethnicity and religion, sex and gender, sexual orientation, marriage or civil partnership status, parental leave and caring responsibility and socioeconomic background (occupation of main household earner when aged 14). A prefer not to say option will always be provided.

9. How might the BRC work to minimise any concerns on collecting data relating to protected characteristics?

CLOSING

10. Is there anything else we have not covered that you would like to highlight?
11. Do you have any final questions?

Thank you for your time today. You will receive a follow-up email shortly which will explain the next steps of the study.

[END]

Appendix C: NVivo codebook

Code	Description
1. Awareness of Oxford Health BRC	
1.1 Unsure of role with BRC	
2. Data collection	
2.1 Barriers to collecting data	
2.1.1 Categorisation of individuals	People having to select a category to 'fit' into
2.1.2 Challenges keeping data up-to-date and data completeness	People not sharing information (for example, do not feel it relates to them or for other reasons) may lead to missing data or incomplete data. Also relates to challenges with keeping data up to date
2.1.3 Different systems and organisations	Leads to complexity in data processes (for example, sharing, access, control etc.) and how data are captured and recorded
2.1.4 Lack of confidence for asking questions related to protected characteristics	Those recording the data may lack confidence when asking questions to collect protected characteristics
2.1.5 Lack of time, inappropriate timing	The time data are collected may not be appropriate for patients etc. (for example, crisis care)
2.1.6 Lack of trust in research and data collection	There is historical mistrust towards research and healthcare institutions due to malpractice, which has an impact on trust today
2.1.7 Lack of understanding of a question about a protected characteristic	People may not understand what the question is asking or feel the question is not relevant to them

2.1.8	Language barriers	For example, Braille, English as a second language etc.
2.1.9	People need convincing why it is important	This can include staff, research participants and patients
2.1.10	Poor collection methods	This may include badly worded forms and questions, which can be misinterpreted etc.
2.1.11	Relationship with person collecting data	Example perception that healthcare providers do not understand identity
2.1.12	Sharing sensitive protected characteristics	People may fear/be hesitant of sharing sensitive data
2.1.13	Use of 'Other' category and self-description	
2.2 Collection methods		
2.3 Enablers to collecting data		
2.3.1	Campaigns and training for staff	This may include mandatory training
2.3.2	Communications to promote collecting data	
2.3.2.1	A flow chart of process	Specific example to show how data 'flows' through the system – how data are collected, who has access and how data are processed
2.3.2.2	Information in other languages and formats	To tackle language barriers (for example, Braille, other languages)
2.3.2.3	Information on consent and rights processes	
2.3.2.4	Keeping people updated and giving/receiving feedback	
2.3.2.5	Sending reminders	

2.3.2.6	Transparency for who has access to data	Being transparent on who will have access to the data/how access will be granted
2.3.2.7	Transparency for why collecting data and purpose for use	
2.3.2.8	Transparency on data retention	Being clear on how long the data will be kept for
2.3.3	Managing expectations	
2.3.4	Proactive and supportive approach	
2.3.4.1	Co-production and engagement around data collection	This may be with people with lived experience (for example, patients and carers)
2.3.4.2	Displays of allyship and support	Examples include having pronouns in email signature or wearing a lanyard in support of LGBTQIA+ community
2.3.4.3	EDI statements and indicators of values	Organisations may include these on their website or have this displayed in other forums
2.3.5	Providing scripts to help people ask question and collect data	Using the same questions/scripts can help to ensure data collected systematically and is easily understood
2.3.6	Removing 'Other' category and having self-description	
2.3.6.1	Prefer not to say option	
2.3.7	Systems and technology supporting collection	Examples include using AI (artificial intelligence) to support data collection
2.3.8	Trust for data collector	
2.4	Ethical and data protection considerations	
2.4.1	GDPR	

2.4.2	Potential for de-identification	As you collect more data on an individual, it becomes more likely to de-identify them so anonymity cannot be guaranteed
2.4.3	Risks of sharing personal data	
2.5	Mandatory data collection	
2.5.1	Minimising concerns for mandatory data collection	
2.5.1.1	Openness to learning and developing	
2.5.1.2	Support to collect data and set up systems	
2.5.1.3	Transparency of how data are used	
2.5.1.4	Transparency of why data are being collected	
2.5.2	Perceptions of mandatory data collection	
2.5.2.1	Making something mandatory does not always equate to something meaningful	
2.5.2.2	People 'refusing' to provide their data versus choosing not to share it	
2.5.2.3	Purpose of making this mandatory	This may include what is being gained by collecting this data
2.5.2.4	Solutions to support mandatory data collection	
2.5.2.5	Unsupportive of move towards this	
2.5.3	Protected characteristics and other data collected	

2.5.3.1	Age	
2.5.3.2	Caring responsibility	
2.5.3.3	Disability	
2.5.3.4	Ethnicity	
2.5.3.5	Gender including gender reassignment	
2.5.3.6	Intersectionality	
2.5.3.7	Pregnancy and maternity	
2.5.3.8	Religion	Also includes faith and spirituality
2.5.3.9	Sex	
2.5.3.10	Sexual orientation	
2.5.3.11	Socioeconomic status and collecting other personal data	
2.5.4	Settings in which data are collected	
2.5.4.1	In healthcare	
2.5.4.2	In Higher Education	
2.5.4.3	In research	
2.5.5	The importance of data collection	
2.5.5.1	Informing decisions	
2.5.5.2	Monitoring purposes	

3. Implementation

3.1 Challenges or bad implementation

3.1.1	Attitudes towards and understanding of EDI	Includes apathy and lack of motivation, and oversimplifying response to meet for a quick fix. Examples include positive discrimination and misunderstanding of EDI
3.1.2	Complex organisational systems and structures	Collaborating with multiple teams or organisations across BRC and locally. Examples include not working together or working in silos and different policies and ways of working
3.1.3	Failure is demoralising	
3.1.4	Finite resources	May include staff capacity, time, funding and resources generally
3.1.5	Lack of experience and confidence	
3.1.6	Lack of flexibility in implementation	
3.1.7	Lack of leadership	This results in it only being the responsibility of EDI leads
3.1.8	Lack of planning	
3.1.9	Measurement and monitoring of EDI	Includes focusing only on metrics and issues with approaches to how change or success is measured
3.1.10	Not co-produced	
3.1.11	Not led to real change	
3.1.12	Time commitment	

3.2 EDI strategy implementation

3.2.1 Perception of BRC EDI strategy

3.2.2	Role implementing BRC EDI strategy	
3.2.3	Role implementing local EDI strategy	
3.3	Good implementation	
3.3.1	Action leads	
3.3.2	Awareness and commitment to EDI	
3.3.3	Celebrating successes	
3.3.4	Clear actions, process and time for achieving them	
3.3.5	Collaboration	
3.3.6	Dedicated resources	
3.3.7	Embedding EDI and system-level change	Examples of values-based approach
3.3.8	Iterative approach	
3.3.9	Monitoring progress	
3.3.10	Oversight and accountability	
3.3.11	PPIEP	Patient Public Involvement and Engagement and Participation
3.3.12	Shared ownership across all staff levels	
3.3.13	Solution focused	
3.3.14	Sufficient time	
3.3.15	Tailored, bespoke and place-based	

3.3.16 Transforming data into practice

3.4 What is implementation

4. Specific examples

4.1 Athena SWAN

4.2 BPS membership data

4.3 Equality Act 2010

4.4 Limbic

4.5 LGBT Foundation/NHS England LGBTQIA+ Positive Practice Guidance

4.6 NHS Workforce, Race Equality Standard

4.7 Patient and Carer Race Equality Framework (PCREF)

4.8 Race Equality Charter

4.9 Workforce Disability Equality Standard

5. Working with marginalised communities