

A report on indicators of inclusivity in health research- An update



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Inclusive Research Oversight
Board



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Executive summary

Purpose:

Collecting data on indicators for inclusivity, such as the protected characteristics and information on socio-economic background, allows us to observe changes in the level of inclusivity in research within our participants across four National Institute for Health and Care Research (NIHR) infrastructures:

NIHR | Manchester Biomedical Research Centre

NIHR | Manchester Clinical Research Facility

NIHR | Health Determinants Research Collaboration Manchester

NIHR | HealthTech Research Centre
Emergency and acute care

There are two main components to this evolving programme of work:

1. Monitoring workforce, students and research participants: The Inclusive Research Oversight Board (IROB) recommends using the NIHR workforce questions for anonymised non-linked monitoring across the workforce, students and research participants. Collecting the same data in the same way under these NIHR infrastructures allows comparison and analyses to inform us about population-level effects.

2. Collecting demographic research data: In this report, updated in 2024, we provide guidance for researchers to use for collecting demographic data in their research as part of their study design for sampling strategies and analysis purposes. In this context, the demographic data will be linked to the study data. IROB makes recommendations regarding these indicators, but researchers need to fit them to their own research context and purposes across the BRC, CRF, HDRC and HRC.

Findings:

In the indicator report 2023, we identified 17 socio-demographic and economic indicators and their sub-indicators. In light of the new 2024 NIHR funding requirement for inclusive research, the Inclusive Research (IR) Methods team conducted a new literature search and identified additional sub-indicators for 9 main indicators.

1. Recommendations to the NIHR researchers: IROB makes recommendations regarding these indicators. BRC researchers and Principal Investigators (PIs) should contact the IR Methods Team through your designated IR Methods Team lead linked to BRC Clusters as soon as possible when thinking about projects. CRF, HDRC and HRC teams – please email Prof. Arpana Verma at arpana.verma@manchester.ac.uk with any requests.
2. For BRC, CRF, and HRC, researchers/PIs are encouraged to speak to Vocal, the lead organisation for Public and Patient Involvement and Engagement (PPIE). Similarly, please contact the PPIE teams for HDRC.
3. Within the BRC, some Clusters are running joint (PPIE and IR Methods) first meetings with PIs (where possible) to gain an understanding of support required and timescales.

4. Researchers/PIs are encouraged to speak to the Equality, Diversity and Inclusion (EDI) Team for queries about Workforce EDI.
5. If in doubt speak to a member of the relevant team (EDI, IR Methods, PPIE) so we can work out who is best suited to help and when.

Recommendations on inclusive research training:

1. To support and enhance your knowledge of **inclusive research** a free eLearning module has been produced for the Manchester BRC/CRF by Prof. Bella Starling and Vocal. The module is open to all. It can be accessed via the University of Manchester's online platform, Lifelong Learning (search for 'Inclusive Research').
2. The **Manchester Measuring Inequalities Toolkit** is designed to help public health professionals, policymakers, researchers, and others assess and identify inequalities. It was developed by the Manchester BRC (IR Methods Team) with input from the Public Health Team at Manchester City Council. It is freely available through the University of Manchester's Lifelong Learning Platform.
3. **NIHR** advise staff and students to undertake training available on their portal (account required): <https://learn.nihr.ac.uk>

Recommendations on inclusive research methods:

1. Start considering as early as possible how your chosen methods (sample selection, recruitment methods, inclusion/exclusion criteria, geographical coverage etc) may impact on the inclusivity of your research.
2. Think about the whole research cycle including but not limited to: the research question and design; sampling frame; sampling strategy; the participants recruited; the research methods; data collection; analysis; and dissemination of findings.
3. If you are looking for an inclusivity related literature review to inform research/prepare for a grant application, we sometimes have MPH/MRes students seeking such opportunities. Tutors are encouraged to suggest a suitable methodology (e.g., systematic review) that aligns with MPH/MRes requirements. If you are interested in having a student conduct a review, please fill out the expression of interest form below (click link): [Qualtrics Form](#).

Future steps:

With our commitment to following NIHR guidelines on inclusive research and as “a living document”, this report will be updated next year with a new literature search.

Table of abbreviations

BRC	Biomedical Research Centre
BSL	British Sign Language
CRF	Clinical Research Facility
EDI	Equality Diversity and Inclusion
HISG	Health Inequality Steering Group
HRA	Health Research Authority
IR	Inclusive Research
IROB	Inclusive Research Oversight Board
PI	Principal Investigator
PPIE	Patient and Public Involvement and Engagement
MBRC	Manchester Biomedical Research Centre
MCRF	Manchester Clinical Research Facility
MHDRC	Manchester Health Determinants Research Collaboration
MHRC	Manchester Healthtech Research Centre
NHS	National Health Service
NIHR	National Institute for Health and Care Research
NS-SEC	National Statistics Socio-economic Classification
ONS	Office for National Statistics
SOC	Standard Occupational Classification
UKRI	United Kingdom Research and Innovation
WHO	World Health Organisation

Introduction

Inclusive health research has a crucial role in improving the healthcare and well-being of a population (Bibbins-Domingo et al., 2022; Frankena et al., 2019). Individuals and groups within a population have widely varying demographic features. Historically, the underrepresentation of diverse groups and individuals in clinical and health research has remained a problem (NIHR, 2021; Shah and Kandula, 2020). Due to the disproportionate impacts of Covid-19, socioeconomic disparities and differences in health and well-being have once again been amplified in the general population (Mude et al., 2021).

This report suggests which socio-demographic and economic indicators need to be considered to adequately measure the inclusivity of research studies and ensure compliance with the [National Institute for Health and Care Research \(NIHR\)](#), the [Office for National Statistics \(ONS\)](#),¹ and the [United Kingdom Research and Innovation \(UKRI\)](#) Equality Diversity and Inclusion (EDI) strategies as well as [the Data Protection Act 2018](#) and the [Equality Act 2010](#). The Equality Act recognises 9 protected characteristics: age, disability, gender, marriage or civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. Indicators are measurable ways to comprehend the length and breadth of health inequalities and deprivation in a population (Schlotheuber and Hosseinpoor, 2022). This report offers a preliminary template, suggesting which socio-demographic and economic indicators could be monitored to help ensure health research is as inclusive as possible. Researchers can use the report in terms of their study design (for sampling, analysis purposes – linked to data collected) to think about how they can bring more inclusive methods into what they are going to do throughout the whole research cycle.

This report addresses the topic of inclusivity in health research among the participants across the Biomedical Research Centre (BRC), Clinical Research Facility (CRF), Health Determinants Research Collaboration (HDRC), and HealthTech Research Centre (HRC) in Manchester. The [Manchester BRC](#) (MBRC) leads the scientific research to develop life-saving treatments and diagnostics for patients. The [Manchester CRF](#) (MCRF) provides opportunities for the diverse population in Manchester to participate in experimental medicine. The geographical area covered by the MBRC — Greater Manchester, Blackpool and Preston — is diverse, and it is important to monitor the inclusivity of medical and health research being undertaken to ensure benefit to the population as a whole. The [Manchester HDRC](#) (MHDRC) works to address the research priorities of local communities and other stakeholders from Manchester relating to the wider determinants of health and health inequalities for developing health policy. The [Manchester HRC](#) (MHRC) is hosted by Manchester University NHS Foundation Trust working in partnership with the National Health Service (NHS) and industrial partners to ensure the early adoption of innovative health technologies in relation to Emergency and Acute Care(HRC). The [Inclusive Research Oversight Board](#) (IROB) supports and provides oversight to research and activities related to inclusivity in research for the MBRC, MCRF, MHDRC and MHRC.

¹ The latest census in the UK was in 2021 and we use the questions from this survey for the purpose of this report.

Staff, patients, and the public are the key stakeholders in this context. Ensuring inclusivity in the whole research cycle is important because healthcare interventions and treatments are designed to be applicable to the general population. With increasing diversity in the general population, health research needs to routinely monitor those who take part in research activity. This will help researchers to actively respond to the changes in the local population groups and communities in Manchester (Keane et al., 2023). Collecting demographic data from research participants is important as it enables researchers to collect and present more accurate information about the identities of survey participants, highlighting a commitment to inclusion and diversity in the research process (Hughes et al., 2016). Promoting inclusivity throughout the research cycle (from initial ideas to dissemination) is also important. This can be achieved by using an EDI lens throughout the research process including questions in study design, recruitment and enrolment, data collection analysis, and dissemination. Patient and public participation need to be at the heart of all the stages of the research cycle (Gregory et al., 2018; Skovlund et al., 2020).



This report is an evolving piece of work and will contribute to the efforts to widen the participation of under-represented individuals and groups in different forms of health research.



In Autumn 2023, the IROB endorsed the recommendations of the Inclusive Research (IR) Methods team for collecting anonymised unlinked data for monitoring by using the NIHR workforce questions across the workforce, students and research participants. In updated guidance, NIHR made a few changes to the response texts for questions related to 6 indicators (ethnicity, religion, gender, sexual orientation, marriage or civil partnership, parental leave and caring responsibility). You can access the NIHR diversity monitoring questions 2023 via NIHR Learn.



In July 2024, NIHR announced that all applicants for their domestic funding stream will be expected to embed inclusive research in the entire research cycle. To execute their operating principle of inclusion in research, the NIHR announced that inclusive research is a condition for gaining research funding from 27 November 2024.



This updated report is for researchers to use as a resource for collecting demographic data in their research as part of their study design for sampling strategies and analysis purposes. In this context, the demographic data will be linked to the study data.

Methodology

This report is based on a rapid literature review. Google Scholar was used to refine various search terms related to inclusive research methods and the research life cycle, including the research question and design, participant recruitment, research methods, data collection and analysis, and dissemination of findings. We then searched healthcare databases (e.g. Medline, CINAHL Plus, PsycInfo, and Web of Science) with different key words for sources of data on protected characteristics and socio-economic status currently recommended for monitoring and research. We focused on these databases to find out which socio-demographic and economic indicators need to be considered to adequately measure the inclusivity of research studies with the help of free text terms and subject headings related to inclusive research and inclusive methods. These databases cover different health topics with a focus on biomedical and life sciences, nursing and allied health, psychology, social sciences and humanities. We also added the literature found from looking at the reference lists of some cited articles in this report. We identified recommendations from the NIHR², [Health Inequalities Steering Group](#) (HISG, BRC1)³, [Office for National Statistics](#), UKRI⁴ and compared these with additional recommendations identified in the literature search. We compiled different aspects of indicators from these sources and report the findings in tables below. We identify relevant indicator categories for IROB recommendation. We present a list of demographic questions and response options that reflect what we consider to be current best practices in fostering inclusivity.

Main indicators for inclusive research

1. Age indicator

- a) NIHR asks for *“Year of Birth. Please select “Yes” if you are willing to provide NIHR with information about your age”*. The response category is ‘Free text space or drop-down menu for years’. NIHR also adds that the age data could also be collected by asking participants to select an age group from a list provided.
- b) HISG recommends using *“What is your year of birth? (YYYY) (write your year of birth in the box on the left)”* to calculate age.
- c) ONS asks *“What is your date of birth?”*
- d) UKRI states *“Please provide your age”* with response categories ‘18-34’, ‘35-44’, ‘45-54’, ‘55+’ and ‘Prefer not to say’.
- e) The Literature review suggests the age at key life events (see also Appendix 1) is a significant indicator to trace the milestones in the lives of participants (Bruce et al., 2013; Kern and Friedman, 2009, ; Laster, 1997; Settersten and Hägestad, 1996 a; Settersten and Hägestad, 1996 b; Settersten and Mayer, 1997). The age of onset is another inclusive

² You can access the NIHR diversity monitoring questions 2023 via NIHR Learn. [Please visit NIHR Learn to log in or set up your account.](#)

³ Health Inequality steering group in Manchester worked on research inclusivity. It evolved into IROB.

⁴ Research England (RE) UKRI shared the RE equality, diversity and inclusion monitoring questionnaire with team on 17/7/2023.

measure (Mattina and Steiner, 2016) especially in relation to studying disability (Mann and Honeycutt, 2013) and mental disorders (Solmi et al., 2022). Moreover, generational cohorts are important for understanding the evolution of age-related experiences and outcomes (Nunn et al., 2021).

Table 1 A comparison of age indicator

NIHR	HISG	ONS	UKRI	Literature
Year of birth	Year of birth	Year of birth	Age group/Age range	Age at key life events
Age group				Age of onset
				Generational cohort

IROB recommends using the question *“What is your year of birth? (YYYY) (write your year of birth in the box on the left)”* with the addition that month of birth can be added if investigators need to generate a decimal age.

It is beneficial for analyses when studies are less than a year in length and for their follow-up studies (Eid, 1970) and if accurate measures of age are required (Liversidge et al., 2010). Year of birth can help to stratify data by age group of the participants to understand how interventions influence various age groups and the respective outcomes (Waldenström et al., 2017). This can also help the researchers to compare the effect sizes of interventions in different age groups (for example, psychotherapies in young adults and middle-aged adults (Cuijpers et al., 2020)). Researchers can decide the sampling method for this question. For example, stratified sampling is useful for analysing age-related effects in an ethnically balanced sample (Mitani et al., 2021). Studies including year of birth offer more accurate mortality data (Richards et al., 2006). Literature suggests for psychiatry services it is important to consider age of onset as child/adolescent services stop at 18 and become adult services (Solmi et al., 2022).

2. Disability indicator

- NIHR recommends using *“Do you consider yourself to be a disabled person?”* with response categories ‘Yes’, ‘No’, and ‘Prefer not to say’. Their second question is *“Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?”* with response categories ‘Yes’, ‘No’, and ‘Prefer not to say’.
- HISG recommends using *“Under the Equality Act 2010, the definition of disability is “if you have a physical or mental impairment that has a substantial and long-term adverse effect on your ability to carry out normal day to day activity”. According to this definition, do you consider yourself to have a disability?”* with response categories ‘Yes’, ‘No’ and ‘I do not wish to disclose whether or not I have a disability’.

- c) ONS asks “Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?” People who chose ‘Yes’ to this question were then asked: “Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?” with response categories ‘Yes, a lot’, ‘Yes, a little’, and ‘Not at all.’
- d) UKRI asks “Under the Equality Act 2010, a person is Disabled ‘if they have a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on his or her ability to carry out day-to-day activities’. Do you consider yourself to have a disability or long-term health condition? This could be a visible or non-visible health condition” with response categories ‘Yes’, ‘No’, and ‘Prefer not to say’.
- e) The literature review suggests that assistive devices or accommodations used (Baldrige and Kulkarni, 2017), and access to services or accommodations (Hewett et al., 2017), are also aspects to be measured in relation to disability status (Observatory, 2016) (see also Appendix 1). The type of disability⁵ is another sub-indicator we found in the literature (Melugbo et al., 2021). Number of illnesses or conditions can help to track comorbidities of a sample population (Tanderup et al., 2018).

Table 2 A comparison of disability indicator

NIHR	HISG	ONS	UKRI	Literature
Disability status	Disability status	Disability status	Disability status	Assistive devices or accommodations used
Severity of disability		Disability impact on everyday life		Access to services or accommodations
				Type of disability
				Number of conditions or illnesses

IROB recommends using “Do you consider yourself to be a disabled person?” and “Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?” People who choose ‘Yes’ to this question can be asked “Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?” with response categories ‘Yes, a lot’, ‘Yes, a little’, and ‘Not at all.’

⁵ The type of disabilities are communicative-hearing (those with deafness and hearing impairment), communicative-speech-hearing (those with dyslexia, voice disorder, stuttering, or a language/speech), communicative-vision (those who were blind or with vision impairment), psychological, medical and physical disabilities (Melugbo et al., 2021).

Studies showed that self-identification of disability can be biased as the study participants might exaggerate the seriousness of the health problem (Benítez-Silva et al., 2004). It is important not to use the word ‘problem’ in questions related to disability (ONS). Researchers need to assess the underreporting or overreporting of disabilities known in disability research areas (Landes and London, 2018). Intersectional framework studies allow the researchers to understand how disability status interacts with factors like sexual orientation and race/ethnicity in self-reported health (Levandowski et al., 2024). However, asking questions on functional limitations to research participants needs to be limited whenever possible as there is no consensus on the functional limitation language and also it can overestimate some groups (Blaser and Ladner, 2020). The inclusion of the right stakeholders in the study (for example, pharmacists) who can provide the right information to patients is key to the adherence to treatments in long-term studies (Fernandez-Lazaro et al., 2019). A tailored approach needs to be used for closely monitoring the progression of the long-term condition, as patients may drop out of studies (Gebert et al., 2021).

3. Gender indicator

- a) NIHR recommends using *“Which of the following best describes your gender?”* Response categories are ‘Man’, ‘Non-binary’, ‘Woman’, ‘Prefer to self-describe (specify, if you wish)’ and ‘Prefer not to say’. *“Do you identify as trans?”* is another question used with response categories ‘Yes’, ‘No’ and ‘Prefer not to say’
- b) HISG recommends the question *“What is your gender?”* with response categories ‘Male’, ‘Female’, ‘Other (please specify)’, and ‘Prefer not to say’.
- c) ONS asks *“Is the gender you identify with the same as your sex registered at birth?”* with response categories ‘Yes’ and ‘No, write in gender identity’.
- d) UKRI uses the question *“Is the gender you identify with the same as your sex registered at birth?”* with response categories ‘Yes’, ‘No, I identify as Non-Binary’, ‘No, I identify as Questioning or unsure’, ‘No, I identify as a Trans man’, ‘No, I identify as a Trans woman’, ‘No, I would describe myself in a way that does not fit in to the above categories’, and ‘Prefer not to say’.
- e) The literature review suggests that medical interventions received, or gender reassignment (see also Appendix 1) are important measures of gender inclusivity (Bauer et al., 2017; James, 2016; Nolan et al., 2023).

Table 3 A comparison of gender indicator

NIHR	HISG	ONS	UKRI	Literature
The term to describe gender	Gender	Gender identity	Gender identity	Medical interventions received or Gender reassignment
Identifying as trans				

IROB recommends using *“Which of the following best describes your gender?”* with NIHR response categories (please see section ‘a’ above). Also, the question *“Is the gender you identify with the same as your sex registered at birth?”* can be asked as the second question with response categories ‘Yes’ and ‘No, write in gender identity’.

Open-ended and single-item questions are gender inclusive (Cameron and Stinson, 2019). Also, a two-question method will help to gather data on gender assigned at birth in addition to self-identified gender (Tate et al., 2013). Asking these questions about gender and sex assigned at birth will help the researcher to examine the relationship between continuous outcomes like blood pressure or Body Mass Index (BMI) across different gender groups (Wu et al., 2023). Putting these questions in self-administered surveys increases the chance of obtaining sensitive information from participants. In large surveys, researchers need to consider how collecting data on a small sample of gender minority groups may not provide statistically significant data related to the small groups when compared to the general population (Badgett et al., 2014). Investigators interested in studying gender transition can include questions on medical interventions received or gender reassignment (Spanos et al., 2021).

4. Sexual orientation indicator

- a) NIHR suggests *“Which of the following best describes your sexual orientation?”*. The response options include categories ‘Asexual’, ‘Bi/bisexual’, ‘Gay or lesbian’, ‘Queer’, ‘Straight/heterosexual’, ‘Pansexual’, ‘I identify in another way (specify, if you wish)’ and ‘Prefer not to say’. HISG recommends using *“Which of the following options best describes how you think about yourself?”*. The options are ‘Heterosexual or straight’, ‘Gay or Lesbian’, ‘Bisexual’, ‘Other sexual orientation not listed’, ‘Undecided’, and ‘Not stated’.
- b) ONS asks *“Which of the following best describes your sexual orientation?”*. Most of the NIHR response options are included here too. A response category that is not in the NIHR list is ‘Other sexual orientation, write in’ in the given box.
- c) UKRI asks *“How would you describe your sexual orientation?”* with similar responses to those given by NIHR.
- d) We found nothing additional to report from the literature review.

Table 4 A comparison of sexual orientation indicator

NIHR	HISG	ONS	UKRI	Literature
The term to describe sexual orientation	The term to describe sexual orientation	Sexual orientation	Sexual orientation	

IROB recommends *“Which of the following best describes your sexual orientation?”* with response categories ‘Asexual’, ‘Bi/bisexual’, ‘Gay or lesbian’, ‘Queer’, ‘Straight/heterosexual’, ‘Pansexual’, ‘I identify in another way (specify, if you wish)’ and ‘Prefer not to say’.

Fear of disclosing sexual orientation information can be higher among gender-diverse people when compared to the general population (Pho et al., 2023). Giving participants the ‘Prefer not to say’ option gives some respondents who may find it difficult to answer the question and do not want to disclose the information an opportunity to provide a response in a study (NZ, 2019). While using self-administered data collection tools, researchers need to check the level of non-response in the study for the purpose of quality of data during the study with minority gender groups or hard-to-reach communities (Morgan et al., 2020). Moreover, the combination of indicators (e.g. sexual orientation, ethnicity) can be used in intersectional analysis to find out how different indicators influence each other in terms of disease progression and physical and mental health outcomes (Boehmer et al., 2022).

5. Indicator of sex

- a) NIHR suggests “*What is your sex?*” with response categories ‘Male’, ‘Female’, and ‘Prefer not to say’.
- b) HISG does not collect data on sex.
- c) ONS asks “*What is your sex?*” with response categories ‘Male’, and ‘Female’.
- d) UKRI question for sex indicator is “*What is your legal sex?*” This question has similar responses to NIHR but with an additional option for ‘other’.
- e) We found no additional information to report from the literature.

Table 5 A comparison of sex indicator

NIHR	HISG	ONS	UKRI	Literature
Biological sex		Biological sex	Legal sex	

IROB recommends using “*What is your sex?*” with response categories ‘Male’, ‘Female’, and ‘Prefer not to say’.

Sex-stratified analyses, for example, can show how girls and boys are differentially influenced by prenatal and childhood adversity at different life stages (Marini et al., 2020). A systematic review found that women were not being recruited in randomised control trials due to older age. In this context, the lack of evidence in sex-stratified outcomes for both efficacy and adverse events is a challenge for the generalisability of study findings, which the researchers need to consider in their projects (Daitch et al., 2022). Best practices such as considering sex differences in disease incidence, prevalence, and survival, as well as the sex-specific incidence of disease are useful (Rich-Edwards et al., 2018). Journals have also started creating guidelines for authors to include the sex indicator as an experimental variable in their studies if possible (Docherty et al., 2019).

6. Ethnicity indicator

Figure 1 Ethnicity categories from NIHR recommendation

Response text:	Asian or Asian British Bangladeshi Chinese Indian Pakistani Any other Asian background (specify, if you wish) Black, black British, Caribbean or African African Caribbean Any other black, African or Caribbean background (specify, if you wish) Mixed or multiple ethnic groups White and black Caribbean	Mixed or multiple ethnic groups (cont) White and Asian White and black African Any other mixed or multiple ethnic background (specify, if you wish) White English, Welsh, Scottish, Northern Irish or British Irish Gypsy or Irish Traveller Roma Any other white background (specify, if you wish) Other ethnic group Arab Any other ethnic group (specify, if you wish) Prefer not to say
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Figure 2 Ethnicity categories from HISG recommendation

White British	☐	Mixed White and Black Caribbean	☐	Asian or Asian British Indian	☐	Black or Black British Caribbean	☐
White Irish	☐	Mixed White and Black African	☐	Asian or Asian British Pakistani	☐	Black or Black British African	☐
Gypsy or Irish Traveller	☐	Mixed White & Asian	☐	Asian or Asian British Bangladeshi	☐	Any other Black or Black British Background	☐
Other White background	☐	Other Mixed Background	☐	Any other Asian or Asian British Background	☐	Chinese	☐
						Arab	☐
Any other Ethnic Group (please write here)					☐	Prefer not to say	☐

- NIHR asks “What is your ethnic group? Choose one option that best describes your ethnic group or background.” The response categories can be seen in figure 1.
- HISG provides a list of categories to choose from as seen in figure 2.

- c) ONS asks “*What is your ethnic group?*” with response categories similar to NIHR.
- d) UKRI uses the question “*How would you describe your ethnicity or ethnic background?*” with response categories ‘Asian/Asian British’, ‘Black/African/Caribbean/Black British’, ‘Mixed or multiple ethnic groups’, ‘White’, ‘Any other ethnic group’, and ‘Prefer not to say’.
- e) We found nothing additional to report from the literature review.

Table 6 A comparison of ethnicity indicator

NIHR	HISG	ONS	UKRI	Literature
Ethnic group	Ethnic group	Ethnic group	Ethnic group	

IROB recommends the question “*How would you describe your ethnicity or ethnic background?*” with the response categories in Figure 1.

Self-description of ethnicity is helpful for the data collection on ethnicity (Cardemil and Battle, 2003). Treating ethnicity as a signifier of health inequality in combination with indications like age, gender, sexual orientation, and education can reveal how different ethnic groups experience discrimination as embedded in institutional practices and individual behaviours and can potentially affect mental health (Ronzi et al., 2023). Researchers need to consider minority communities' lack of trust in the Government and health professionals when designing a study by including culturally sensitive approaches for data collection (Armstrong et al., 2022). Communicating how health-related data will be used in research and the reasons for asking those data questions to the communities is essential to developing trust. Sustainable ways of keeping in touch with the community's research participants are also important. Giving individuals the mechanism to update and self-declare their ethnicity over time and the right to opt-out from giving or sharing their data are key to addressing the lack of completeness and improving the quality of the ethnicity data. Moreover, training should be given to the staff collecting data on how to collect data sensitively and with cultural competence (Quattroni, 2024). Researchers also need to be mindful of the implication of applying innovative methods in research (for example, artificial intelligence) as it may reproduce historical biases towards some disadvantaged groups in research (Trang et al., 2024). Finally, researchers keeping up-to-date with the related health/medical journal guidelines for reporting ethnicity data is recommended (Flanagin et al., 2021).

7. Indicator of national identity or nationality

- a) NIHR asks “*How would you describe your national identity? (select all that apply)*” with response categories ‘British’, ‘English’, ‘Welsh’, ‘Scottish’, ‘Northern Irish’, ‘Other (free text box to provide identity)’, and ‘Prefer not to say’.
- b) HISG asks no question.
- c) ONS asks “*How would you describe your national identity? (Tick all that apply)*” with similar response categories to NIHR. The instruction “This relates to where you feel you belong, such

as the country or countries you think of as home. This could be different from your citizenship or ethnic group” appears only on the electronic version of the questionnaire, but not on paper form (due to space constraints).

- d) UKRI does not ask a question.
- e) The literature review suggests country of origin or ancestry are important indicators to be measured (Stern et al., 2016). In addition, generational status in relation to migration to another country is a measure that could be included. This measure is defined as ‘Generations since a family's migration from [other parts of the world] to the UK’, where “first generation” refers to those who immigrated to the UK during their lifetime, “second generation” to their children, and “third generation” to their grandchildren’ (Husain et al., 2024). The type of residence permit/visa is also a valuable indicator to understand access of individuals to public healthcare dependent on status (Gibson-Helm et al., 2014).

Table 7 A comparison of national identity or nationality indicator

NIHR	HISG	ONS	UKRI	Literature
National identity		National identity		
		Country of birth		Country of origin or ancestry
				Generational status
				Type of residence permit/visa

IROB recommends using “How would you describe your national identity? (Select all that apply)” with response categories ‘British’, ‘English’, ‘Welsh’, ‘Scottish’, ‘Northern Irish’, ‘Other (free text box to provide identity)’, and ‘Prefer not to say’.

For studies looking at demographic variabilities of diseases, collecting data on country of origin or ancestry (Richman et al., 2010) and country of birth (see also Appendix 1) (Gimeno-Feliu et al., 2019; Holguin et al., 2005; Kingston et al., 2010; Morison et al., 2004) can be beneficial. If a study compares multiple nationalities and the budget is limited, it is sensible to use a mixed methods approach and collect data simultaneously for quantitative and qualitative parts of the project. Designing a sample population with a nationality indicator as well as other indicators like migration backgrounds is also important. Translating documents into different languages is key for research participants to feel included too (Tomás and Ravazzini, 2021). Eurocentric bias in researchers can be addressed via cultural competency training as well as with participatory, action research and with the involvement of participants as interlocutors to frame the research questions and in the recruitment process. Researchers are encouraged to do power calculations before undertaking group comparisons to be able to inform effect sizes even if there is not enough statistical significance. Because these data can help with meta-analysis in future (Mechanic and Pole, 2013). The option to ‘Select all that apply’ encourages

granular collection of data as it provides an opportunity for choosing multiple response categories for self-description. The data collector needs to read out the instruction with the question. Self-description of national identity is encouraged and ideally should be asked along with ethnicity and religion if possible (GSS). If some respondents do not see or understand the instruction about multiple responses, it can lead to the underrepresentation of individuals who want to be recorded in terms of multiple national identities (Scotland, 2009).

8. Language indicator

- a) NIHR does not ask a question.
- b) HISG has no question on language indicator.
- c) ONS asks “*What is your main language?*” with response categories ‘English’, and ‘Other, write in (including British Sign Language)’.
- d) UKRI has no question on language.
- e) The literature suggested proficiency in English as a key language indicator that can be critical for health literacy and the ability of patients to understand instructions and laboratory test results (Lazaro, 2023). Literature also suggested multiple main languages spoken in households is a key indicator to understand the access to health services (Flores and Tomany-Korman, 2008).

Table 8 A comparison of language indicator

NIHR	HISG	ONS	UKRI	Literature
		Main language		Proficiency in English
				Multiple main languages in household

IROB recommends “*What is your main language?*” with response categories ‘English’, and ‘Other, write in (including British Sign Language (BSL))’.

Specific studies researching services offered could benefit from collecting data on multiple-language proficiency at the household level (Elsworth et al., 2016; Gao et al., 2020; Yu et al., 2015) (also see Appendix 1, (Roberts et al., 2007)). Asking the right questions about language to the people who experience health inequality is important as their level of comprehension of the health message is key for them to understanding their conditions, accessing services and taking action in relation to health outcomes (Lazaro, 2023). Language spoken at the regional level may show considerable differences when compared to the national picture. Cross-tabulating language indicators with the ethnicity composition of a household, the age and sex distribution of people living in a household can give a nuanced understanding of diverse needs. Researchers need to be mindful of the possibility that sometimes the respondents may be confused about how to answer language-related questions for their

young children whose language skills are under development. Also, individuals whose birthplaces are outside the UK can be unclear about the language they learned and the language they use more often. The option ‘Other, write in (including British Sign Language)’ can give important data on disability and users of BSL (ONS, 2016). Researchers should include the cost for translated documents and translator services (including BSL) if appropriate in their study protocol, as this can help to increase the diverse enrolment (MacLennan et al., 2023).

9. Parental leave and caring responsibility

- a) NIHR asks “*In the last 12 months, have you taken any of the following types of leave? (Select all that apply)*” with responses ‘Adoption leave’, ‘Maternity leave’, ‘Paternity leave’, ‘Parental Bereavement Leave’, ‘Shared parental leave’, ‘None’, ‘Other (specify, if you wish)’, and ‘Prefer not to say’.
- b) HISG does not have a question on parental leave and caring responsibility.
- c) ONS does not ask about parental leave and caring responsibility.
- d) UKRI suggests “*Have you taken any of the following types of leave in the last 12 months? (Select all that apply)*” with similar options to NIHR ones.
- e) The literature indicates pregnancy status, antenatal care received as well as breastfeeding status as important variables (Taylor et al., 2021).

Table 9 A comparison of parental and caring indicators

NIHR	HISG	ONS	UKRI	Literature
Adoption, maternity, paternity leave			Adoption, maternity, paternity leave	Pregnancy status
Parental bereavement leave				Antenatal care received
Shared parental leave			Shared parental leave	Breastfeeding status

IROB recommends the question “*In the last 12 months, have you taken any of the following types of leave? (Select all that apply)*” with responses ‘Adoption leave’, ‘Maternity leave’, ‘Paternity leave’, ‘Parental Bereavement Leave’, ‘Shared parental leave’, ‘None’, ‘Other (specify, if you wish)’, and ‘Prefer not to say’.

Involvement of culturally diverse groups at the earlier stages of a research project can help overcome any Eurocentric bias in the research question where individual autonomy assumptions take precedence over collectivist family norms. For participants with multiple jobs, parental as well as caring roles, reasonable compensation should be given for research participation, but it should not lead to any

coercion in recruitment (Mechanic and Pole, 2013). Data on ‘Maternity leave’, ‘Paternity leave’, and ‘Shared parental leave’ can vary depending on the sample population characteristics. Care should be taken around this indicator due to potential triggers such as pregnancy loss/complication for diverse gender groups (Rose and Oxlad, 2022). The objective of the research and data collection method will inform how any indicator on breastfeeding could be beneficial (Greiner, 2014). Intersectionality frameworks are helpful for research questions addressing people from different gender groups with varying sexual, reproductive, and obstetric-gynecologic needs (Greiner, 2014; McGlothen-Bell et al., 2023). Also, a feminist approach based on participant observation can give insights into experiences of research participants when they fulfill multiple caring and parental responsibilities (Bravo-Moreno, 2021).

10. Indicator of religion or belief

- a) NIHR asks “*What is your religion?*” with response categories ‘No religion’, ‘Buddhist’, ‘Christian (including Church of England, Catholic, Protestant, and all other Christian denominations)’, ‘Hindu’, ‘Jewish’, ‘Muslim’, ‘Sikh’, ‘Any other religion (specify if you wish)’, and ‘Prefer not to say’.
- b) HISG asks “*Which of the following options best describes your religion or belief?*” with similar response categories to NIHR.
- c) ONS recommends “*What is your religion?*” with similar response categories to NIHR.
- d) UKRI does not have a question.
- e) According to literature, multi-religion households is an indicator category gaining significance (Arweck and Nesbitt, 2010). We also found spiritual practice, existential view or unaffiliated religion as a sub-indicator (Hughes et al., 2022).

Table 10 A comparison of religion or belief indicator

NIHR	HISG	ONS	UKRI	Literature
Religion	Religion or belief	Religion		Multi-religion household
				Spiritual practice, existential view or unaffiliated religion

IROB recommends using “*With which of the following do you identify?*” with response categories ‘No religion’, ‘Buddhist’, ‘Christian (including Church of England, Catholic, Protestant, and all other Christian denominations)’, ‘Hindu’, ‘Jewish’, ‘Muslim’, ‘Sikh’, ‘spiritual but not religious’, ‘Other religion, worldview, or belief system, please specify’ (provide free text box)’, and ‘Prefer not to say’.

Asking “*With which of the following do you identify?*” to study participants ‘allows the question to be inclusive of those with theistic faiths, spiritual nontheistic beliefs, and nonspiritual worldviews within the same demographic question’ (Hughes et al., 2022).

11. Marriage and civil partnership indicator

- a) NIHR asks *“Are you currently? (select all that apply)”* with responses ‘Cohabiting or living with a partner’, ‘Divorced or civil partnership dissolved’, ‘Married or in a civil partnership’, ‘Separated’, ‘Single’, ‘Widowed or a surviving partner from a civil partnership’, ‘Other (specify, if you wish)’ and ‘Prefer not to say’.
- b) HISG does not have a question.
- c) ONS asks *“On 21 March 2021, what is your legal marital or registered civil partnership status? And “who is (was) your legal marriage or registered civil partnership to?”*.
- d) UKRI does not ask a question.
- e) We found multiple relationship with consent of partners additional to report from the literature review (Manley et al., 2015).

Table 11 A comparison of marriage or civil partnership indicator

NIHR	HISG	ONS	UKRI	Literature
Marriage or civil partnership		Marriage or civil partnership		Multiple relationship with consent of partners
		Information on partner		

IROB recommends using the question *“Are you currently? (Select all that apply)”* with similar responses to NIHR question.

If a researcher wants to examine sexual health and relationship status, they can consider adding additional response categories ‘in a ‘polyamorous relationship (multiple relationship with the consent of partners)’ (Hughes et al., 2022). Asking the question on multiple relationship status will allow researchers to adopt a more inclusive approach and to better capture the diversity of intimate relationships.

12. Geographic location indicator

- a) NIHR does not ask a question.
- b) HISG asks *“What is the first part of your postcode e.g., BL6, OL3, SK11?”*
- c) ONS asks *“what is the address of your workplace or depot?”* In addition, method used to travel to work is measured using the question *“How do you usually travel to work?”* with response categories ‘Work mainly at or from home’, ‘Underground, metro, light rail, tram’, ‘Train’, ‘Bus, minibus or coach’, ‘Taxi’, ‘Motorcycle, scooter or moped’, ‘Driving a car or van’, ‘Passenger in a car or van’, ‘Bicycle’, ‘On foot’ or ‘Other’. There is also a second address question: *“Do you stay at another address for more than 30 days a year?”* with response categories ‘No’, ‘Yes, write in other UK address below’, and ‘Or yes, outside, the UK, write in country’. If the

response to address outside UK is applicable, the follow up question is *‘What is that address?’* with response categories ‘Armed forces base address’, ‘Another address when working away from home’, ‘Student’s home address’, ‘Student’s term-time address’, ‘Another parent or guardian’s address’, ‘Partner’s address’, ‘Holiday home’ and ‘Other’. Regarding students, ONS asks *“Are you a schoolchild or student in full-time education?”*. The follow up question is *“During term time, where do you usually live?”* with response categories ‘At the address on the front of this questionnaire’, ‘At the address in question 6?’ (Which is second address as mentioned before), and ‘At another address’.

- d) UKRI does not ask a question.
- e) The literature review suggests collecting data on residential address, full postcode (Lindgren et al., 2010) as well as on urban/rural location (Mohan et al., 2008).

Table 12 A comparison of geographic location indicator

NIHR	HISG	ONS	UKRI	Literature
	First part of the postcode	Workplace address and method of travel		Urban/rural
				Residential address
				Full postcode

IROB recommends using the question *“Please enter your address”* for the location of the participant. If it is not possible to get the full address, consider obtaining the full postcode. If there is a specific interest in workplace and travel *“What is the address of your workplace or depot?”*, and *“How do you usually travel to work?”*

For studies conducted in person within a single country, researchers can directly ask participants where they currently reside for location accuracy. However, in multinational studies, asking respondents to specify their location helps researchers identify if participants are outside the primary study area. When participants are based in a different country, researchers may prefer using an open-ended question to determine the respondent’s country of residence (Hughes et al. 2016).

13. Employment/income indicator

- a) NIHR asks *“What was the occupation of your main household earner when you were about aged 14?”* with the following response categories below (Figure 3).

Figure 3 Response categories for employment or income indicator from NIHR

Answer Options (to be presented in the order listed below)
Modern professional & traditional professional occupations such as: teacher, nurse, physiotherapist, social worker, musician, police officer (sergeant or above), software designer, accountant, solicitor, medical practitioner, scientist, civil / mechanical engineer.
Senior, middle or junior managers or administrators such as: finance manager, chief executive, large business owner, office manager, retail manager, bank manager, restaurant manager, warehouse manager.
Clerical and intermediate occupations such as: secretary, personal assistant, call centre agent, clerical worker, nursery nurse.
Technical and craft occupations such as: motor mechanic, plumber, printer, electrician, gardener, train driver.
Routine, semi-routine manual and service occupations such as: postal worker, machine operative, security guard, caretaker, farm worker, catering assistant, sales assistant, HGV driver, cleaner, porter, packer, labourer, waiter/waitress, bar staff.
Long-term unemployed (claimed Jobseeker's Allowance or earlier unemployment benefit for more than a year).
Small business owners who employed less than 25 people such as: corner shop owners, small plumbing companies, retail shop owner, single restaurant or cafe owner, taxi owner, garage owner.
Other such as: retired, this question does not apply to me, I don't know.
I prefer not to say.

- b) HISG asks “Are you currently?” and provides a list of categories to choose from including ‘Retired’, ‘A student’, ‘Looking after home or family’, ‘Working’, ‘Unable to work’, ‘Unemployed’, and ‘Other (please write here)’. A second question follows “If you are working, please write your job title here”.
- c) ONS uses 6 questions on employment history as shown below.

Figure 4 Employment history questions and response categories from ONS

	Employment history questions	Response categories
1.	<i>In the last seven days, were you doing any of the following?</i>	Working as an employee
		Self-employed or freelance
		Temporarily away from work ill, on holiday or temporarily laid off
		On maternity or paternity leave
		Doing any other kind of paid work
		Or none of the above
2.	<i>Which of the following describes what you were doing in the last seven days?</i>	Retired (whether receiving pension or not)
		Studying

		Looking after home or family
		Long-term sick or disabled
		Other
3.	<i>In the last four weeks, were you actively looking for any kind of paid work?</i>	Yes
		No
4.	<i>If a job became available now, could you start it within two weeks?</i>	Yes
		No
5.	<i>In the last seven days, were you waiting to start a job already accepted?</i>	Yes
		No
6.	<i>Have you ever done any paid work?</i>	Yes, in the last 12 months
		Yes, but not in the last 12 months
		No, have never worked

ONS also asks 7 questions on the participant's main job (see below). Main job is defined as the job in which respondent usually works (worked) the most hours.

- I. *"In your main job, what is (was) your employment status?"*
Response categories: 'Employee', 'Self-employed or freelance without employees' and 'Self-employed with employees'
- II. *"What is (was) name of the organisation or business you work (worked) for?"* If there is no name to be written in the space provided for the first response category, the respondent can fill out the category 'Or no organisation or work (worked) for a private individual.
- III. *"What is (was) your full job title?"*.
- IV. *"Briefly describe what you do (did) in your main job".*
- V. *"What is (was) the main activity of your organisation, business or freelance work?"*
- VI. *"Do (did) you supervise or oversee the work of other employees on a day-to-day basis?"*

- VII. *“In your main job, how many hours a week do you usually work?”* with response categories: ‘0 to 15’, ‘16 to 30’, ‘31 to 48’, and ‘49 or more’
- d) UKRI asks *“What was the occupation of your main household earner when you were about aged 14?”* with similar response categories to NIHR question.
- e) The literature review suggests household income as a measure of affordability of treatments (Long et al., 2011).

Table 13 A comparison of employment or income indicator

NIHR	HISG	ONS	UKRI	Literature
Occupation	Economic activity status	Employment history	Occupation	Household income
	Job title	Main job		

IROB recommends the question *“What is (was) your full job title”*. Researchers can use the latest UK Standard Occupational Classification (SOC) categories according to the needs of the research project. The 9 major SOC categories are ‘Managers, directors and senior official’, ‘Professional occupations’, ‘Associate professional occupations’, ‘Administrative and secretarial occupations’, ‘Skilled trades occupations’, ‘Caring, leisure and other service occupations’, ‘Sales and customer service occupations’, ‘Process, plant and machine operatives’, and ‘Elementary occupations’.⁶ The National Statistics Socio-economic Classification (NS-SEC) categories such as ‘Never worked’, ‘Long-term unemployed’, ‘Full-time students’, ‘Occupations not stated or inadequately described’, and ‘Not classifiable for other reasons’ can also be added to the response categories for data collection.⁷

Researchers can consider asking the NIHR question on occupation above if the researcher wants to understand the socio-economic background of a research participant by asking about the occupation of the main household earner when they were about 14 years old. Government guidance highlights this factor as a useful predictor of socioeconomic background, with academic research further indicating that parental or caregiver roles during one’s youth can have lasting effects. These influences may shape one’s future socioeconomic status, educational attainment, and occupational choices in adulthood (Education, 2018; Morgan et al., 2022). In addition, researchers can use the question *“In your main job, how many hours a week do you usually work?”* with response categories ‘0 to 15’, ‘16 to 30’, ‘31 to 48’, and ‘49 or more’, if accurate data on working hours is required to measure health related outcomes such as job

⁶<https://www.ons.gov.uk/methodology/classificationsandstandards/standardoccupationalclassificationsoc/soc2020/soc2020volume1structureanddescriptionsofunitgroups>

⁷<https://www.ons.gov.uk/methodology/classificationsandstandards/otherclassifications/thenationalstatistics socioeconomicclassificationnssecbasedonsoc2010>

satisfaction, sickness absenteeism, and stress (Benavides et al., 2000). Collecting data on employment history is useful for comparative demographic studies measuring the impact of institutional factors among diverse groups (Möhring, 2015).

14. Household indicator

- a) NIHR does not ask a question on household indicator.
- b) HISG does not have a question.
- c) ONS asks 12 questions on household indicator (Please see figure 5).
- d) UKRI asks no question.
- e) We found homelessness to be an additional indicator to be considered (Richard et al., 2024).

Figure 5 Household questions and response categories from ONS

Question numbers	Household questions	Response categories
1	Who usually lives here? (H1, household questionnaire)	Me, this is my permanent or family home
		Family members including partners, children, and babies born on or before 21 March 2021
		Students and/or schoolchildren who live away from home during term time
		Housemates, tenants, or lodgers
		People who usually live outside the UK who are staying in the UK for 3 months or more
		People who work away from home within the UK, or are members of the armed forces, if this is their permanent or family homes
		People who are temporarily outside the UK for less than 12 months
		People staying temporarily who usually live in the UK but do not have another UK address, for example, relatives, friends
		Other people who usually live here, including anyone temporarily away from homes
		Or no one usually lives here, for example, this is a second address or holiday home
2	Counting everyone you included in question H1, how many People usually live here (H2, household questionnaire)	
3	Starting with yourself, list the names of all the people counted in question H2 including children, babies, and lodgers (H3, household questionnaire)	

4	<i>Apart from everyone counted in question H2, who else is staying overnight here on 21 March 2021? These people are counted as visitors. Remember to include children and babies</i> (H4, household questionnaire)	People who usually live somewhere else in the UK, for example, boy/girlfriends, friends, relatives People stay here because it is their second address, for example, for work. Their permanent or family home is elsewhere People who usually live outside the UK who are staying in the UK for less than 3 months People here on holiday Or there are no visitors staying overnight here on 21 March 2021				
5	<i>How are members of this household related to each other? If members are not related, tick the "Unrelated" box</i> (H6, household questionnaire)	Husband or wife Legally registered civil partner Partner Son or daughter Stepchild Brother or sister (including half-brother or half-sister) Stepbrother or stepsister Mother or father Stepmother or stepfather Grandchild Grandparent Relation – other Unrelated (including foster child)				
6	<i>What type of accommodation is this?</i> (H7, household questionnaire)	A whole house or bungalow that is:	Detached	Semi-detached	Terraced (including end-terrace)	
		A flat, maisonette or apartment that is:	In a purpose-built block of flats or tenement	Part of a converted or shared house (including bedsits)	Part of another converted building (for example, former school, church, or warehouse)	In a commercial building (for example, in an office building, hotel, or over a shop)

		A mobile or temporary structure:	A caravan or other mobile or temporary structure			
7	<i>Are all the rooms in this accommodation, including the kitchen, bathroom and toilet, behind a door that only this household can use?</i> (H8, household questionnaire)	Yes				
		No, one or more rooms are shared with another household				
8	<i>How many bedrooms are available for use only by this household</i> (H9, household questionnaire)	Number of bedrooms				
9	<i>What type of central heating does this accommodation have?</i> (H10, household questionnaire)	No central heating				
		Mains gas				
		Tank or bottled gas				
		Electric (including storage heaters)				
		Oil				
		Wood (for example, logs, waste wood or pellets)				
		Solid fuel (for example, coal)				
		Renewable energy (for example, solar thermal or heat pumps)				
		District or communal heat network				
		Other				
10	<i>Does your household own or rent this accommodation?</i> (H12, household questionnaire)	Owns outright				
		Owns with a mortgage or loan				
		Part-owns and part-rents (shared ownership)				
		Rents (with or without housing benefit)				
		Lives here rent-free				
11	<i>Who is your landlord?</i> (H13, household questionnaire)	Housing association, housing co-operative, charitable trust, registered social landlord				
		Council or local authority				
		Private landlord or letting agency				
		Employer of a household member				

		Relative or friend of a household member
		Other
12	In total, how many cars or vans are owned, or available for use, by members of this household? (H14, household questionnaire)	None
		1
		2
		3
		4
		5 or more, write in number

Table 14 A comparison of household indicator

NIHR	HISG	ONS	UKRI	Literature
		Household		Homelessness

IROB recommends using the 6 household indicator questions we found in the literature: 1. *“Who usually lives here?”*; 2. *“How many?”*; 3. *“What type of accommodation is this?”*; 4. *“Does your household own or rent this accommodation?”*; 5. *“How many bedrooms are available for use only by this household?”* ; and 6. *“What type of central heating does this accommodation have?”*.

The questions *“Who usually lives here?”* and *“how many?”* can be beneficial to examine the association between household members’ behaviours and long-term risk factors (Ayo-Yusuf et al., 2007) as well as for surveying data at individual level (Rosano et al., 2009). *“What type of accommodation is this?”* can be beneficial to correlate the health impacts of physical and non-physical interactions in urban space (Dempsey et al., 2010). The question *“Does your household own or rent this accommodation?”* will be beneficial for cohort studies examining environmental factors affecting population health (Tin Tin et al., 2016) and for designing public health interventions on housing conditions (Samuels et al., 2022). *“How many bedrooms are available for use only by this household?”* and *“What type of central heating does this accommodation have?”* will help to measure the housing stressors (e.g., overcrowding, dampness, hazards) for suggesting housing policies (Ellaway and Macintyre, 1998). Sensitive topics like homelessness can be explored through use of administrative health data if it is recorded systematically (Richard et al., 2024). Researchers may also consider housing instability as a predictor of various health conditions (Montgomery et al., 2024). Partnering with organisations that support individuals with experiences of homelessness can facilitate participant recruitment and engagement in research (Plett et al., 2024).

15. Education level indicator

- a) NIHR does not ask a question.
- b) HISG recommends the question *“What is the highest education level you have attained?”* with response categories ‘No formal education’, ‘Primary education (educated to age 11 or before)’, ‘Secondary education (educated to age 18 or before)’, ‘Higher education (e.g., Diploma, HNC)’, and ‘University education’.
- c) ONS asks *“Are you a schoolchild or student in full-time education?”* with response categories ‘Yes’ and ‘No’. Two additional questions are, *“Have you completed an apprenticeship?”*, *“Have you achieved a qualification at degree level or above?”*. Another ONS question is *“Have you achieved any other qualifications?”* with four response categories (please see figure 6). Final question is *“Have you previously served in the UK Armed Forces?”* with response categories ‘Yes, previously served in Regular Armed Forces’, ‘Yes, previously served in Reserve Armed Forces’, and ‘Or no’.
- d) UKRI does not ask a question.
- e) The literature review suggests informal education (Nind, 2016), and access to educational resources (Beyene et al., 2023) as useful additional indicators.

Figure 6 Responses to ONS question

	Response categories	Sub-categories
1	GCSEs or Equivalent	5 or more GCSEs (A* - C, 9 – 4), O levels (passes) or CSEs (grade 1)
		Any other GCSEs, O levels or CSEs (any grades) or Basic Skills course
2	AS, A level or equivalent	2 or more A levels, 4 or more AS levels
		1 A level, 2 – 3 AS levels
		1 AS level
3	NVQ or equivalent	NVQ level 3, BTEC National, OND or ONC, City and Guilds Advanced Craft
		NVQ level 2, BTEC General, City and Guilds Craft
		NVQ level 1
4	Or other no qualifications	Any other qualifications, equivalent unknown
		No qualifications

Table 15 A comparison of education qualification indicator

NIHR	HISG	ONS	UKRI	Literature
	Highest education level achieved	Highest level of qualification		Informal education
				Access to educational resources

IROB recommends using *“What is the highest education level you have attained?”* with response categories from ONS (Figure 6), plus an additional response category of ‘Higher education (degree/ masters/PhD)’.

Researchers can use art-based methods (e.g. Photovoice) in designing educational information on specific diseases (for example, diabetes self-management education) by giving participants a means to express their lived experiences (Robertson et al., 2022). Self-reported questions can be helpful in understanding the impact of a break in education in relation to a diagnosed condition like cancer (Braun et al., 2023).

16. General Health Indicator

- NIHR does not ask a question.
- HISG does not ask a question.
- ONS uses the question *“How is your health in general?”* with response categories ‘Very good’, ‘Good’, ‘Fair’, ‘Bad’, and ‘Very bad’.
- UKRI asks no question.
- The literature review suggests indicator categories such as GP registration status (Szczepura et al., 2008), distance to the nearest GP surgery (Lewis and Longley, 2016) and health literacy (Bostock and Steptoe, 2012) could help explain some differences in general health. The Mental Health and Access to Care Survey in Canada asks a set of questions. Regarding health: *“In general, how is your health? Would you say:”* with response categories ‘Excellent’, ‘Very good’, ‘Good’, ‘Fair’, ‘Poor’, ‘Don't know, refusal’. Information is asked regarding health now in comparison to a year ago using the question *“Compared to one year ago, how would you say your health is now?”* with response texts ‘Much better now than 1 year ago’, ‘Somewhat better now (than 1 year ago)’, ‘About the same as 1 year ago’, ‘Somewhat worse now (than 1 year ago)’, ‘Much worse now (than 1 year ago)’, ‘Don't know, refusal’. Similar questions are asked in relation to general mental health over a period of time. The first question is *“In general, how is your mental health? Would you say:”* with response categories ‘Excellent’, ‘Very good’, ‘Good’, ‘Fair’, ‘Poor’, ‘Don't know, refusal’. A follow-up question about mental health now is asked in relation to a year ago using the question *“Compared to one year ago, how would you say your mental health is now?”* with response texts ‘Much better now than

1 year ago’, ‘Somewhat better now (than 1 year ago)’, ‘About the same as 1 year ago’, ‘Somewhat worse now (than 1 year ago)’, ‘Much worse now (than 1 year ago)’, ‘Don't know, refusal’ (Canada, 2023).

Table 16 A comparison of health indicator

NIHR	HISG	ONS	UKRI	Literature
		General health		GP registration status
				Distance to the nearest GP surgery
				Health literacy
				General mental health

IROB recommend using the following four questions to measure general health as follows with the same response categories from section e as above: 1. *“In general, how is your health? Would you say:”*; 2. *“Compared to one year ago, how would you say your health is now?”*; 3. *“In general, how is your mental health? Would you say:”*; and 4. *“Compared to one year ago, how would you say your mental health is now?”*.

Depending on the context of the research, asking about GP registration status, distance to the nearest GP surgery, and health literacy may be helpful in identifying gaps in disease prevalence and spatial analyses (Weimann et al., 2016). Considering hospital admission rates among various groups can add evidence to designing intervention programmes in public health (e.g. asthma hospitalisation and management) (De La Cruz et al., 2021). Comparing vaccination coverage among older and younger populations of diverse population groups in relation to different income levels is another possible indicator of general health in understanding health inequality in relation to pandemics (Peña et al., 2023). Researchers can ask for information about access to essential medicines⁸ as a signifier of unmet medicine needs in a study on the right to health among undocumented migrant populations, refugees and asylum seekers (Aljadeeah et al., 2024).

17. Carer status indicator

- a) NIHR recommends the question *“Do you have any caring responsibilities? (If you share care responsibilities equally then please answer as the primary carer):”* with response categories ‘Yes’, ‘No’, ‘Prefer not to say’. The follow up question is *“If yes, please select all that apply”*

⁸ The World Health Organisation defines essential medicines as ‘those that satisfy the priority health care needs of a population’ (WHO, 2023).

with response categories ‘Primary carer of a child or children (under 18 years)’, ‘Primary carer of a child or children who is disabled or has a health condition, or illness, or temporary care needs (under 18 years)’, ‘Primary carer or assistant for a disabled adult or adults (18 years and over)’, ‘Primary carer or assistant for an older person or people (65 years and over)’, ‘Secondary carer (another person carries out main caring role)’, and ‘Prefer not to say’.

- b) HISG does not ask a question.
- c) ONS asks the question *“Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?”* with response categories ‘No’, ‘Yes, 9 hours a week or less’, ‘Yes, 10 to 19 hours a week’, ‘Yes, 20 to 34 hours a week’, ‘Yes, 35 to 49 hours a week’, and ‘Yes, 50 or more hours a week’.
- d) UKRI questions on caring responsibilities are *“Are you a parent or guardian of a child/children under the age of 18?”* with response categories ‘Yes’, ‘No’ and ‘Prefer not to say’. The follow up question is *“If you answered ‘Yes’ to this question, please select the category which best corresponded to the number of hours of unpaid care they provided in a typical week:”* with response categories ‘9 hours or less’, ‘10 - 19 hours’, ‘20 - 34 hours’, ‘35 - 49 hours’, ‘Over 50 hours’, and ‘Prefer not to say’.
- e) We found nothing additional to report from the literature review.

Table 17 A comparison of carer status indicator

NIHR	HISG	ONS	UKRI	Literature
Caring responsibilities		Provision of unpaid care	Caring responsibilities	

IROB recommends using the question *“Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?”* with response categories ‘Yes’, ‘No’, ‘Prefer not to say’. The follow up question is *“If yes, please select all that apply”* with response categories ‘Primary carer of a child or children (under 18 years)’, ‘Primary carer of a child or children who is disabled or has a health condition, or illness, or temporary care needs (under 18 years)’, ‘Primary carer or assistant for a disabled adult or adults (18 years and over)’, ‘Primary carer or assistant for an older person or people (65 years and over)’, ‘Secondary carer (another person carries out main caring role)’, and ‘Prefer not to say’. In addition, accurate data on caring hours can be collected using the question *“If you answered ‘Yes’ to this question, please select the category which best corresponds to the number of hours of unpaid care they provide in a typical week:”* with response categories ‘9 hours or less’, ‘10 - 19 hours’, ‘20 - 34 hours’, ‘35 - 49 hours’, ‘Over 50 hours’, and ‘Prefer not to say’.

In the paediatric study context, a researcher needs to include families from diverse backgrounds (Fisher et al., 2024). In relation to carer status, researchers need to consider the possibility of limited diversity in the study sample if they are running a single-centre study. Moreover, recall bias can be a potential

issue if participants are asked to reflect on their past experiences (Flewelling et al., 2022). Researchers need to critically think about the suitability and level of inclusivity of universally used questionnaires (e.g. The Ages and Stages Questionnaire-3) in non-English speaking and low-income settings (Colbert et al., 2021). Reporting recruitment strategies of carers can help in designing interventions targeting both patient and carer in behavioural trials involving both patients and carer (Trivedi et al., 2013). Conducting longitudinal studies about carers can help researchers understand how caring responsibilities change over time in relation to other indicators such as gender and change in relationship status (Houde, 2002).

Key considerations for inclusive research

Some caveats about the report: This report is an evolving piece of work, with new evidence being added annually. This report is presented as a set of recommendations for helping researchers understand the inclusiveness of their research. Depending on the characteristics of sample population/laboratory sample, researchers can select any number of indicators to collect/monitor in their research design if it is feasible. This report is not a comprehensive document for all the indicators related to health research. There may also be research area/context specific indicators. We will review this list annually and update it with the most relevant new indicators. Researchers need to be aware of these developments while interpreting the recommendations from this report. We have not considered all the research methods and every type of research study in conceiving the report, and it is written for the research context in the UK. The researchers leading individual studies need to consider the IROB recommendations in terms of embedding inclusivity across all stages of the research lifecycle, including the research question and design, the participants recruited, the research methods, data collection and analysis, and dissemination of findings. The following table summarises the key considerations researchers should think about when choosing indicators to collect/monitor during their research to help improve inclusivity.

Table 18 Key considerations

Aspects of a recommended indicator question may be applicable to another indicator.
Anticipate and allocate additional time and resources for inclusive research design and its implementation.
Consider the cultural competency of the research workforce and provide training opportunities for researching sensitive topics/conditions.
Provide a self-reporting option for relevant survey questions with 'Prefer not to say' response.
See the task of explaining the purpose of the research and why the data is being collected in recruitment documents in accessible language(s) and media to English and non-English speaking groups as embedded in transparent research practice and significant for reducing the rate of dropouts.
Assess the trust level of diverse groups regarding official data on the research topic.
Consider the mode of data collection: self-reporting or not; selection bias; recollection bias, social desirability bias in collected data.
Consider strengths and limits of the intended method in terms of generalisability and in relation to inclusivity of the research sample.

Collect data to monitor the inclusivity of study participants till completion of the project.
Consider approaches like intersectionality, creative and community-based methods.
Consider data collection mode (remote, self-administered, led by a researcher) and compensation system in place for research participation.
Include Patient and Public Involvement and Engagement (PPIE) in the entire research cycle, especially during the design of data collection instruments.
Consider curating and presenting the anonymised and non-linked data for inclusivity monitoring during and after the research lifecycle.

Conclusion

This report is recommended to be used by researchers across MBRC, MCRF, MHDRC and MHRC from the earliest stages of starting their research. It gives a detailed description of inclusive demographic questions that may be used for quantitative, qualitative and mixed-methods studies. Using these questions will improve data quality on socio-demographic and economic indicators. Updating and outlining the culturally sensitive questions across sample population characteristics helps the researcher to report on diversity and monitor it in studies during and beyond the research cycle. Ensuring a comprehensive ethical approach in the collection of these data in research and monitoring of participation amplifies the relevance and acceptability of research findings. This report encourages researchers to take up inclusivity and cultural competency skills training. By considering this report as a living document, researchers can reflect on their research design to anticipate the methodological and practical considerations for inclusive health research. These indicator questions and response categories have been updated based on a new literature review in a way that promotes research inclusion and to help researchers collect demographic data that reflects the population they work in and with. We encourage BRC, CRF, HDRC and HRC researchers to regularly review their chosen demographic questions to ensure they reflect inclusive, current terminology that accurately represents individuals' identities.

A summary of the updates in the indicator report 2024 is as follows. Column 2 shows the sub-indicators included in the 2023 report. Column 3 provides the additional sub-indicators found in the new literature search.

Table 19 Update to the list of indicators

Main Indicator	Sub-indicators (2023)	Additional sub-indicators (2024)
1. Age	- Year of birth - Age group/Age range - Age at key life events	- Age of onset - Generational cohort
2. Disability	- Disability status - Severity of disability - Disability impact on everyday life - Assistive devices or accommodations used	- Type of disability - Number of conditions or illnesses

	Access to services or accommodations	
3. Gender	- The term to describe gender - Identifying as trans - Gender identity - Medical interventions received or Gender reassignment	
4. Sexual orientation	The term to describe sexual orientation	
5. Sex	- Biological sex - Legal sex	
6. Ethnicity	Ethnic group	
7. National identity or nationality	- Country of birth - Country of origin or ancestry	- Generational status - Type of residence permit/visa
8. Language	Main language	- Proficiency in English - Multiple main languages in household
9. Parental leave and caring responsibility	- Adoption, maternity, paternity leave - Parental bereavement Leave - Shared parental leave - Pregnancy status - Antenatal care received - Breastfeeding status	
10. Religion or belief	Multi-religion household	Spiritual practice, existential view or unaffiliated religion
11. Marriage and civil partnership	Information on partner	Multiple relationship with consent of partners
12. Geographic location	- First part of the postcode - Workplace address and method of travel - Urban/rural	- Residential address - Full postcode
13. Employment/income	- Occupation - Economic activity status - Job title - Employment history - Main job - Household income	
14. Household		Homelessness
15. Education level	- Highest education level achieved - Highest level of qualification - Informal education - Access to educational resources	
16. General Health	- GP registration status - Distance to the nearest GP surgery - Health literacy	General mental health
17. Carer status	- Caring responsibilities - Provision of unpaid care	

Inclusive health research is the cornerstone of an equitable and fair health system. The EDI strategies of NIHR and UKRI suggest a way forward for identifying indicators of inclusivity across society. This report recommends the questions (and answer categories, where appropriate) that could be used for both the well-known and less-known indicators to support the community-centered efforts of IROB for the MBRC, MCRF, MHDRC and MHRC across their various geographical footprints.

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Appendix 1: Additional information on indicators and response categories

The following section is a list of less explored aspects of indicators for inclusive health research at the MBRC, MCRF, MHDRC and MHRC. This list is helpful for deciding which categories are important before starting an inclusive research project on a health topic. This is not a comprehensive list, and it will be modified in consultation with experts and patient representatives.

1. Age indicator

- *Age at key life events:*
 1. *Educational achievements:* This could include completing primary school, secondary school, university, or any other educational milestones.
 2. *Career milestones:* This could include starting a first job, reaching a certain level of seniority, or achieving a significant professional goal.
 3. *Relationship milestones:* This could include first romantic relationship, first serious relationship, getting married, or having children.
 4. *Personal milestones:* This could include moving out of the family home, buying a first car, or owning a home for the first time.
 5. *Health milestones:* This could include recovering from a serious illness or injury, being diagnosed with a chronic condition, or becoming physically disabled.
 6. *Travel milestones:* This could include taking a first trip abroad, visiting a particular country, or travelling for an extended period of time.
 7. *Financial milestones:* This could include paying off debt, saving a certain amount of money, or reaching a particular net worth.
 8. *Cultural milestones:* This could include participating in a significant cultural event or festival, such as a wedding, religious ceremony, or cultural celebration.
 9. *Creative milestones:* This could include publishing a book, releasing an album, or exhibiting artwork for the first time.
 10. *Athletic milestones:* This could include completing a marathon, reaching a certain level of athletic performance, or achieving a personal fitness goal.

2. Disability indicator

- *Assistive devices or accommodations used:*
 1. Screen readers or Braille displays for people with visual impairments
 2. Large print or high-contrast materials for people with visual impairments
 3. Captioning or sign language interpretation for people with hearing impairments

4. Closed captioning or transcripts for videos or audio recordings for people with hearing impairments
 5. Voice recognition or dictation software for people with motor impairments
 6. Tactile graphics or 3D models for people with visual impairments
 7. Assistive listening devices or amplification systems for people with hearing impairments
 8. Alternate formats (e.g., PDF, Word, HTML) for electronic documents for people who use assistive technologies such as screen readers or text-to-speech software
 9. Accessible web forms or online surveys that are designed to be navigated using keyboard or other input devices
 10. Extended time or breaks for people with cognitive or attention impairments
 11. Written or verbal instructions or prompts for people with cognitive impairments
 12. Assistance from a caregiver or personal assistant for people with physical or cognitive impairments
- *Access to services or accommodations:*
 1. Assistive technology (e.g., screen readers, hearing aids, speech-to-text software)
 2. Accessible transportation (e.g., accessible parking spaces, ramps, lifts)
 3. Sign language interpreters or other communication support services
 4. Accessible formats (e.g., large print, Braille, audio, easy-read)
 5. Personal support (e.g., attendant care, personal care assistants)
 6. Flexible working arrangements (e.g., telecommuting, part-time hours)
 7. Adaptations to physical environments (e.g., adjustable furniture, accessible washrooms, wheelchair ramps)
 8. Accommodations for mental health needs (e.g., additional breaks, quiet workspaces)
 9. Access to emotional or psychological support (e.g., counselling, therapy)
 10. Accommodations for sensory needs (e.g., quiet spaces, sensory rooms)

3. Gender indicator

- *Medical interventions received or gender reassignment:*
 1. Hormone replacement therapy (HRT): This involves taking hormones (testosterone or oestrogen) to bring a person's hormone levels in line with their gender identity.
 2. Gender confirmation surgery: This refers to surgical procedures to alter a person's genitalia to match their gender identity.
 3. Facial feminisation surgery (FFS): This refers to a series of surgical procedures designed to alter a person's facial features to create a more feminine appearance.
 4. Breast augmentation or reduction surgery: This refers to surgical procedures to alter the size and shape of a person's breasts.
 5. Voice therapy: This involves training to modify a person's voice to match their gender identity.

6. Electrolysis or laser hair removal: This refers to hair removal procedures to eliminate unwanted hair growth in areas like the face or chest.
7. Counselling or therapy: This can include individual or group counselling to help individuals navigate the social and emotional challenges of transitioning.

4. National identity or nationality indicator

1. Passport held
2. Age of arrival in the UK
3. Length of residence

5. Language indicator

1. Proficiency of Welsh