

Demographic and equity, equality, diversity and inclusion (EEDI) survey

Survey template and reporting guidance

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This document contains a template guide for how to ask demographic and equity, equality, diversity and inclusion (EEDI) questions, in a way that's clear, respectful and inclusive. It also contains guidance on how to report this data back to us.

We're committed to making MS research more inclusive. Collecting demographic and EEDI information helps us understand who's taking part in research. And, most importantly, who isn't. That's why we now require all the clinical research we fund to collect demographic and EEDI information from their participants. We also ask for this data to be reported back to us. We'll use the data to identify gaps in representation and to be more transparent about how inclusive the clinical research landscape is for people with MS in the UK.

We've developed this template following the [Diversity and Inclusion Survey \(DAISY\) guidance](#), and in consultation with UK MS clinical trial experts. It's designed to help research teams ask questions in a way that helps participants feel comfortable sharing information about themselves.

Using this template helps you make sure:

- Questions are clear, respectful and inclusive for all participants
- Participants can provide accurate responses that best reflect their identity
- Data can be collected and reported consistently across studies. To help us see how inclusive UK MS research really is.

We encourage all MS clinical trials in the UK to use this template. Not just the ones we fund.

You can find additional guidance to help you collect, store and share demographic and EEDI data in our FAQ's document within the resources section on our [EEDI hub](#).

How to use this template and guidance

When collecting and reporting demographic data, we recommend that all clinical studies use the question format provided in this template. This helps us combine data across all our studies, to get a clear, consistent picture of who's taking part in MS research

We know that asking all the questions provided places an additional burden on both trial teams and participants. If you can't ask every question, choose as many as you can that're the most relevant and practical for your study. You can also split the questions up to make things easier. For example, you could ask about age, sex and ethnicity at trial screening stage, and ask the remaining questions later at randomisation stage.

When reporting results, share them as numbers and percentages (for example, 45 out of 100 participants = 45% identify as women). Some questions have extra reporting requirements. These additional requirements are detailed below each question.

To protect participants' privacy, only report data once you have at least 10 participants.



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For many trials, prior analysis plans require that a response must be entered. If so, “Prefer not to say” options may be removed. But we ask you to think about whether a response is always needed when your designing your analysis plans.

If you have questions, please contact us at research@mssociety.org.uk.

Demographic survey template questions

1. Age

What is your age?

- Up to and including 24 years
- 25-34 years
- 35-44 years
- 45-54 years
- 55-64 years
- 65-74 years
- 75+ years
- Prefer not to say

Key notes:

- You may also collect date of birth and retrospectively calculate age at participation according to the above categories
- Don't report individual ages, or as a summary of mean and standard deviation. Data should be reported to us as frequency and proportions of people within each of the age categories above (i.e 10/100: 10% of the trial population are 25-34 years of age).
- Report age once per participant (age at screening or randomisation), to avoid confusion if participants move between age categories over the course of a trial.

2. Ethnicity

What ethnic group do you identify with?

Choose **one** option that best describes your ethnic group or background:

Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, please describe
.....

Black/African/Caribbean/Black British

- African
- Caribbean

<ul style="list-style-type: none"> Any other Black/African/Caribbean background, please describe
<p>Mixed/Multiple ethnic groups</p> <ul style="list-style-type: none"> Asian and White Black Caribbean and White Black African and White Any other Mixed/Multiple ethnic background, please describe
<p>White</p> <ul style="list-style-type: none"> British/English/Welsh/Scottish/Northern Irish Irish Gypsy or Irish Traveller Roma Any other White background, please describe
<p>Any other ethnic group</p> <ul style="list-style-type: none"> Arab Hispanic Latina/Latino/Latinx Any other ethnic group, please describe
<p>Prefer not to say</p>

Key notes:

- We understand that these ethnicity options may not completely describe a person’s individual background, particularly being limited to choosing one ethnicity description. However, we’ve chosen these questions to allow us to compare with the UK 2021 census and make conclusions based on the general UK population.

3. Sex, Gender and Gender Identity Questions

Asking participants about their gender identity rather than their biological sex can provide a more accurate reflection of their lived experience. In some studies, collecting gender identity only may be sufficient, to minimise the amount of data collected. However, in other studies, it may be necessary to collect sex as well. You should choose the approach that’s most appropriate for your study.

<p>What is your Sex assigned at birth?</p> <ul style="list-style-type: none"> Male Female I would prefer to use my own term which is: (self describe)

-
- Prefer not to say

Key notes:

- If you're concerned about the burden on participants or staff on collecting demographic data, you may choose to prioritise when questions are asked. For example, by asking a core set of questions at the pre-screening or screening stage, and the remainder of questions at later screening or randomisation stages. The following questions may be asked at a later stage to manage burden.

Which of the following best describes your gender identity?

- Female
- Male
- Non-binary
- I would prefer to use my own term which is
.....
- Prefer not to say

Do you identify as trans?

- Yes
- No
- Prefer not to say

5. Sexual orientation

Which of the following best describes your sexual orientation?

- Straight/heterosexual
- Gay man
- Gay woman/ lesbian
- Bi/Bisexual
- Asexual
- Queer
- Pansexual
- Other - I identify in another way, which is:
.....
- Prefer not to say

6. Caring responsibilities

Do you have any caring responsibilities?

That is, do you provide unpaid care anyone who could not manage without your help?
(tick all that apply)

- None
- Primary carer of a child or children (under 18)
- Joint primary carer of a child or children (under 18)
- Primary carer of a disabled child or children
- Joint primary carer of a disabled child or children
- Primary carer or assistant for a disabled adult (18 years or over)
- Joint primary carer or assistant for a disabled adult (18 years or over)
- Primary carer or assistant for an older person or people (65 and over)
- Joint primary carer or assistant for an older person or people (65 and over)
- Secondary carer (another person carries out the main caring role)
- I have caring responsibilities but prefer not to specify what these are
- Prefer not to say

7. Religion

What is your religion or strongly held belief, if any?

- No religion
- Buddhist
- Christian
- Hindu
- Jewish
- Muslim
- Sikh
- Spiritual
- Any other religion or belief (please describe)
.....
- I have a religion or strongly held belief but prefer not to specify what this is
- Prefer not to say

8. Socioeconomic background or status

We understand there's no standard measure of socioeconomic background/status that works for all areas or is suitable for international comparison. Ideally, multiple questions would be asked to best determine socioeconomic background/status. However, if you were to only ask one question, we suggest the following, which has been reported as the best measure of someone's socioeconomic background. We acknowledge this question does not consider social mobility.

What was the occupation of your main household earner when you were aged about 14?

- 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.
- 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.
- 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).
- Other such as: retired, this question does not apply to me, I don't know.
- Prefer not to say

Reporting Socioeconomic background

We suggest reporting socio-economic background in three groups, following this guide:

1. Professional backgrounds - modern professional & traditional occupations (1); senior or junior managers or administrators (2).
2. Intermediate backgrounds - clerical and intermediate occupations (3); small business owners (4).
3. Lower socio-economic backgrounds - technical and craft occupations (5); routine, semi-routine manual and service occupations (6); long-term unemployed (7).
4. Exclude - other (8); I prefer not to say (9).

Socioeconomic Status

We acknowledge many studies ask for socioeconomic status in different ways. We consider the above question on socioeconomic background is the minimum requirement. If you would like to ask further questions to assess socioeconomic status, we recommend you use the following question to report relative deprivation. If this is unsuitable (for example if you have concerns about unblinding participants), please contact us to discuss alternate approaches to reporting socioeconomic status.

What is the first half of your postcode?

For example "AA1"

.....

Reporting Socioeconomic Status

Don't report individual participant postcodes. Please report frequency and percentage of participants in each quintile of the Index of Multiple Deprivation (IMD), according to the most suitable version of the indices. The IMD is a measure of relative deprivation for small, fixed geographic areas of the UK. IMD classifies these areas into five quintiles based on relative disadvantage, with quintile 1 being the most deprived and quintile 5 being the least deprived. Guidance about using IMD can be found [here](#).

If you have questions about this template survey or the reporting guidance, please email us at research@mssociety.org.uk

We're the MS Society.

Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

mssociety.org.uk

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