



## **MRS Best Practice Guide on Collecting Sample Data on Physical Disabilities and/or Mental Health Conditions**

**Updated April 2024**

### **Introduction**

MRS has produced this Best Practice Guide to help practitioners act legally and ethically in collecting data and asking research participants questions on physical disabilities and/or mental health conditions.

### **Scope**

Practitioners are required to give priority to local guidance i.e., where research practice takes place. This guidance is focusing on the collection of data from the UK, although the general principles and examples could apply and/or be adapted for other countries depending upon the cultural and language norms for collecting physical disabilities and/or mental health conditions data.

This guidance does not cover methodological issues relating to inclusive data such as sampling. The methodological issues are explored in separate FAQs which have been developed by the MRS Representation in Research working group.

### **Context**

MRS best practice recommendation is that for research and data collection to be inclusive of the population, all relevant personal characteristics should be included. This ensures that all participants are equally valued, and their opinions and attitudes are being gathered and represented.

Practitioners can also use this guidance to assess whether they are complying with the MRS Code of Conduct in collecting demographic information for these areas including for the purposes of National Representative (Nat Rep) samples. For UK Nat Rep samples to be inclusive of the population age, gender identity, social grade, region, ethnicity, physical disabilities and/or mental health conditions and sexual orientation should all be collected.

This Guidance Note should be used in conjunction with the MRS Code of Conduct and Guidelines.

### **Interpretation of Requirements**

When requirements use the word "must" these are mandatory requirements and is a principle or practice that applies the MRS Code of Conduct, which Members and Company Partners are obliged to follow.

The requirements which use the phrase “should” describe implementation and denotes a recommended practice. “May” or “can” refer to the ability to do something, the possibility of something, as well as granting permission.

### **Explanation of Key Terms**

**Physical disabilities and/or mental health conditions** refer to physical disabilities and/or mental health conditions, illnesses or impairments. These include permanent health conditions and temporary conditions which may occur from time-to-time.

**Legal definition of disability**, as defined by the Equality Act 2010, is if an individual has a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on an individual’s ability to do normal daily activities.

- ‘Substantial’ is more than minor or trivial, e.g., it takes much longer than it usually would to complete a daily task like getting dressed.
- ‘Long-term’ means 12 months or more, e.g., a breathing condition that develops as a result of a lung infection.

There are special rules about [recurring or fluctuating conditions](#), e.g., arthritis.

A progressive condition is one that gets worse over time. People with progressive conditions can be classed as disabled. Individuals automatically meet the disability definition under the Equality Act 2010 from the day they are diagnosed with HIV infection, cancer or multiple sclerosis.

There are some conditions which are not covered by the Equality Act definition of disability such as addiction to non-prescribed drugs or alcohol.

The term ‘disability’ is not always favoured by participants as it can be seen as less inclusive for those with milder long-term health conditions and illnesses. For example, research for the UK Census 2021 found that the term ‘disability’ was considered to be more linked to physical than mental health conditions.<sup>1</sup> However, disabilities is a term that is widely understood. Furthermore, it is important to distinguish between physical and mental health conditions to ensure that all conditions are being included. Therefore, for the purposes of this guidance MRS uses the terms **physical disabilities and/or mental health conditions**.

### **Relevant Definitions from the MRS Code of Conduct (2023)**

**Client:** *A client includes any individual, organisation, department or division, including any belonging to the same organisation as an MRS Member, which is responsible for commissioning or applying the results from a project.*

**Participant:** *is any individual or organisation from or about whom data is collected.*

**Practitioners:** *includes all individuals within the data collection supply-chain e.g., researchers, moderators, interviewers, recruiters, mystery shoppers, contractors, freelancers and temporary workers.*

**Research:** *is the collection, use, or analysis of information about individuals or organisations intended to establish facts, acquire knowledge or reach conclusions. It uses techniques of the applied social, behavioural and data sciences, statistical principles*

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<sup>1</sup> See Health and unpaid care question development for Census 2021: <https://www.ons.gov.uk/census/censustransformationprogramme/healthandunpaidcarequestiondevelopmentforcensus2021>

and theory, to generate insights and support decision-making by providers of goods and services, governments, non-profit organisations and the general public.

**Special category data:** *if the processing reveals racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union Membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.*

**Vulnerable people:** *Vulnerable people means individuals whose permanent or temporary personal circumstances and/or characteristics mean that they are less able to protect or represent their interests (see [MRS Best Practice Guide on Research Participant Vulnerability](#)).*

## **Legal and Regulatory Obligations**

**The MRS Code of Conduct (2023)** contains several requirements covering design, data collection and reporting which are relevant to collecting, using and reporting physical disabilities and/or mental health conditions data. The following are the key requirements:

### Design

The MRS Code (2023) requires practitioners to design research to the specification agreed with clients and to ensure that any data collection is fit for purposes and appropriate for the audience being analysed. When collecting participant data practitioners must not harm or adversely affect participants.

Rule 9 of the MRS Code of Conduct:

*Members must take all reasonable precautions to ensure that participants are not harmed or adversely affected by their professional activities and ensure that there are measures in place to guard against potential harm.*

Rule 11 of the MRS Code of Conduct:

*Members must take reasonable steps to design projects to the specification and/or quality standards agreed with clients.*

### Data Collection

The MRS Code (2023) requires participants to be able to express their views, in a way which they prefer and with the option to not respond.

Rule 28 (c) of the MRS Code of Conduct:

*Members must take reasonable steps to ensure ... c. that participants are able to provide information in a way that reflects the view they want to express, including don't know/prefer not to say.*

### Reporting

The MRS Code (2023) requires practitioners to include sufficient technical information within published data and reports to enable assessment of the validity of the results. In the context of inclusive data, reporting must clarify what sampling characteristics and parameters are used when defining Nationally Representative ('Nat Rep') or City Representative samples. Characteristics which should be considered include physical disabilities and/or mental health conditions.

**MRS' best practice recommendation is that all relevant characteristics should be included for Nat Rep samples to be inclusive of the population e.g., age, gender identity, social grade, region, ethnicity, physical disabilities and/or mental health conditions and sexual orientation.**

The relevant rules are:

Rule 58 of the MRS Code of Conduct:

*Members must ensure that data include sufficient technical information to enable reasonable assessment of the validity of results.*

Rule 59 of the MRS Code of Conduct:

*Members must ensure that reports include sufficient information to enable reasonable assessment of the validity of results*

**The Data Protection Act 2018 and the UK GDPR** requires a legal basis for processing of personal data. Some personal data is categorised as 'special category data' and is subject to additional requirements when being collected.

Personal data categorised as special category data is data on:

- religious or philosophical beliefs
- health
- racial or ethnic origin
- trade union membership
- political beliefs
- sex life or sexual orientation
- genetic data
- biometric data (including photos when used for the purpose of uniquely identifying a natural person) of data subjects

Data on physical disabilities and/or mental health conditions is categorised as special category data.

Special category data needs to be treated with greater care as collecting and using it is more likely to interfere with individual's fundamental rights or result in discrimination. This is part of the risk-based approach of the UK GDPR.

Researchers processing physical disabilities and/or mental health conditions data as well as personal data will need to have a legal basis for the data being processed. When processing special category data practitioners must have a lawful basis under Article 6 of the GDPR in addition to meeting a special condition under Article 9 of the GDPR but these grounds do not have to be linked. The MRS GDPR in Brief No.10 - Collection of Ethnic Data and Other Special Category Data provides guidance on what practitioners need to do to meet these requirements and checklists to help to identify what practitioners need to do to collect sensitive special category data such as physical disabilities and/or mental health condition data in accordance with GDPR.

There is no restriction for processing any special category data such as physical disabilities and/or mental health conditions as long as the requirements of Article 6 and Article 9 are being met, and practitioners fully document what they do when collecting special category data and how they do it.

**Equalities Act 2010** protects people from discrimination in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law

easier to understand and strengthening protection in some situations. It sets out the different ways in which it is unlawful to treat someone.<sup>2</sup>

It is against the law to discriminate against anyone because of:

- age
- gender reassignment
- being married or in a civil partnership
- being pregnant or on maternity leave
- [disability](#)
- race including colour, nationality, ethnic or national origin
- religion or belief
- sex
- sexual orientation

These are called 'protected characteristics' and some physical disabilities and/or mental health conditions are included as disabilities within the legislation.

Individuals are protected from discrimination:

- at work
- in education
- as a consumer
- when using public services
- when buying or renting property
- as a member or guest of a private club or association

### **Ethical Design Considerations**

1. Practitioners must take reasonable steps to design projects collecting physical disabilities and/or mental health condition data to the specification or quality standards agreed with clients; this includes which characteristics and parameters are to be used when identifying participants with physical disabilities and/or mental health conditions. Collection of physical disabilities and/or mental health conditions questions need to be appropriately tailored to the data collection tool.
2. Practitioners must ensure that participants will be able to proceed with any data collection about physical disabilities and/or mental health conditions without being required to respond if they do not wish to.
3. Practitioners must include the response options 'don't know' and 'prefer not to say' when gathering physical disabilities and/or mental health data from participants to meet the MRS Code of Conduct data collection requirements.
4. Practitioners must consider the [MRS Best Practice Guide on Research Participant Vulnerability](#) when collecting physical disabilities and/or mental health condition data as participants with such conditions may also be vulnerable.
5. Practitioners should consider the following when collecting physical disabilities and/or mental health condition data from participants:
  - ***Provide adequate preamble/context before physical disabilities and/or mental health questions are asked: this is an example of a very sensitive question, and it is important that participants are pre-warned that this type of questioning is to be included***

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<sup>2</sup> The Equality Act 2010 does not apply to Northern Ireland although the obligations are very similar. See: <https://www.nidirect.gov.uk/articles/your-rights-if-you-have-disability>

- **Be clear as to which category of physical disabilities and/or mental health condition data needs to be collected:** physical disabilities and/or mental health conditions are combined concepts, and the aims and nature of any data collection may determine whether practitioners need to separate the characteristics or collect them together or consecutively. It should be noted that physical disability health conditions significantly increase the risk of developing mental health problems and vice versa. For example, one in three people with a long-term physical disability health condition also has a mental health condition such as depression or anxiety.
- **Physical disabilities and/or mental health conditions questions should be placed together:** research such as that undertaken for the England and Wales Census 2021, shows that questions on the same topic should be placed together where possible.<sup>3</sup>
- **Encourage clients to consider the level of detail required:** collecting data about physical disabilities and/or mental health conditions can be considered intrusive. Ensuring that only necessary information is collected is particularly important when collecting in-depth information about physical disabilities and/or mental health conditions. The level of detail required for a project should be reviewed to ensure that it is appropriate, proportionate and balanced.
- **Respect privacy of participants:** ensure that steps are taken to maintain confidentiality of responses, and this is conveyed to participants. Persons who reveal physical disabilities and/or mental health conditions may be particularly concerned about the privacy and confidentiality of their responses.

6. Practitioners must report on the characteristics and parameters used when reporting on samples which are described as either Nat Rep or City Rep.

### **Examples of Question and Response Options**

There is no one size fits all question and response approach to collecting data about physical disabilities and/or mental health conditions.

The following are real examples of how physical disabilities and/or mental health conditions data can be collected.

#### **1. Determining the general health of participants**

**An example of a low participant burden question and response option to determine general state of health (taken from the England and Wales Census 2021). The response options to this question are not aligned to the MRS Code of Conduct requirements as it did not include don't know and prefer not to say. If practitioners were to use this question, they would need to expand the response options to include these two additional options. These have been added (in red text) to show how this question could be used and be in adherence to MRS Code requirements.**

*How is your health in general?*

- Very good
- Good
- Fair
- Bad
- Very bad
- Don't know

<sup>3</sup> See Health and unpaid care question development for Census 2021: <https://www.ons.gov.uk/census/censustransformationprogramme/healthandunpaidcarequestiondevelopmentforcensus2021>

- Prefer not to say

## **2. Determining longer-term physical disabilities and/or mental health conditions**

**An example of a medium participant burden question and response option to determine if participants have any physical and/or mental health conditions (taken from the England and Wales Census 2021). This includes an explanation of terms although this is not necessary if terms are commonly understood.**

**The response options to this question are not aligned to the MRS Code of Conduct requirements as it did not include don't know and prefer not to say. If practitioners were to use this question, they would need to expand the response options to include these two additional options. These have been added (in red text) to show how this question could be used and be in adherence to MRS Code requirements.**

*Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?*

- Yes
- No
- Don't know
- Prefer not to say

What we mean by "physical and mental health conditions or illnesses": This is about health conditions, illnesses or impairments you may have. Consider conditions that always affect you and those that flare up from time to time. These may include, for example, sensory conditions, developmental conditions or learning impairments.

## **3. Determining the impact of physical disabilities and/or mental health conditions**

**An example of a low participant burden question and response options to determine if participants have any physical and/or mental health conditions (taken from the England and Wales Census 2021). This includes an explanation of terms. This would be a follow-up question for those who provide a 'yes' response to a question such as question 2 above.**

**The response options to this question are not aligned to the MRS Code of Conduct requirements as it did not include don't know and prefer not to say. If practitioners were to use this question, they would need to expand the response options to include these two additional options. These have been added (in red text to show how this question could be used and be in adherence to MRS Code requirements**

*Do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?*

- Yes, a lot
- Yes, a little
- Not at all

- Don't know
- Prefer not to say

What we mean by "reduce your ability"

This is about whether your health condition or illness currently affects your ability to carry out day-to-day activities.

Consider whether you are still affected while receiving any treatment, medication or using any devices for your condition or illness. For example, if you use a hearing aid and are not restricted in carrying out your day-to-day activities when doing so, select "Not at all".

You should select "Yes, a lot" if you usually need some level of support from family members, friends or personal social services for most normal daily activities.

**An example of a low participant burden question and response options to determine the degree to which participants have physical and/or mental health conditions. This example meets MRS Code requirements by allowing participants to respond with either 'don't know' or 'prefer not to say'.**

*Does your condition or illness reduce your ability to carry out day-to-day activities?*

- *Yes, a lot*
- *Yes, a little*
- *Not at all*
- *Don't know*
- *Prefer not to say*

*To assist with interpretation of day-to-day activities, these can include:*

- *washing and dressing*
- *household cleaning*
- *cooking*
- *shopping for essentials*
- *using public or private transport*
- *walking a defined distance*
- *climbing stairs*
- *remembering to pay bills*
- *lifting objects from the ground or a work surface in the kitchen*
- *moderate manual tasks such as gardening*
- *gripping objects such as cutlery*
- *hearing and speaking in a noisy room*

The participant should answer based on their current activity restriction. They should consider any treatment they receive, medication they take or other devices they use (such as a hearing aid).

**An example of a medium burden question and response options to determine types of physical and/or mental health conditions (created by Voices4All). This example meets MRS Code requirements by allowing participants to respond with either 'don't know' or 'prefer not to say'. Practitioners however would**



**need to have a specified purpose to require this level of detail e.g., the focus of a project is physical disabilities and/or mental health conditions.**

*Do you have any of these long-standing physical and/or mental health conditions so much that you have substantial difficulties with any of these areas of your life?*

*By 'long-standing' we mean anything that has troubled you over a period of at least 12 months or that is likely to affect you over a period of at least 12 months.*

- a. Mobility (moving about)
- b. Lifting, carrying or moving objects
- c. Manual dexterity (using your hands to carry out everyday tasks)
- d. Continence (bladder and bowel control)
- e. Communication (speech, hearing or eyesight)
- f. Memory or ability to concentrate, learn or understand
- g. Recognising when you are in physical danger
- h. Your physical co-ordination (e.g., balance)
- i. Other health problem or disability
- j. None of these
- k. Prefer not to say

## **Checklist:**

Practitioners should ask themselves and their clients the following questions when undertaking projects which use, collect or report data on physical disabilities and/or mental health conditions:

### **Design**

1.  What type of data does the client want me to collect?
2.  If a project is using Nat Rep or City Rep samples, does this definition include participants with physical disabilities and/or mental health conditions?

### **GDPR**

3.  Do I need to collect physical disabilities and/or mental health conditions information?
4.  Is there a research purpose for collecting physical disabilities and/or mental health condition data?
5.  Are the physical disabilities and/or mental health conditions data being collected relevant and not excessive?
6.  Are the physical disabilities and/or mental health conditions data needed to meet Nat Rep requirements or is it for another purpose?
7.  Is a Data Protection Impact Assessment (DPIA) and/or an ethics review required for this project?
8.  Has a DPIA and/or ethics review been completed and are there any changes and/or mitigations needed?

### **Question Design**

9.  What information do I need to gather from the participants?
10.  Is the question/s suitable for the physical disabilities and/or mental health information I need to gather?
11.  Do I need to combine physical disabilities and/or mental health conditions?
12.  Should I separate the physical disabilities and/or mental health conditions? If so, should the questions be asked consecutively, and in what order?

### **Response Options**

13.  Can the physical disabilities and/or mental health conditions responses be optional?
14.  What response options should I provide?
15.  Should I provide closed categories for response options or open fields?
16.  Are 'don't know' and 'prefer not to say' options included in the response options?

### **Vulnerability**

17.  Are the participants from whom physical disabilities and/or mental health conditions data is being collected likely to be vulnerable?

18.  If there are vulnerable participants, has the [MRS Best Practice Guide on Research Participant Vulnerability](#) been referred to?

### **Reporting**

19.  Does the report detail the characteristics and parameters used for determining any Nat Rep or City Rep samples?
20.  Does the report contain sufficient information to determine the validity of any results reported, including sampling parameters?

### **Useful Information Sources**

- MRS: [MRS Code of Conduct 2023](#)
- MRS: [GDPR in Brief: Collection of Ethnic Data and Other Special Category Data](#)
- MRS: [MRS Guidelines: Essential Safeguards – Dealing with discriminatory comments](#)
- MRS: [Best Practice Guide on Research Participant Vulnerability](#)
- Government Statistical Service (GSS): [Mental health harmonisation guidance](#)
- GSS: [Long lasting health conditions and illness harmonised standard](#)
- GSS: [Activity restriction harmonised standard](#)
- ONS: [Health and unpaid care question development for Census 2021](#)
- NISRA: [Health and disability question for Census 2021](#)
- Scope: [General disability guidance and best practice](#)
- Voices4All: [Demographic questions](#)
- Voices4All: [Sampling and weighting questions](#)
- UK Government: [Disability Unit](#)