



MRS Best Practice Guide on Accessible Data Collection Activities

June 2025



Introduction

The aim of this document is twofold:

- To provide an overview of the European Accessibility Act 2025 and its implications for practitioners; and
- To bring together relevant, existing MRS guidance into one document as a useful reference of the legal and ethical issues to be considered when undertaking research with practitioners with accessibility considerations. The guidance includes:
 - MRS Senior Client Council Diversity & inclusion Best Practice Guides: Accessibility by Design Guidance for Clients
 - MRS Best Practice Guidance: Collecting Sample Data on Physical Disabilities and/or Mental Health Conditions
 - MRS Guidance: Essential Safeguards series: 7. Conducting Data Activities with Neurodiverse Individuals

The European Accessibility Act (EAA) 2025

The European Accessibility Act (EAA), which aims to improve the accessibility of products and services for people with disabilities within the EU, will come into force on June 28, 2025. The EAA applies to any organization that provides products and services to consumers in the EU, including businesses and public bodies in the UK. While the UK is not a member of the EU, it is still expected to comply with the EAA if it sells products or services to EU consumers.

Key aspects of the EAA

Scope:

The EAA covers a wide range of products and services, including digital products like websites and apps, and physical products like ATMs and ticketing machines.

Compliance:

Businesses must ensure their products and services meet specific accessibility requirements, aiming for a minimum level of accessibility.

Accessibility standards:

The EAA aims to harmonize accessibility requirements across the EU, potentially reducing costs and simplifying cross-border trade for businesses.

Impact on UK businesses:

While not directly bound by the EAA, UK businesses that sell products or services to EU consumers will need to ensure compliance to avoid legal and reputational risks.

Benefits for individuals:

Persons with disabilities and elderly people should benefit from the EEA in the following ways:

- More accessible products and services in the market
- Accessible products and services at more competitive prices
- Fewer barriers when accessing transport, education and the open labour market
- More jobs available where accessibility expertise is needed

Enforcement and Penalties:

Each member state is responsible for enforcement, which means they can appoint the body in charge of enforcement and decide penalties. Failure to comply with the EAA could result in fines and other penalties, depending on the severity of the non-compliance. Each Member states oversee their own penalties for noncompliance, which should be “effective, proportionate, and dissuasive.”

Reporting Non-Compliance:

Each member state must make it possible for consumers to report noncompliance to either the courts or the body in charge of enforcing the law in that country.

Products and services covered:

The EAA covers products and services that have been identified as being most important for persons with disabilities while being most likely to have diverging accessibility requirements across EU countries.

The European Commission consulted stakeholders and experts on accessibility and took into account the obligations deriving from the UN convention on persons with disabilities. These products and services include:

- computers and operating systems
- ATMs, ticketing and check-in machines
- smartphones
- TV equipment related to digital television services
- telephony services and related equipment
- access to audio-visual media services such as television broadcast and related consumer equipment
- services related to air, bus, rail and waterborne passenger transport
- banking services
- e-books
- e-commerce

Scope of the EAA

There are a few specific instances that are exempt from compliance:

- Pre-recorded time-based media (e.g., videos) published before June 2025
- Office file formats published before June 2025
- Online maps, if essential information is otherwise provided in an accessible way
- Third-party content that is not funded, developed, or under the control of an organization that must be compliant
- Archived content that won't be updated after June 2025

There is also an exception for what the act calls "micro-enterprises," which are companies with less than 10 employees and an annual balance sheet total not exceeding €2 million.

The EEA and Research Activities

Whilst the Act is primarily aimed at public-facing digital services, its scope extends to any research activities which are public/consumer facing, e.g., research panels and survey platforms where participants use digital access.

Practitioners engaged in direct public/consumer activities such as managing research panels and research platforms, must ensure these systems comply with accessibility standards, such as the Web Content Accessibility Guidelines (WCAG). This includes features such as text-to-speech, keyboard navigation, screen reader compatibility, colour contrast for visual clarity, etc.

The EEA requirements will also apply when practitioners are working with third parties and subcontractors providing public facing services. Where appropriate, the requirement to adhere to the EEA should be included in contractual obligations.

More generally, Practitioners within scope of the EEA should start with a general "Design for All" approach that ensures that digital activities are equally usable and accessible by everyone.

EEA Useful Information Sources

Below are some guidelines and resources to help practitioners to meet the requirements of the EEA:

- Web Content Accessibility Guidelines 2.2:
<https://www.w3.org/TR/WCAG22/>
- Understanding WCAG2.2: <https://www.gov.uk/service-manual/helping-people-to-use-your-service/understanding-wcag>
- Making your services accessible – an introduction:
<https://www.gov.uk/service-manual/helping-people-to-use-your-service/making-your-service-accessible-an-introduction>
- Testing for accessibility: <https://www.gov.uk/service-manual/helping-people-to-use-your-service/testing-for-accessibility>
- Sample accessibility statement:
<https://www.gov.uk/government/publications/sample-accessibility-statement/sample-accessibility-statement-for-a-fictional-public-sector-website>
- Designing for different browsers and devices:
<https://www.gov.uk/service-manual/technology/designing-for-different-browsers-and-devices>

The following are existing MRS guidance documents which provide some further advice on accessibility by design, and when conducting data collection with participants with physical disabilities and/or mental health conditions including specific advice when conducting research with neurodiverse individuals.

Practitioners may find this further guidance helpful when considering the wider implications of accessibility across all methods and modes.

Introduction

This guidance provides a client perspective on inclusion and has been prepared by members of the MRS Senior Client Council and client colleagues.

The MRS Code of Conduct requires transparent information about which sampling characteristics and parameters have been used when defining samples as representative of segments of the population, such as when reporting Nationally Representative samples. For detailed guidance on the ethical and legal issues, including MRS Code of Conduct requirements, please refer to the following:

- [MRS Best Practice Guide on Collecting Sample Data on Sexual Orientation](#)
- [MRS Best Practice Guide on Collecting Data on Sex and Gender](#)
- [MRS Best Practice Guide on Collecting Sample Data on Physical disabilities and/or mental health conditions](#)
- [MRS Best Practice Guide on Collecting Ethnicity Sample Data](#)

For accessibility issues it is recommended that the [MRS Best Practice Guide on Collecting Sample Data on Physical disabilities and/or mental health conditions](#) is referred to in conjunction with this document.

For further advice about client-side inclusion issues, it is recommended that the following MRS Senior Client Council guidelines are referred to in conjunction with this document:

- [Diversity & Inclusion Best Practice Guides: Working with Research Agencies and Suppliers to Ensure Inclusive Samples](#)
- [Diversity & Inclusion Best Practice Guides: Use of Language](#)
- [Diversity & Inclusion Best Practice Guides: Use of Different Methods](#)
- [Diversity & Inclusion Best Practice Guides: Sampling Methods](#)

Why Accessibility is Important

Representation is about more than just quotas; it's about ensuring participants can respond. An important step in preparing for research is understanding who is in the sample and their needs and requirements for reasonable adjustments. As clients look to make samples more diverse and inclusive, clients need to consider issues around accessibility.

ALL methodologies come with compromises: clearly recognise the limitations, and declare them as part of the research process.

Good design principles are applicable to everyone and not just those with access needs, and clients should be building accessibility into the design of research rather than retrofitting after build is complete.

There are many different types of disabilities or difficulties that may restrict participants access to research:

- When client content is accessible, clients can connect with a larger audience
- If individuals cannot access client materials such as questionnaires, they will abandon it, causing clients to lose their participation and feedback

Remember, even if clients are sampling on certain characteristics, clients will never truly know what each participant is dealing with. Therefore, it's important to design research projects as accessible as possible, for all.

Whilst one of the benefits of online research is that participants can take their time and read, and re-read, content as often as required, clients should also be making sure the content is as easy to understand as possible from the start.

There are several things to consider for our research to be easier to understand:

- Use clear, concise language
- Avoid jargon and idioms
- Identify and explain abbreviations
- Keep reading level at, or below, secondary education level where possible

- Use labels or instructions when content requires input
- Phrase questions so they can be answered with short responses
- Provide text alternatives for any non-text content (controls, images etc.)
- Ensure videos are appropriately captioned
- Headings, labels, and titles should be used to describe topics and the purpose of the content
- Use descriptions if an input error occurs
- Consider providing a glossary of key terms within the questionnaire
- Provide context-sensitive help

It is important to remember that participants may be utilising their own tools which help them (such as screen readers). Clients need to ensure that any research outputs, such as surveys and questionnaires, are properly compatible and programmed to function appropriately with assistive technology.

- Content should be simply navigated with a range of input devices
- Content should be operable with a keyboard interface

As well as ways to make the content easier to understand, practitioners need to ensure they are presenting client surveys in the most accessible manner possible. Clients should be considering with their suppliers different ways of presenting information, balancing what is appropriate to the content of the research with what is going to be most universally understandable

Some examples include:

For Quantitative research:

- Using visual stimuli and images to illustrate ideas or concepts
- Using faces (rather than a number scale) can be more inclusive for those who English isn't first language, as well as those with specific learning difficulties
- Ensure adequate contrast between text, background, and images
- Do not use colour as the only means of conveying information

For Qualitative research:

- Consider any materials being shown (colour of text etc.)
- Consider how you set up the room – and allow people to choose where they sit
- Allow participants to complete tasks in their own time/at their own

speed

- Have the technology to support virtual groups, such as closed captioning
- Allow participants extra time if needed

Remember to consider the compromise between amount of content covered and the length of any data collection: Staring at a screen is exhausting which can have an underlying effect upon participants' cognitive abilities and focus – especially for participants with specific learning difficulties but is an important consideration for all participants.

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.¹ 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***.

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

Relevant Definitions from the MRS Code of Conduct (2019)

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 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 (2019) 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 (2019) 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 (2019) 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 (2019) 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.²

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.

² 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>

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
 - **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.³
- **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.
- **Balance data collection needs against the potential for intrusion:** whilst collecting inclusive data is important, participants also should be protected from harm and have the right to a private life. Consider how physical disability and/or mental health conditions data is collected, why it is being collected and implement measures to reduce the level of intrusion and potential for participant harm.
- **Privacy notice:** The inclusion of Special Category of Personal Data must be covered in the Privacy Notice. Consideration on whether there should be a link to the Privacy Notice at the appropriate point in any data collection materials.
- **Open responses:** Self-completion and online tools should, as a minimum, include an open field for participants to answer in a way that reflects their response if it does not fit in with any of the response options provided. Interviewer-aided techniques for collecting information need to build in a level of discretion and flexibility for interviewers, to ensure the questions are responsive and are handled sensitively by interviewers.
- **Provide additional guidance:** the language for physical disabilities and/or mental health conditions can be challenging, and practitioners should consider providing additional guidance to support participants when selecting response options appropriate to their conditions (see GSS example below).

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

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

An example of extra guidance: the GSS long lasting health conditions and illness harmonised standard provides some guidance on what is and is not covered by the standard. This list could be used and adapted by practitioners to provide support for participants when answering questions about physical disabilities and/or mental health conditions.

As a guide long lasting health conditions and illnesses includes physical or mental health conditions:

- lasting or expected to last for 12 months or more
- that a person is likely to have for the rest of their life
- that are likely to need some level of supervision and treatment over a long period of time
- that are not curable, even if medication or treatment can control symptoms
- which flare up intermittently, but the exacerbation has a shorter duration than 12 months (e.g., hay fever)
- which may not be perceived as serious and do not affect day-to-day activities but are nevertheless long lasting
- which are managed by treatment and lifestyle adjustments and do not affect day-to-day activities, but are nevertheless long lasting

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. There is however some guidance and established questions and response options covering physical and mental health conditions available from GSS and ONS which are widely used in the UK. For example:

- GSS mental health guidance is available [here](#).
- GSS long lasting health conditions and illness harmonised standard is available [here](#).
- GSS activity restriction harmonised standard is available [here](#).

It should be noted that the GSS is updating the current standard looking at evidence such as the ethnic group questions and output classifications for the Census 2021 for England and Wales, the Census for Northern Ireland and the recommended questions for Scotland's 2022 Census.

In October 2020, the National Statistician established the [Inclusive Data Taskforce](#). It was designed to improve the UK's inclusive data this includes disability and mental health conditions within its priorities. In response to the recommendations, the ONS oversaw the publication of an [Implementation Plan](#) in January 2022. This gives information about the current and planned initiatives across the UK statistical system. It refers to a [GSS Harmonisation workplan](#), which was published in February 2022. This workplan includes reviewing, refining, and updating harmonised standards.

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

7. Determining the general health of participant

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
- Prefer not to say

This standard does not capture temporary conditions, however serious they might be.

1. 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.

1. 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

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

Question Design

1. What information do I need to gather from the participants?
2. Is the question/s suitable for the physical disabilities and/or mental health information I need to gather?
3. Do I need to combine physical disabilities and/or mental health conditions?
4. 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

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

Vulnerability

1. Are the participants from whom physical disabilities and/or mental health conditions data is being collected likely to be vulnerable?
2. If there are vulnerable participants, has the [MRS Best Practice Guide on Research Participant Vulnerability](#) been referred to?

Reporting

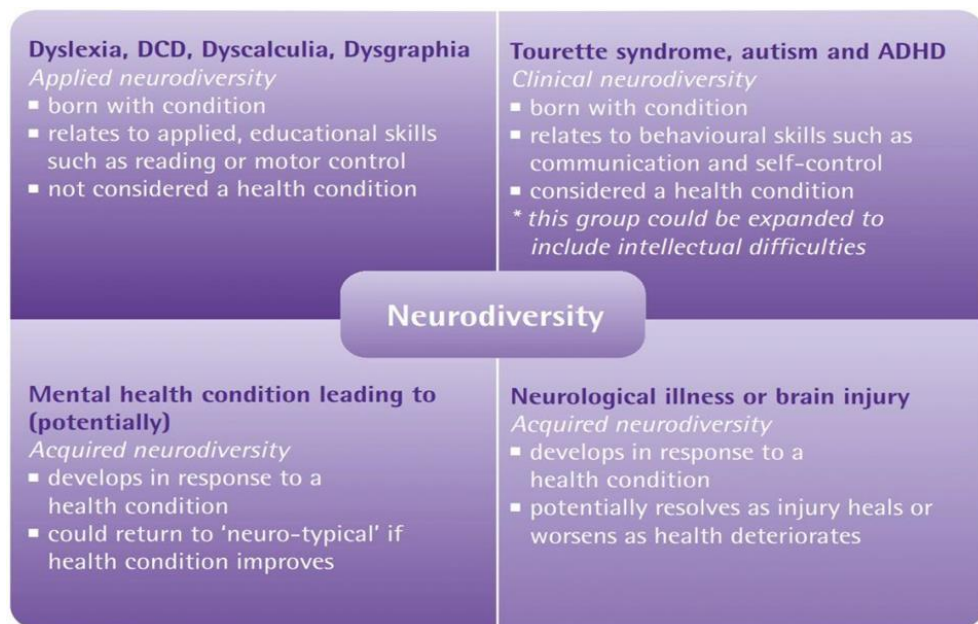
1. Does the report detail the characteristics and parameters used for determining any Nat Rep or City Rep samples?
2. Does the report contain sufficient information to determine the validity of any results reported, including sampling parameters?

Useful Information Sources

- MRS: [MRS Code of Conduct 2019](#)
- 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](#)

MRS Guidance:
 Essential Safeguards series: No.7
 Conducting data activities with neurodiverse individuals
 (August 2024)

Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits. Many neurodivergent individuals, including those with conditions like ADHD, autism, or dyslexia, may not display noticeable signs of their neurodivergence. It exists on a spectrum, from mild to severe, so some people can excel in daily life and may not identify as disabled or seek a formal diagnosis. This variability is common, affecting about 1 in 4 people. ND types, spectrum conditions and where they overlap



Scope of guidance

The guidance aims to help practitioners consider the needs of mild, moderate and severe neurodiverse individuals when conducting their professional activities. The relevant clause within the MRS Code of Conduct (2023):

MRS Code Rule 9:

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.

What to keep in mind when conducting data activities with neurodiverse individuals

Keep in mind that an individual's processing style can affect their experience in research and data collection participation, including interactions with and reactions to research and data materials, such as stimulus materials. It's important to remember that task completion may vary for people with diverse cognitive profiles, and not all research and data tools are accessible to them. Practitioners also need to be mindful of managing impressions and interactions. Neurodiverse participants may need a greater sense of stability and predictability, as well as more time to process questions and think through answers. Neurodiverse participants may interpret social cues uniquely, and their levels of energy and enthusiasm may differ. Practitioners need to check their social expectations, such as engagement in qualitative research discussions, be aware of biases, and avoid judging mannerisms, repetitive movements, or a lack of interest in small talk.

Designing inclusive research sessions

When designing research practitioners should consider neurodiverse participant needs. For example:

Accessibility

- Need for multiple formats
- Clear and concise instruction - sign post who to ask if any queries
- Assistive tools - let people use any assistive tools they would find helpful, or they normally use for reading etc
- Think about physical environment if face to face, is it comfortable, well lit, no annoying noises etc and how session is organised, and timings e.g. have some fidget toys available in group discussions for anyone to use
- Offer breaks or regular opportunities to move about - e.g. stand up and stretch

Communication

- Encourage open communication and make sure everyone knows they can ask questions or for clarification if they need it/ want to as it will help everyone
- Use clear, concise, everyday language
- Offer written & verbal communication options and one to one feedback if needed
- Give enough time to think, pause and reply, don't try and cram too much in and keep firing questions.

Inclusivity

- Actively recruit an inclusive sample and ask what people need to be able to participate in the research comfortably
- Allow participants to self-identify
- Don't make assumptions - contact beforehand to make sure you aren't assuming what they need or can/ can't do, listen to them instead!

Plan session stimulus

During the planning phase, practitioners should ensure that any participant stimulus materials (design, mock-ups, concepts, images) are accessible. For example:

- Use accessible authoring tools to prepare content to be shared.
- Any content shown should create clear expectations at all levels (including titles, links, labels, instructional text, etc.).

- Reduce presentation animations and flickering.
- Provide written transcripts or pictorial summaries which can be useful for people with cognitive differences, such as those who may not remember details of content previously presented.

Remove participation barriers

Practitioners should start removing participation barriers from the beginning of any research or data collection activities such as when issuing research invitations.

Practitioners should also state that they are happy to discuss any reasonable adjustments required for participating in research and data collection activities.

Practitioners should communicate details of the research and/or data collection process, so participants know what to expect from the beginning.

Make participants feel comfortable

Practitioners should help orient and make users feel comfortable, by setting clear expectations from the beginning, and provide predictability during any research or data collection activities. For example:

- Go over logistics.
- Provide an overview of what to expect during any discussion.
- Allow for additional time to enable neurodiverse research participants to adjust to new environments.

Practitioners can also find ways to block out distractions. If practitioners conduct a virtual interview or focus group, make sure pets or family members won't interrupt, and there are no distracting noises in the background. For in-person meetings, choose a quiet room and ask everyone to silence their mobile devices. Avoid large groups and sensory overload.

During the session:

When practitioners are undertaking research and data collection activities they should:

- Avoid jargon and metaphors and spell out acronyms.
- Read instructions out loud – even if written text is provided.
- Speak in a direct manner, as opposed to hinting or using irony. Keep your questions short, clear and direct.

- Keep tasks short.
- Create interactions that allow for multiple methods to achieve the same goal. For example, if users are not comfortable expressing their opinion while talking, allow them to write it down instead.
- If neurodiverse research participants get mentally or physically tired, provide breaks or offer to finish up another day.

Useful information sources

[MRS Diversity and Inclusion Best Practice Guides and FAQs](#)

[MRS Unlimited](#)

[ADHD Aware](#)

[The ADHD Foundation](#)