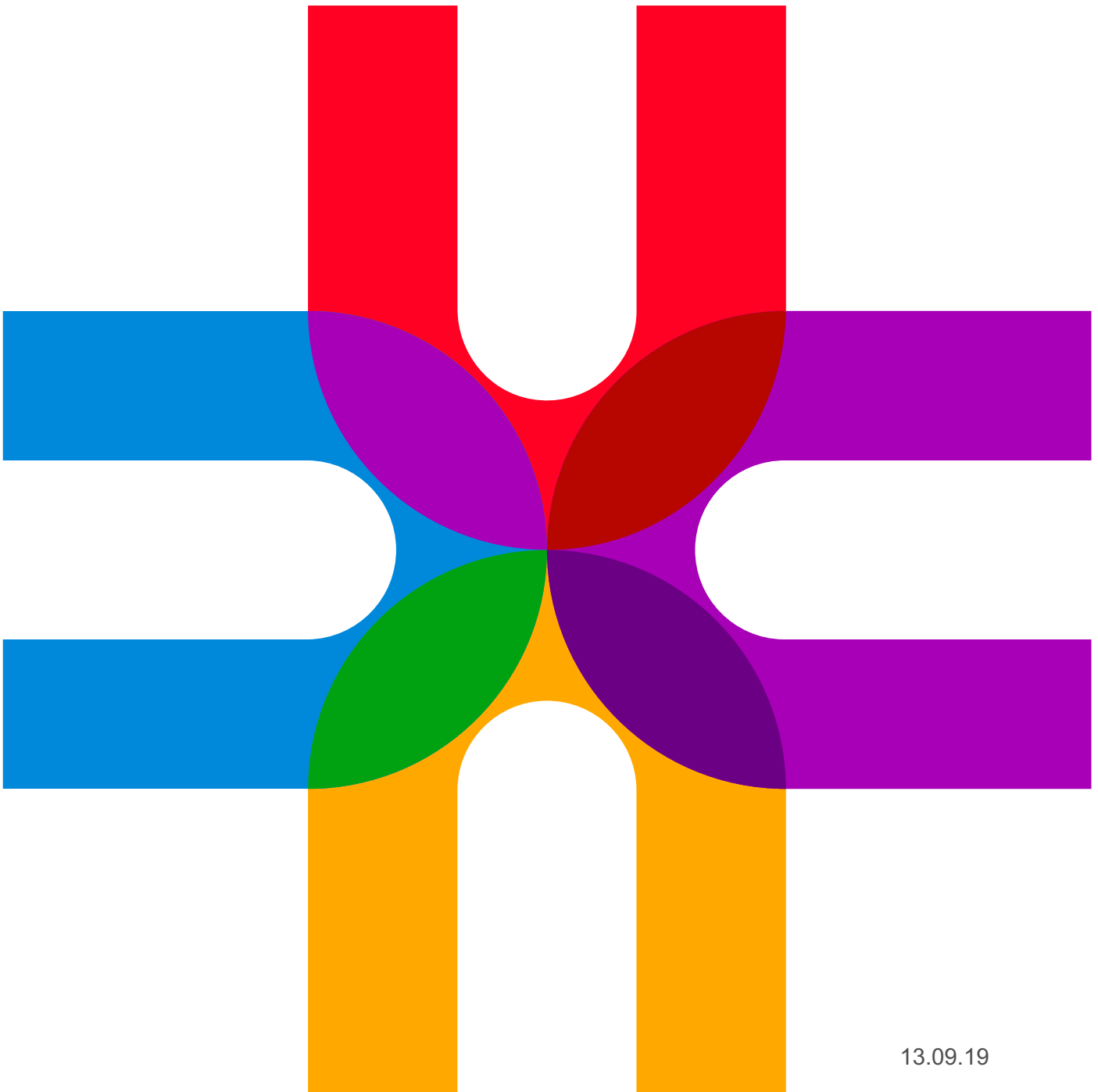


# Standards for the collection of equalities data – Disability and Impairment



# Standards for the collection of equalities data – Disability and Impairment

## Introduction

This document provides guidance on the adoption and use of the recommended standards for the collection of equalities data about disability and impairment.

The data standards for the collection of disability and impairment monitoring information are targeted for:

- Staff working in civil society organisations who are involved with recruitment of staff, or volunteers.
- Staff working in civil society organisations who are involved with collecting personal information from beneficiaries.
- Data analysts and researchers in civil society organisations working to understand issues around equality and diversity.

The standards have been developed by the working group for equalities monitoring data standards for Deaf and Disabled people. The group comprises of representatives from civil society groups in London, including Disabled People's Organisations (DPOs). The process of defining the standards included three meetings with the working group, analysis of current standards for the collection of data about disability and/or impairment used in national surveys and civil society organisations, and a survey of 65 civil society organisations based in London.

These standards are primarily meant as a guide, and not to be taken as prescriptive. Data collection will be most effective if organisations follow the same standards, enabling comparison across organisations and a better picture of the whole sector. However, organisations can add additional questions if that fits theirs and their service users' needs. It is encouraged that organisations add to the standards, rather than change the terminology included or include fewer categories than recommended.

## Why equalities data standards

Standards in the collection of equalities data is important to enhance our understanding of inequalities within and across organisations. This is a vital first step in identifying and addressing barriers based in a persons' characteristics. The data captured should support the purposes of the organisation collecting the data, including their delivery of services, reporting and management monitoring.

## Specific requirements for disability data standards

Below is a list of requirements, put together by the working group before defining the standards, to ensure they are fit for purpose for civil society organisations in London. This list is not extensive but represented a minimum expectation.

1. The standards will include recommendations for the presentation of questioning, definitions, structure and content of data collection methods.



2. They should take into account the negative feelings many people associate with questions related to equalities issues, and the fears many people have about the misuse of such data.
3. In consideration of (2), the standards should also be conscious of the power dynamic between the questioner and respondent and be designed in a way in which the respondent has power over their own data.
4. The standards should be usable by small and large organisations alike.

## The Social model of disability

The working group agreed that, to meet the requirements set out above, it was a priority to adhere to the social model of disability when defining the standards to recommend to civil society organisations.

The Social Model of Disability holds that people with impairments are 'disabled' by the barriers operating in society that exclude and discriminate against them.

The Social Model not only identifies society as the cause of disability but, equally importantly, it provides a way of explaining *how* society goes about disabling people with impairments. Sometimes referred to as a "barriers-approach", the Social Model provides a "route map" that identifies both the barriers that disable people with impairments and how these barriers can be removed, minimised or countered by other forms of support.

Key disabling barriers from a Social Model approach include:

Attitudinal barriers - The social and cultural attitudes and assumptions about people with impairments that explain, justify and perpetuate prejudice, discrimination and exclusion in society.

Physical barriers - The barriers linked to the physical and built environment.

Information/Communication Barriers - These are barriers linked to information and communication, such as lack of British Sign Language interpreters for Deaf people.

The majority of standards used in large scale, national surveys do not follow this model, instead drawing on legal definitions of disability according to the Equality Act (2010). This is discussed in more detail in next section. For this reason, it was agreed that the standards would not follow the same format as national datasets. Whilst this means that the data cannot be directly combined or compared with these datasets, they are a better representation of language and terminology currently used both by disabled people and organisations. This should lead to better engagement with equalities monitoring forms, and more accurate responses.

## Understanding current data collection practices

The first piece of work the group undertook was to analyse current data collection practices for disability equalities data in large scale, national surveys.

These surveys are frequently used by central government departments to report national statistics (e.g. unemployment rates), to estimate the number of Disabled



people living in the UK, and for data about the experiences of disabled people. They included Understanding Society (the British Household Panel Survey), the Labour Force Survey, the Family Resources Survey, the 2011 Census, the Integrated Household Survey 2013, the Health Survey for England 2012, and the NHS approved National Codes for disability.

Figure 1 outlines the typical question structure followed in these surveys. There were a number of features of the question formats that the group agreed did not adhere to the social model of disability, including

- The questions do not allow people to self-identify as Disabled. They follow the Equalities Act (2010) definition of disability as having a physical or mental health condition lasting 12 months or more.
- The questions focus on the individual's ability to complete tasks, or carry out activities, rather than how social environments can disable people with particular impairments.
- The categories included do not reflect current best practice recommended by representatives from Disabled People's Organisations.

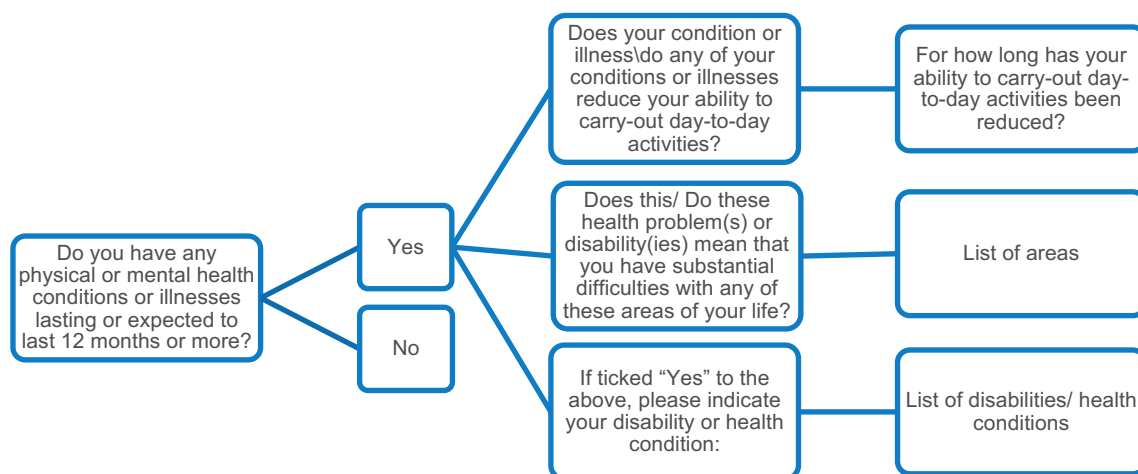


Figure 1: Typical question format in large scale, national surveys to capture disability and impairment data

### Data standards survey

A survey was used to gather information about the current data collection practices of civil society groups in London.

Individuals were asked to respond on behalf of their organisation, with the majority of questions focused on the organisation's characteristics and practices. After gathering some information about the size and focus of the organisation, people were asked whether their organisation was a Disabled Peoples Organisation (DPO), whether they were not a DPO but their main beneficiaries were Deaf and/or Disabled, or whether they were neither a DPO nor were their primary beneficiaries Deaf and/or Disabled.

A total of 65 people responded to the survey, each from a unique organisation. A detailed summary of results from the survey can be found in Appendix A.



The question defined an organisation as a DPO if:

- Their Management Committee or Board has at least 75% of representation from Deaf and Disabled people and;
- At least 50% of their paid staff team are Deaf or Disabled people with representation at all levels of the organisation and;
- They provide services for or work on behalf of Deaf and Disabled people.

This definition was based on Inclusion London's definition of a DPO and was included to avoid confusion about the meaning of the term, as well as to ensure consistency of the characteristics of organisations defining themselves as DPOs.

There were two strands of questions for the remainder of the survey.

1. For the first strand, all organisations were asked about the data they currently collect about disability, impairment and access needs, how they defined disability, what categories they include, and how frequently they collect this data. They were also asked how much they agree or disagree with statements about their organisations data collection practices, and how this data was used. Finally, they were asked whether they would be interested in adopting a new set of standards for disability equalities data collection that was coproduced by civil society and user groups, and to explain their responses.
2. An additional set of questions was asked only of individuals who responded that their organisation was a DPO, or that their main beneficiaries were disabled (23 respondents). A set of standards discussed in the working group were put forward to respondents with four variations. The standards were:
  - Visual Impairment*
  - Physical Impairment*
  - Deaf/ British Sign Language user*
  - Hearing Impairment*
  - Mental health or mental distress issue*
  - Learning difficulties*
  - Neurodiverse (e.g. Autism, Dyslexia)*
  - Long term health condition*

Another variation of the standards included Mental Health support needs instead of *Mental Health or Mental distress issue*, and the final variation combined *Learning difficulties or Neurodiverse* as one category. These were each included with the two alternative variations, such that there were four variations in total. These variations were included because specific questions were raised in working group meetings about which of these terminologies was most suitable for the standards going forward.

Respondents were asked to choose the set of standards they felt their users or members would prefer, with the option of choosing other/ no preference. They were then asked to feed back any comments or suggestions they had about the standards presented.



A number of comments were made about the categories and terminology used in the standards, which have been incorporated in the final version of the standards.

## Recommended standards and categories

The recommended standards of data collection, and categories to include, are listed below. They are split into two sections. The first asks whether the individual defines themselves as a Disabled person, the second asks for more detailed information about which impairment group applies to them.

### Disability

We recommend that organisations allow people to self-identify as Disabled. The question about whether a person is disabled or not should be worded:

#### ***Are you a Disabled person?***

- Yes**
- No**

### Impairment

The question about impairment categories should be asked if people have identified as a disabled person. The question allows people to choose more than one category that applies to them, to account for the fact that many people will have more than one impairment.

***If you are a Disabled person, please tell us which of the following impairment groups apply to you. You may tick more than one box.***

- Blind or visual impairment***
- Physical impairment***
- Deaf/ sign language user***
- Hard of hearing/ Hearing loss***
- Mental health issue***
- Learning difficulties or Neurodiverse***
- Learning disability***
- Long term health condition or hidden impairment***
- An impairment or medical condition that is not listed above (please describe)***

Our scoping work suggested that most disabled people would be able to categorise their impairment in one of the options included in the list. However, where a person feels their impairment is not represented by the categories above, we have included the option for them to describe their impairment in their own words.

### Access needs

Access needs are separate to disability status and impairment groups, and collection of this information would be used for more practical considerations, for example adjustments at work or when organising events.



Here the focus is on the ways organisations can provide support/ adjustments, rather than the individual's impairment. Along with being in line with the social model of disability, this approach is designed to help individuals and organisations identify the range of ways they can make adjustments to make events and workplaces more inclusive. The list of access needs are taken from Inclusion London's equalities monitoring approach.

As with impairment groups, people are able to choose more than one option if required.

***Please detail any access needs you have in order to take part in \_\_\_\_\_ as detailed below.***

- Step- free access**
- Wheelchair accessible venue and facilities**
- Blue badge parking**
- British Sign Language Interpreters**
- Electronic notetaker / palantypist**
- Hearing induction loop**
- Information in Easy Read**
- Information in Large Print**
- Information in electronic format**
- Information in Braille**
- Information in advance**
- Personal Assistants / support worker costs**
- Assistance at meeting**
- Any other access needs, please describe**

Organisations would fill in the blank space with their organisations name, or the name of the event, where required.

## **Guidance**

### **When to collect equalities data**

It is encouraged that organisations collect equalities monitoring data from staff and beneficiaries at the beginning of their involvement with the organisation, including in job applications for employees. It is also encouraged that organisations update this information, through regular reviews. It is likely that employees and beneficiaries' situations will change during the course of their contact with the organisation, and it is important to capture this change for accurate reporting. We recommend annual reviews of individuals information.

### **Collecting the data**

The standards do not mandate any specific way to capture data around disability and impairment, however it is encouraged that organisations consider the accessibility of the forms and presentation. For example, paper forms may be more appropriate for people with less access to digital technology and skills.



Organisations are also encouraged to include an explanation of the purpose of collecting the data, how it will be used, and that the data will be safe, anonymised, and GDPR compliant. For example:

**Purpose of questionnaire:** The purpose of equalities monitoring forms are to ensure that we as an organisation are doing our best to support and encourage equality and diversity. The data will not be linked to you individually but will be aggregated with data collected from all individuals completing the form. Please answer all the questions fully and accurately so that we can get a true picture of the organisation.

**Confidentiality:** All information provided by you in completing this questionnaire will be treated in the strictest confidence. Data will be anonymised so that your responses cannot be linked to you individually. We keep all records and personal information gathered in accordance with the requirements of the General Data Protection Regulation (GDPR).

Under the Data Protection laws, you have the right to:

- see any information we hold about you and correct it if it's wrong
- request your data is deleted at any time
- request your data is not used for certain purposes

### Presenting results from analysis of the data

Organisations have ownership of the data and are able to conduct analysis according to their strategic needs and objectives.

Several recommendations are included in this document about the presentation and reporting of data with the aim of ensuring individuals cannot be identified. These recommendations are informed by the [Statistical Disclosure Control](#) guidelines.

- All frequencies, whether presented as observed counts or relative frequencies, should meet or exceed the threshold value 5.
- No cell should contain less than 5 observations. Check that the number of observations underlying each value meets this threshold. Be aware of data that is disclosive by providing exact values, for example medians which show an exact salary that fewer than five employees earn.
- We recommend that, where required, researchers round numbers under 5 to 5.
- Avoid statements like as 'all people with X impairment earn below Y.' Statements like this can still be disclosive. If another individual knows a person's impairment status, they will now have information about their salary.





## Template for an equalities monitoring form (disability and impairment information only)

The purpose of equalities monitoring forms are to ensure that we as an organisation are doing our best to support and encourage equality and diversity. The data will not be linked to you individually but will be aggregated with data collected from all individuals completing the form. Please answer all the questions fully and accurately so that we can get a true picture of the organisation.

All information provided by you in completing this questionnaire will be treated in the strictest confidence. Data will be anonymised so that your responses cannot be linked to you individually. We keep all records and personal information gathered in accordance with the requirements of the General Data Protection Regulation (GDPR).

Are you a Disabled person?

- Yes
- No

If you are a Disabled person, please tell us which of the following impairment groups apply to you. You may tick more than one box.

- Blind or visual impairment
- Physical impairment
- Deaf/ sign language user
- Hard of hearing/ Hearing loss
- Mental health issue
- Learning difficulties or Neurodiverse
- Learning disability
- Long term health condition or hidden impairment
- An impairment or medical condition that is not listed above (please describe)

